

# Design for All



*“Quality of life of living with spinal cord injury in India- Rehabilitation Design Challenges and Solutions”*

**Guest Editor: Prof Dr. Ketna Mehta, Nina Foundation, India**

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*(Photo Credit: Mahesh Hiremath)*

***Prof Dr. Ketna Mehta, MMM, FIMC, PhD is Founder Trustee & Editor Nina Foundation an NGO for rehabilitating people with spinal cord injury in India, a socially conscious Indian, Editor, writer, thinker, author, professor, researcher, inspirational speaker and management curator.***

***She has instituted several innovative solutions to empower and motivate friends with spinal cord injury through their NGO Nina Foundation.***

***Significant milestones:***

***1) Project Nirmaan, A free OPD for non affording friends with spinal cord injury with a world class multi disciplinary team of doctors, therapists, peer mentors etc once a week in Mumbai since 2014.***

***2) Initiated for the first time in India spinal cord injury awareness day on 25th June since 2009 to create awareness, interest & positive action. Successfully celebrated ten years.***

**3) Editor of the first and only publication exclusively to disseminate information about spinal cord injury - One World since 2001.**

**4) A PhD thesis on the need for a world class spine injury rehabilitation centre in Mumbai was awarded in 2008.**

**5) Authored Several Research Papers and articles on Disability which have been published both nationally & internationally!**

**6) Advisor for TIFAC (Technology Information, Forecasting and Assessment Council- Ministry of Science & Technology, GOI) for Research Report, Vision:2035, inclusive products and assistive technology for people with disabilities.**

**Ketna has won many accolades and recognitions for her devotion to Nina Foundation including the prestigious NCPEDP Shell Helen Keller Award, NASEOH Award, Moneylife Women Achievers Award, ISIC & Spinal cord Society Award, DNA Winners in Life Award and many others.**

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## **GUEST EDITORIAL:**

# **Design Opportunities for friends with spinal cord injuries in India**

*Dr. (Ms.) Ketna L. Mehta, PhD*

*Founder Trustee, Nina Foundation*

**Nina my elder sister (an ace Homoeopath doctor) and myself as children loved reading mystery books. We voraciously read popular authors like Agatha Christie, Arthur Conan Doyle, Alfred Hitchcock and many others. More complex the problem higher our interest levels. This fascination for solving mysteries as well as real problems and challenges, I retain at my young age of only 57 years with 25 years of living with spinal cord injury in India and as many years understanding, empathizing, problem-solving, counselling several other friends with spinal cord injury as part of our NGO, Nina foundation.**

**My approach towards spinal cord injury has been that of wonder, curiosity, mysticism encompassing the realm of anatomy to the cosmic and the spiritual. The most mystical mystery is why did humans supposedly the highest evolutionary mammal discontinue and stop regenerating our nerves in the spinal cord, the main communicating medium between the brain and the rest of our body? Squirrels, also mammals, fall on their spine several times while climbing trees and yet regenerate their nerves thus going about their life as usual?**

**For those uninitiated about the impact and severe implications of spinal cord injury allow me to enlighten you. Causes of Spinal Cord Injuries are:**

- ***Road Traffic Accidents/Motor Vehicular Accidents/Mishaps-Whiplash Injuries***
- ***Fall from Height (fall from Tree/ Terrace)***
- ***Work Injuries: Fall of Load on Neck/Back***
- ***Sports Injuries***
- ***Violence: Bomb Blast/Bullets***
- ***Tuberculosis / Infections / Tumors/diseases of spine***
- ***Earthquakes & other natural disasters.***

**Spinal Cord Injury:** A spinal cord injury usually begins with a sudden, traumatic blow to the spine that fractures or dislocates the vertebrae. The damage begins at the moment of injury when displaced bone fragments, disc material, or ligaments, bruise or tear into spinal cord tissue. Most injuries to the spinal cord don't completely sever it. Instead, an injury is more likely to cause fractures and compression of the vertebrae, which then crush and destroy axons -- extensions of nerve cells that carry signals up and down the spinal cord between the brain and the rest of the body. An injury to the spinal cord can damage a few, many, or almost all of these axons. Some injuries will allow almost complete recovery. Others will result in complete paralysis, medically termed paraplegia or quadriplegia.

**How does Spinal Cord Injuries affect the Body? It affects the,**

- ***Motor System ( movement of toes, ankles, knees, legs, arms, shoulders, fingers)***
- ***Sensory System ( touch, ant bites etc)***
- ***Bladder incontinence ( catheterisation to be done in order to void)***
- ***Bowel incontinence ( either train or digital stimulation)***
- ***Temperature Regulation (Autonomic Functions)***
- ***Sexual Function***
- ***Mind- psychological trauma and depression.***

**In fact no other injury affects so many parts of the body as a spinal cord injury- Mobility, Hot- cold- bite sensation, Skin, Bones, muscle strength, urine and stool control.**

**There are over 1.2 million friends with Spinal Cord Injury in India (in 2019) making it the capital with this disability in the world. Spinal cord Injury is a permanent disability transforming a person's life and comprehensive rehabilitation is the key to facing life with dignity in the world.**

**WHO (World Health Organization) has declared Spinal cord Injury as the most devastating disability in the world. ([https://www.who.int/disabilities/policies/spinal\\_cord\\_injury/en](https://www.who.int/disabilities/policies/spinal_cord_injury/en))**

**Problems faced specifically by our Indian friends with spinal cord injury on wheelchairs are:**

- ***lack of world class holistic rehabilitation facilities even in Mumbai and most cities & towns. Rural areas are worse.***
- ***The Rights of Persons with Disabilities Bill (Act) does not list spinal cord distinctly as a SEPARATE disability giving it the importance in policy and plans.***
- ***There is no spinal cord injury Registry on causes, incidence and prevalence which collates and shares real time data for future action.***
- ***lack of complete rehabilitation team to provide guidance. Till date Occupation Therapy, Assistive Technologist & Rehabilitation specialist majorly missing.***
- ***lack of trained rehabilitation professionals to guide in the entire journey of life.***
- ***No awareness about prevention of spinal cord injury. Even now we observe construction sites workers work without a safety harness.***
- ***Post road accidents the 'golden hour' precautions need to be taught to every citizen like CPR. Poor handling by well meaning samaritans like rushing the victim in a rickshaw causes further damage and a permanently disability. Scoop stretchers are invisible in India which can save lives.***
- ***Schools, colleges, offices, government buildings, movie halls, restaurants, hotels, public washrooms and every infrastructure is NOT wheelchair accessible. Surprisingly even the new structures violate the guidelines and laws. The parents, family members and the wheelchair users all have to suffer very much due to this apathy and disdain towards this huge population.***

- ***Medical curriculum does not have descriptive spinal-cord injury rehabilitation details. Thus cases are not properly managed.***
- ***lack of information & access to good quality affordable customised wheelchairs, cushions etc locally.***
- ***Disability pension ranges from a meagre Rs. 800-1200/ per month which does not cover most of the cost of living for 80% of friends with spinal cord injuries thus burdening the NGOs and social charities.***

**My rehabilitation in Mumbai was totally at home with minimal equipments but top class, highly experienced physiotherapist Dr V C Jacob leading the 'Challenge Walk' ably supported by Dr Milka Vivek ( Nina's friend), Sharone, Vijayalaxmi and many others from the talented team. The compounded complexity was we stayed on the first floor without an elevator. I used to be willingly carried piggyback by my kind hearted, athletic brother-in-law Dr Himanshu Doshi for hospital visits. An idea of adjusting the walker given by Dr Riten Pradhan and enthusiastically accepted & action by Dr V C Jacob ( with Dr Himanshu Doshi waiting like a cricket fielder, arms positioned at the foot of the stairs, just in case;). Such and many more ideas ensured that I learnt to climb & descend the entire two flights of stairs independently- enabling me to reclaim my freedom and life! Nina taught me CIC and with family support I learnt other activities of daily living. Nina also got me some basic computer based part time work for the Homoeopathic journal she was contributing to. This turned out to be a real game changer immersing me in work, my elixir.**

**The wide spectrum of knowledge on spinal cord injury I owe to a fabulous team around me:**

**My late parents for instilling the never-say-die confident spirit, independence and giving a quality education with ethical values.**

**My loving late sister Dr Nina Doshi for making me believe in my talent, abilities & dreams to boldly stride full steam ahead and with twinkling eyes prophetically challenging me 'prove the medical books wrong and achieve the impossible.' Well today she is not physically with me but the NGO Nina Foundation that my younger brother Dhaval & I set up 19 years ago in her memory has empowered thousands of lives already.**

**My positive, handsome, magnanimous younger brother Dhaval has a heart of gold and has looked after me throughout my life fulfilling all my desires. The day tour that we jointly took to Swiss Rehab Centre, Nottwil, Switzerland still inspires gasps, awe & wonder at the 7 star spinal cord injury rehabilitation facility and the value of a human life accorded by them. Dhaval also funded the seed money to start Nina Foundation- the purpose of my life. His advertising agency Kreate & young and efficient team provides creative, design communication as well as timely administrative support.**

**The astuteness, depth and superlative communication command that Dr Riten Pradhan (a fantastic human being coupled with vast knowledge and creative wisdom) an Orthopedic surgeon based in UK now, who saved my life post my paragliding accident on 12th Feb 1995 is unmatched. His genuine interest and constant solutions for my various questions and issues which he brilliantly explained and solved on an on going basis through my entire rehabilitation enabled**

**me to quickly scale unsurmountable peaks. He continues to do so even now. His personal visits, timely phone calls, fax, letters and emails has shaped my thinking as well as approach towards spinal cord injury rehabilitation.**

**Dr Himanshu Doshi my brother-in-law ( Nina's husband) has with his actions, knowledge, medical wisdom, simple problem-solving approach and clarity been an integral part of my rehabilitation solving myraid problems as they arose always joking & smiling and making light of any situation. I owe it to him to have learnt self-catheterisation and many other life skills.**

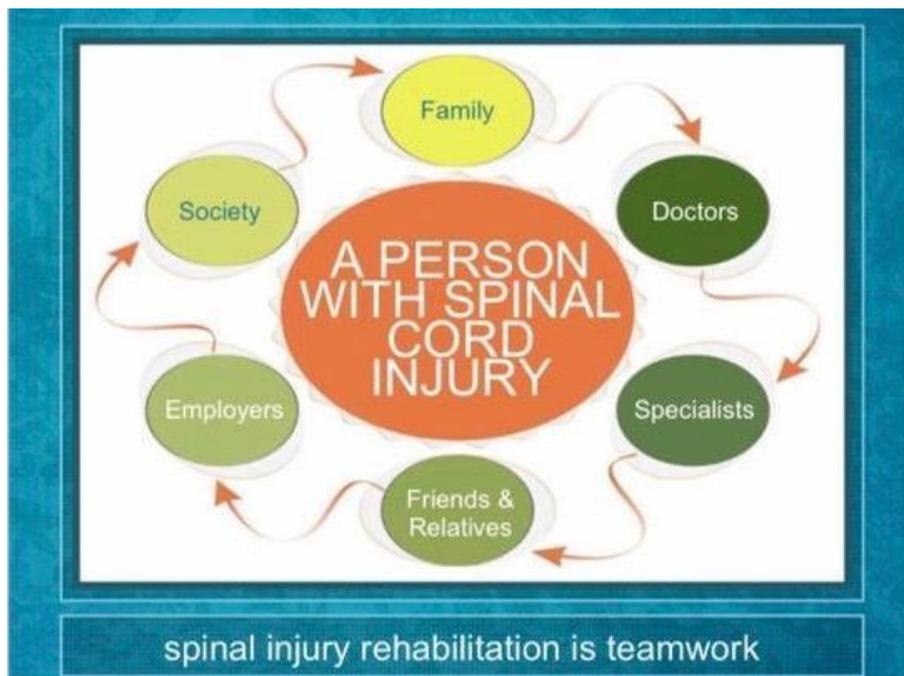
**Through the years and my PhD research study I have had the blessings of so many eminent surgeons, academicians and people. Our other eminent Nina Foundation Board of Trustees Dr S Y Bhojraj, Late Dr S. Sagade, my dearest angel sister and internationally reputed Homoeopath Dr Parinaz Humranwala who has played a role of mentor, supporter, family member and through all my health lows & ebbs stood like a rock of Gibraltar each time lifting my spirits to soar higher.,Dr Dhruv Mehta and Anupama Ganesh. My close circle of family and friends Rupal, Dev, Meera Mehta, Darshika Thacker, Divya Suvarna, Namrata Shah, Mr G Shanker, Mr & Mrs Vieira, Rohinton Surti, Satish Kulkarni, Dr Razia Manjrekar, Mr R J Khambatta, Late Mr S K Nagpal, Soli Doctor, & several others have expanded my horizons about different aspects of rehabilitation.**

**Dr H S Chhabra ( ISIC), Dr Patrick Kluger, my mentor late Dr Vijaya Manerikar, Prof Ernest Fernandes, Dr N H Atthreya, my PhD guide Dr Uday Salunkhe, all my esteemed physiotherapists, caregivers, family, associates and so many friends with spinal cord Injury I**

**proudly call them as my close knit family and whom I covered in my research sample.**

**Our NGO Nina Foundation activities has not only given me the opportunity to meet, talk & understand the primitive plight of our rural, urban poor and other friends with spinal cord injury but also to guide, mentor students, scholars from various academic fields like architecture, fashion, technology, physiotherapy, occupational therapy, assistive technology, media, advertising, management, medicine, design, disability studies, social sciences, sports, rehabilitation and many more.**

**As a management professional I always focus on the other - the user experiences, user requirements and latent desires. The bandwidth of the lifecycle of a person with spinal cord injury has six levels of rehabilitation as devised by me through my PhD in healthcare spinal cord injury rehabilitation management in 2005.**





**In spinal cord injury there is need for understanding and association from various stakeholders in the society as the quality of life is highly dependent on the quality of rehabilitation and the quality of inter personal relationships.**



***Painting by Dev Mehta***

**I'm extremely overwhelmed and grateful for this opportunity offered by Dr. Sunil Bhatia, editor of Design For All Institute, inviting me as the Guest Editor for this special December 2019 issue and granting me the freedom to pursue my passion & purpose in life of improving the quality of life of friends with spinal cord injury in India.**

**The THEME of this issue is**

***"Quality of life of living with spinal cord injury in India- Rehabilitation Design Challenges and Solutions"***

***Come to think of it I see a pattern with the way the Universe has given me such golden opportunities.***

**•*First my PhD on healthcare spinal cord injury rehabilitation management in 2005.***

**•*This led to me being invited as a Regional Consultant for WHO's ( World Health Organization) IPSCI -International Perspectives on Spinal Cord Injury, the first ever global research study in 2010.***

**•*The very first national mainline publication Success & Ability on the theme of spinal cord injury, they invited me as their Guest Editor in 2012.***

**•*And now this.....***

***Thank you God.***

***Thank you Dr Bhatia.***

## ***SPINAL CORD INJURY (SCI) DESIGN LAB PROPOSAL***

**I see tremendous potential and possibilities across disciplines to work out affordable low-cost innovations, design and solutions for improving the life of Indians with spinal cord injury.**

**My Guest Editorial can be taken as a proposal for a spinal cord injury design lab to re-calibrate our thinking amongst academic institutions, schools, colleges, the government, institutions, makers lab, hackathons, and more.**

**This Guest Editorial can also be given as design innovation challenges or caselets to both young and experienced minds to find creative, local solutions.**

### **(1) DESIGN IDEAS FOR PREVENTION OF SCI- ROAD TRAFFIC ACCIDENTS.**

***Road Traffic Accidents are a major cause for spinal cord injury in India.***

***a] Develop Crash proof vehicles,cars,bikes,buses, tempos, rickshaws, rural vehicles etc.***

***b] Design safety features inside the vehicles such that occupants are completely protected and unharmed.***

***c] Design road surfaces with such materials that do not form pot holes and huge craters and there is no skidding.***

***d] Design burst proof vehicle tyres which are also a cause for road accidents.***

***e] Design predictive alarm & brakes inside the vehicle if any object like a tree, animal or other vehicles or pedestrians come within one feet of your vehicle.***

***f] Automatic speed limit during nights and also perceptive sensors if the driver closes her or his eyes for more than five minutes. Many drivers tend to sleep on the wheel which cause irreversible accidents.***

***g] Many of our villages are still without regular electricity, rural roads generally don't have any street lighting and there are huge stretches of farmlands many accidents happen because of driving in the dark. Design Vehicles like intelligent buildings which automatically illuminates during nights when more light is required making the surroundings brighter.***

***h] In India there are several people who do not have a valid driving license for light motor vehicles, heavy motor vehicles or two wheelers etc. Vehicles to be designed such that as soon as the driver is behind the wheel and switches on the ignition it searches for a valid digital driving license match in the database and only when found the vehicle starts.***

***i] There is increase in the consumption of alcohol and other substances across stratas of society and gender in India despite a law and breath analyzing tests by the traffic police. Such incidences do occur of drunk driving causing RTA. Design built-in sensors in vehicles to smell breath & not start. A recorded admonition that the driver is not 100% alert to drive plays repeatedly, as well a loud siren goes off from the vehicle.***

## **2) DESIGN IDEAS FOR PREVENTION OF SPINAL CORD INJURY-FALLS:**

**Another leading cause of spinal cord injury in India is fall from heights like construction sites, balconies, terraces & roofs ( Barsaati), trees, pyramid formations during festivals like Janmashtami ( Govinda), adventure sports, diving in shallow water bodies, falling off overcrowded trains, buses, or alighting while the public transport is in motion. Interiors of homes, restaurants, hotels, airports, malls & retail shops have granite, marble and generally very smooth slippery surfaces. Especially washroom tiles with a combination of soap & water cause falls (most are fracture cases which heal over time but this also causes head & spine injuries.)**

***a] Design a Bomber suit or similar clothing for such occupations where safety harness and rules are ignored. This suit would protect the head and spine. Design a behavioral change campaign such that people actually heed this before embarking on risky activities.***

***b] To avoid falls on smooth surfaces especially bathrooms, design such tiles especially for wet surfaces. Washroom tiles to have a natural absorption of on all flowing water and the same is recycled for flushing, gardening etc. This would prevent the common reason for falling inside and outside washrooms.***

***c] Sleeping on the terrace of rural homes typically called Barsaatis is a common practice in India. Waking up in the night to go to the washroom without lights and still sleepy, many roll down the terrace & fall to grave spinal cord injuries. Design such materials for edges and parapets of terraces which self illuminate warning red colours or beep on approaching the wrong exit.***

***d] To safely fall from stairs, balcony, ladder, heights, design special clothing which opens like parachutes or wings and one to glide down safely.***

### **(3) DESIGN IDEAS FOR PREVENTION OF SPINAL CORD INJURIES- MEDICAL FIELD**

***a] A vaccine to be developed and taken as an infant such that spinal cord injury can be prevented.***

***b] A protective sheath for the spine like how an umbrella or raincoat protects us from rains for those activities which generally cause spinal cord injury.***

***c] Possibility of Spine transplant? Spinal-cord transplant?***

***Nerve transplant?***

***d] Like there is artificial heart patented by an Indian scientist, Dr J Yakhmi, lets explore possibilities for: artificial spinal-cord, artificial nerves, artificial bladder sphincter, artificial bowel sphincter, artificial skin for bed sores, artificial fingers for quadriplegics, artificial arms and artificial legs for mobility.***

***e] Design a Bypass technique of surgery to restore major functions caused due to spinal cord injury.***

***f] Medical Design solutions to restore bladder, bowel, fertility, bed sores, brittle bones, muscle tone.***

***g] Superior plastic surgery for use of hands, fingers in quadriplegics and to have trunk strength for getting up on our own, balance and walking in paraplegics.***

***h] Innovations in new drugs, injections, surgeries, implants and therapy to restore & revive the nerve functions.***

***i] Explore multiple & better uses of cord blood stored during childbirth. It may have the magic to restore nerve axons.***

***j] Further research in Alternative Medicines especially Homoeopathy which can reinforce our immune system.***

***k] Explore newer Applications of Neem & Turmeric in healing & repairing the spinal cord.***

***l] In the Hollywood movie Elysium (a space habitat) which is technologically highly sophisticated, has Med- Bays that repairs all bruises, injuries, cure all diseases, and regenerate body parts. Why not this fiction be turned into a reality for spinal cord injury repair***

***m] Like cord blood bank store the placentas at birth and use this periodically to inject till the age of 12 years such that spinal cord injury damage is averted.***

***n] Design and develop new vitamins and minerals, calcium necessary for a fortified spine with a combination of purple coloured food as supplementary diet.***

***o] Just like Folic acid is proven supplement in pregnant ladies which prevent spina bifida research for natural food and nutrition to prevent spinal cord injury.***

## **YOGA, CHAKRAS, MANTRAS FOR HEALING**

***p] Yoga asanas & breathing techniques especially the Power of Kundalini which can internally heal the spinal cord and nerve functioning.***

***q] Power of Aum and other Mantras to be further researched and explored. I know of an old uncle who cannot speak due to a paralytic stroke but when aunty sings Bhajans (devotional songs) he joins her and can articulate all the words clearly!!***

***r] Research and explore the Healing properties of hot springs, volcanic ash, other minerals in nature.***

***s] Immense power of meditation to self-heal ourselves. The processes of such techniques to be able to be communicated and practiced by all newly injured.***

***t] In the world acclaimed Indian Text Bhagwad Gita, Lord Krishna speaks of the seven yogic centres of life energy within the human body, roughly aligned with the spinal cord. Somehow I believe the answer to the age old mystery of the spinal cord maybe in our Indian scriptures. Design research design around this concept.***

***u] Mudras and pressure points to control respiration, sweating, spasms, conjectures, phantom pain, autonomic dysreflexia, bladder and bowel incontinence.***

***v] Explore the Power of the subconscious mind further as the root of all miracles is here.***

#### **4)DESIGN IDEAS FOR SPINAL CORD INJURY- TECHNOLOGY**

***a] Early Detection Wrist Band to be designed which identifies and alerts the beginning of TB or Cancer tumour, other diseases of the spine and preventive action can be taken.***

***b] A controllable switch like a ring finger for bladder and bowel sphincter function.***

***c] Design wings which can be freely available in the market such that people can attach these to themselves allowing them to fly and land safely knowing certain activities are risky.***

***d] Design technology for avoiding bed sores and create a new layer of healthy skin.***

***e] Design technology for restoring sensation of pain, hot, cold temperatures, sensation of pinch, pressure. This will avoid several complications like burning of toes/ legs due to electric blankets or room heaters ( in cold places) which heat the metal of the wheelchair and the person gets burnt due to lack of sensation. We also had a friend who while seated in the front seat of a cab in Mumbai the hot engine during the long commute caused major burns on his legs.***

***f] Crystal ball Predictive Analytics. Dangerous accident prone roads and spots alerts the driver and passengers.***

***g] An external portable spinal cord machine supporting all functions much like an oxygen cylinder used for patients with breathing issues.***

***h] Lab insects to be designed which can weave the nerves back to original form like the baya bird.***

***i] Design Loving Robots trained as caregivers/ attendants for quadriplegics & paraplegics. Helpful in all daily activities like put on calipers, change clothes, bladder, bowel care, bathing, transfers, driving and assisting in work at home as well as the office.***

***j]. The Dalai Lama states that compassion & love work as curative medicines.***

***Design surgeons 'Love Gloves' such that while operating on the spine post injury emits love signals for the nerve axons to heal.***

***k] Eco friendly sustainable, self cleaning diapers, underpads, catheters and other medical supplies to reduce our carbon footprint.***

**5) DESIGN IDEAS FOR INFRASTRUCTURE, LAWS & ENVIRONMENT for an improved Quality of Life for friends with spinal cord Injury.**

***a] Design Experience Zones in all hospitals, physiotherapy & rehabilitation centres pan India for spinal cord injury. Lack of awareness & information causes limitations in living a full life.***

***b]Design universal floor mobility devices for urban homes & rural mud houses.***

***c] Design CSR ( Corporate Social Responsibility) Funding to actually make a difference in this much needed healthcare rehabilitation segment. SCI rehabilitation centres, Activities of Daily Living Modules, safe, customised assistive aids & technology as well as***

***modifications of homes, accessible vehicles and sports centres for recreation.***

***d] Design a policy & process and make foldable scoop stretchers ubiquitous at police stations, traffic islands, railway platforms, taxi & rickshaw stands, hospitals, ambulances, schools, colleges, housing societies sport centres etc. This simple low cost stretcher can save someone from a grievous spinal cord injury.***

***e] Design Indian laws to add spinal cord injury as a separate distinct disability in RPWD Act, such that appropriate policy, processes and funding is duly allocated.***

***f] Design an SCI Registry to collect real time data on incidence & prevalence pan India.***

***g] Design training modules of 'Golden Hour' technique and conduct sessions for school children, drivers, adventure sports trainers, literate & otherwise, everyone just like CPR modules. This would save several lives.***

***h]Design all academic curriculum across disciplines to include awareness about all aspects of spinal cord injury.***

***i] My wish list from Indian Railway Authorities for our friends with disabilities using wheelchairs to go beyond the belated announcement that some outstation trains may soon have a coach dedicated for use of disabled passengers and women, and incorporate the following too:***

***\* Emergency button inside the coach which connects to the Engine driver.***

- \* Intercom Phone in working condition.**
- \* Wheelchair accessible hygienic & clean washroom including a rexine bench for diaper change.**
- \* Incinerator to dispose diapers and sanitary pads.**
- \* Wide doors and a ramp for convenient entry and exit into the coach.**
- \* wheelchair chains for safety while train is in motion.**
- \*A female and male police to guide, support and protect the disabled passengers as well as help with luggage inside as we need to encourage independent travel.**
- \* a water cooler inside for long journeys and regular canteen service.**
- \* A 3 digit special Helpline number as it may happen that there is only 1 disabled woman in the coach and others are male.**

**Lets truly make Indian Railways a safe, reasonable and inclusive mode of transport.**

**JJ I always look at win-win inclusive management solutions for regular problems faced by us, people on wheelchairs in India. ( Believe me its never a smooth ride!)**

**Service Providers like Cabs, Uber, airlines, hotels, restaurants etc can have a box on their app/ websites which while booking we can tick 'Wheelchair User'. Accordingly such a cab with a trained driver is allotted and thus both the user as well as the driver have a happy journey together. As a passenger we are paying EQUAL FARE and the**

***onus of converging their technology, training of drivers with type of vehicle is squarely on the service provider. People with disabilities have Equal Rights for living a full life as per our laws and any denial of this basic Right is a violation.***

***k] Change Indian adoption and other laws until such time that spinal cord injury gets its due importance with the awareness, rehabilitation facilities, centres and trained qualified teams.***

***Persons with spinal cord injury can be adopted by international NGOs, organisations, families, Institutions and companies with massive CSR budgets in such countries like Canada, USA, Europe, UK, Australia where state of the art superlative facilities exist and non affording newly spinal cord injured can experience a good quality of life.***

***l] Taxation laws to exclude people with spinal cord injuries from all taxes- income tax, corporate tax, GST etc. Because their family has to pay extra for non existence of seamless facilities. Also there is loss of earning during rehabilitation. This needs a serious thought to prevent them from hitting poverty levels.***

***m] People on wheelchairs with spinal cord injury despite paying equal fare to any airline whether in economy or business class are unable to access the tiny washroom. Agonising stories of sitting through the 'cold, freezing, high air conditioning' flight duration without being able to catheterize or transfer from the aisle wheelchair ( that is if it exists onboard) causes urinary tract infections, leakages, the indignity of wetting their diapers, clothes and seats. Not everyone can afford a first class seat which comes with privacy and a personal bed or washroom. Airlines have to think***

***through their policies and allow such passengers to either use the first class cabins for self- catheterisation & changing diapers or redesign their aircrafts for special bays like transferable long couches with screens. Till such time these modifications are effected such passengers must be given appropriate concessions for not being able to use the washrooms.***

***n] I believe the architects, interior designers, Urban planners and the respective institutions & faculty must include in their curriculum the legal requirement for wheelchair access . They must firstly have the knowledge and communicate ( just like energy conservation, recycling etc) to their respective clients and build in disabled friendly features in their blue prints & plans. During my research which is published in a peer reviewed journal ( [www.ninafoundation.org](http://www.ninafoundation.org)) we have discovered that it does not cost a penny more to make new establishments disabled friendly.***

***o] The local governing authority like Municipalities must send a Notice and warning to each and every public place for retrofitting and making existing places accessible.***

***Proactively they can give general guidelines along with the notice to make it informative and play a role of nurturers.***

***p] The state municipalities can have a dedicated department for sharing disabled friendly guidelines and hand-hold the existing establishments to incorporate precise changes recommending materials, gradient, location etc. It can begin with their own offices and employ people on wheelchairs for this role!***

***q] Due to lack of comprehensive rehabilitation in activities of daily living several women with spinal cord injury face indignity while***

***travelling. Based on my research it is necessary to have 'nappy change rooms for infants used by parents' ( Chennai domestic airport has a perfect room and long size of couch without arms for easy transfers from wheelchairs) which can ease the bladder discomfort. Similarly all train, bus, airline platforms as well as petrol stations and public washrooms on road expressways to design such facilities. Please realise we too are humans with a bladder.***

***r) Recreational clubs, parks, playgrounds & sports facilities are also very much needed for regular sunlight, fitness, fun and work life balance.***

## **CONCLUSION:**

**The above design ideas are doable, fantastic and some may sound crazy, outlandish or funny too! But the fact of the matter is there is a tremendous need for positive development across disciplines to improve the quality of life of friends with spinal cord injury in India. This is an open invitation and ideas for Thought Leaders, innovators, designers, children, creative citizens, technologists, corporate leaders, management students, architects, urban designers, healthcare professionals, spiritual practitioners and compassionate human beings who can make a difference.**

**I look forward to your opinions, action ideas & views and I believe each one of us has the power to be a changemaker.**

**This citation which I quote below by Rob Siltanen was given to me by young Rotractors post my talk on spinal cord injury impact sums it all: "*Here's to the crazy ones.*"**

***The misfits.***

***The rebels.***

***The troublemakers.***

***The round pegs in the square holes.***

***The ones who see things differently.***

***They're not fond of rules.***

***And they have no respect for the status quo.***

***You can quote them, disagree with them, glorify or vilify them.***

***About the only thing you can't do is ignore them.***

***Because they change things.***

***They push the human race forward.***

***And while some may see them as the crazy ones, we see genius.***

***Because the people who are crazy enough to think they can change the world, are the ones who do."***

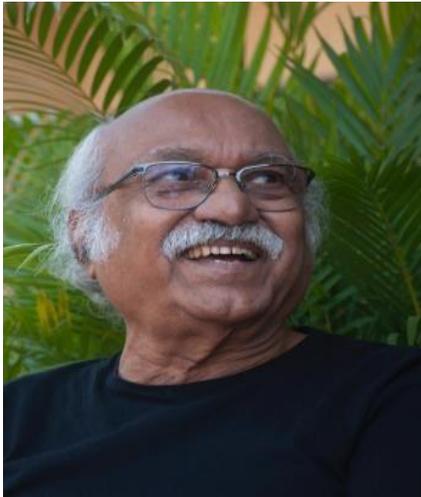
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***Prof. Sudhakar Nadkarni is an iconic Design Educationist & Practitioner***

***Professor Emeritus - Business Design, Welingkar Institute of Management Development & Research, Mumbai.***

***Sudhakar Nadkarni pioneered 'design thinking' in India, and set up not one but three institutions that train young minds in the field Mumbai: "Good design is good business," said Thomas J. Watson Jr., IBM's second CEO. When Mr. Watson said that, sometime in the 1950s, Sudhakar Nadkarni was studying graphic design at the JJ School of Art in Mumbai.***

***As a boy, young Sudhakar loved drawing; he would decorate school magazines and help out his neighbour, a signboard painter. This led to a keen interest in graphic design, and with some parental encouragement, he joined the Department of Commercial Design at the JJ School of Art. (Later, the word 'commercial' changed to 'applied' and it became the School of Applied Arts). "At the time, the course focussed on skills: drawing, illustration," he says in a phone interview, "but did not talk about things like what communication***

***design is, how information flows around, how to translate information into a graphic form.” While in college, he also worked on events and exhibitions (including ones with legends Charles Correa and Pupul Jaykar), which “helped me develop a three-dimensional view of space, and how to place objects around it.” He then joined an advertising agency.***

***In the early 60s, a mentor, Yashwant Chaudhary (later responsible for the ICICI logo) had just got back from Switzerland, full of exciting design stories and theories. This got Mr. Nadkarni thinking about design in a different way from the existing discourse in India.***

***In 1962, Mr. Nadkarni counted his savings, took a deep breath, quit his cushy job, and went off to the Hochschule für Gestaltung (hfg; literally, College of Design) in Ulm, Germany, to study product design, a field not many in India had even heard of. He didn’t even speak German at the time. At hfg, he studied theories and philosophies of design and communication (one of his projects responded to Jawaharlal Nehru’s ideas of nation building; it was called ‘How design can help in national planning and developmental programs’.)***

***Then, a stroke of luck happened. His project guide at hfg was invited by Gautam and Gira Sarabhai to help set up the National Institute of Design. And when Mr. Nadkarni finished his course in Ulm, he was invited to return and pass on his learnings at NID as an Associate Professor. He came back to a developing nation that wanted to maximise the impacts of its spends on its people. In the Sarabhais, he found kindred spirits. “Gira was an architect and Gautam a mathematician, and they already had a great exposure of American***

*design themes. So, I went into an environment conducive to my interests.”*

*Around then, India’s Education Ministry had sent a team to hfg to understand design education. “They already wanted to start a design programme,” Prof. Nadkarni remembers. “There was also an unemployment problem, especially among engineers. So, they thought, why not start one at IIT Bombay?” Of this was born, in 1969, the Industrial Design Centre (IDC), offering Masters degrees in both Product and Communication Design, with Prof. Nadkarni at the helm. There were initial syllabus issues – “At IDC, we wanted to have 30% lectures, 70% practical. At IIT it was the other way around.” – but his view prevailed. He headed IDC for 18 years.*

*In 1997, he was invited to found the Department of Design at IIT Guwahati. He found himself fascinated by bamboo, which grows profusely in the region. “They were making cane and bamboo baskets, which isn’t really enough to financially sustain them. I thought I should work out different type of products that would. I took to areas like school and hospital furniture made of bamboo and cane, so they could be purchased and, when necessary, repaired locally.”*

*His next stint was at the Welingkar Institute of Management Development and Research (We-School), where, from 2003, he led two-year MBA programme in Business Design. He currently serves as Professor Emeritus, Business Design. Aside from his academic and institution-building work, Prof. Nadkarni also collaborated with Mr. Correa again – including on Vistara, the traveling exhibition of Indian architecture, and CIDCO’s city planning project in Navi*

***Mumbai – and did projects with Larsen & Toubro, Mahindra, and the Tatas, though in his words, they’re “so many, I’ve forgotten them now!”***

***Through it all, he has focussed on proliferating good design knowledge, of going beyond the conventional understanding of the field – making nice-looking things – to designing real-time, tangible user interfaces with items and objects that make things go smoother, in real life situations, in urban and rural spaces. In short, to create a better standard of living. His incredible journey gives Prof. Nadkarni a unique perspective on Indian design and its future. What, we asked, would he consider ‘Indian’ design? “When you write in English or Hindi, the grammar is same. Similarly, the grammar of design is the same across the world. It’s how you use it in different environments that matters. Our habits, postures, way of living is different, so if you take that in consideration and develop a product it becomes Indian design! It is when you solve social or functional problems in India through design. This is where innovation comes from, and this is what I am trying to do through my course at We-School!”***

***The Design Journey of Prof. Sudhakar Nadkarni, by Mandar Rane, published by IDC, launches today at the Industrial Design Centre, IIT Bombay, Powai.***

***He has a Diploma in Applied Arts from Mumbai along with a Diploma in Industrial Design from Ulm, Germany.***

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# **Design- Education, Democratization and Thinking**

*Professor Sudhakar Nadkarni*

Dear friends,

At the outset I would like to thank Indian Institute of Science, Bangalore and the selection committee for proposing my name, bestowing me the honour of ICON award and giving me an opportunity to speak on this occasion. However, I should confess that I am a drawing board man. I love designing physical objects but theorizing about is not my forte. Also when I went through the program contents and saw the list of its participants I realized that several of them are my students from IDC, DOD and NID. I am afraid that they are already familiar with my opinions and where I stand in this open and vast arena of design field. As a result, I am left with no key for this keynote address.

So my address will be just a keyhole address, without the key.

To begin this address, as a ritual I should have start by a quote from some great guy. I am afraid I can't remember such a person either as my literary knowledge is very poor, so maybe I quote from my grocer's whom I visit every day to buy my grocery.



He once said " sab, ye Kya sub log design ka bat kar rahen hai, hum bhe designer hai, dekho hamne bhi ye tikiya kaise arrange kiya hai. jai se ki tyohar ke lagaya hua toran. Ek baju lays, kurkure ect. our dusare baju pan masala, gems ki tikia ect. Hame to customer ka awaj our hath me paise dikhaya deta hai". To make him happy and to push his ego, I said tum to natural designer hai.



I believe that Design is not the monopoly of designers only. If you visit our vegetable market you will be amazed to see the way they display their products. Their design sense is prevailed, in their arrangement of the display. They know how to impress and attract the customers. They have developed their sensitivity and the understanding of geometry. This is apparent from their arrangement of vegetables or fruits based on the forms.

The questions then arise are: what is the definition of a designer and design.

It is a difficult question to answer quickly and satisfactorily. Many people have attempted to define 'design' and if I give all those

**definitions, I am sure we will end up with a big confusion. One of the reason is that word design has several meanings. Sometimes it is used as a substitute for a thing or artefact and at other times it is used as a process-the act of design. Our own image of design varies from the other person. The image of design and the meaning that we attribute to it is dependent on our background, the context in which we are looking at design and our own personal experience.**



**An interesting aspect of design is that design has a very wide spectrum. It is an enveloping term for many design disciplines like jewellery, apparel, products, machine tools, electronic equipment, furniture, structural, interior, environmental, theatre, graphics, information and interactive design everything that is manmade and human centric.**



**From products we can design systems. Bigger systems are designed by the assembly of smaller systems and products. For example, transportation system of a city is an assembly of smaller systems like network of a roads, buses, bus stops, maintenance depots etc. Similarly, even bigger or mega systems can be designed, like new urban smart centres, national health care system, even designing a system to introduce design at various levels of school education.**

**Unfortunately design that is integrated, human centric and an investigative process finds no takers in the institutes of higher learning. The world of products, messages, materials, signs and symbols has never been the part of academic discussion. The academic tradition has not taken note of the domain of design in any of its disciplines. In present times one simply cannot ignore the influence of industrialization and the use of technical products in our everyday life. The main ideal of technical and science education is the creation of new knowledge and using this knowledge to improve the quality of life.**

**Design has never achieved the status of establishing itself as parallel leading ideal, that design is also an indispensable activity and search and research is interwoven in design thinking. This fact explains the difficulties of integrating design education in the institute of higher learning with their own traditions and criteria of excellence.**

**The irony of our design institutions is lack of objectivity. In recent years we have seen tremendous growth in design schools. Sponsors of these schools have nothing to do with design or design pedagogy. They have only commercial interest and that questions their quality of deliverables. This has also influenced the minimum standard required for the students to enter in design courses. The main**

**objective is to fill maximum seats for commercial gains disregarding the aptitude of the student. It has created unjustified image of design of being an easy career. It tends to attract the wrong people.**

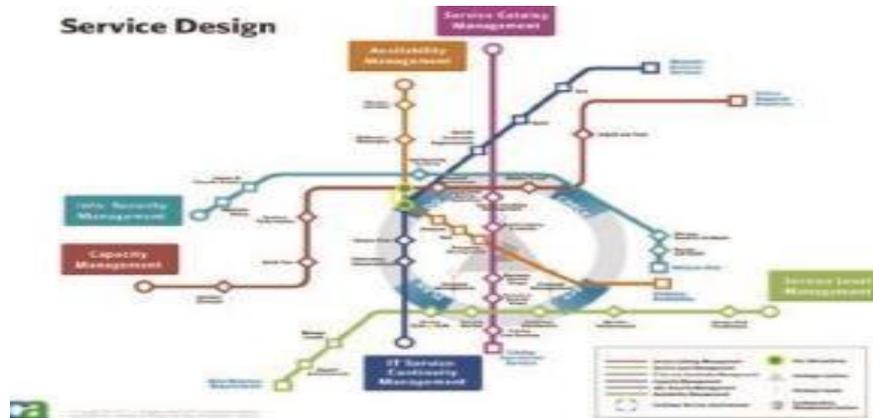


**Introduction of a full-fledged design program in IIT Bombay in 1970's was a landmark event in the world of design education in India. It broke the universal myth that design schools can't be a part of science and technology environment; rather they are more appropriate in art and craft institutes.**

**One of the things that emerged from this endeavour is that in a technological institute a successful design program could be planned, albeit if the marriage between technology and design is handled sensitively i.e. without the dominance of either. Scientists typically approach reality from perspective of what can be known, whereas designers approach reality from the perspective of project ability, of what can be designed. These are different perspectives, and it may be hoped that in the future they will transmute into complementary perspectives. So far design has tried to build bridges to the domain of the science, but not vice versa. We can speculate and hope that in the future, design may become a basic discipline for all scientific areas. This should not be misinterpreted as an attempt to transform design into a science**



However, it's no longer feasible either to limit the notion of design to traditional design discipline such as industrial design, architecture or communication design because scientists are also truly designing. For example, designing of a system for the collection, distribution and transportation of milk by Dr. Kurian, not only helped the farmers but millions of men, women and children to get pure milk at their doorsteps the founder of Amul dairy' program Dr. Kurian and his contribution to designing the collection, distribution and transportation of milk. It not only helped the farmers but millions of men, women and children to get pure milk at their doorsteps. In India we need service designer of various kinds. To make our life safer and to avoid irritants at every moment of our existence, we need hordes of service designers. I say designers and not planners. The distinction between designer and the planner is that the designer sees the problem holistically and has to account for social, psychological and environmental impact. On the other hand, the planner, I presume, is obligated to look at humans with impassive objectivity and delve into the constraints imposed by logistics.



**If we have to avoid the misery of the people and in many cases deaths, a well-trained service designer is a must in planning teams. It is high time that we include service design as a specialization in design curriculum.**

**In a large and a diverse democratic environment like ours, the basic objective of design is for its benefits to touch the masses and not just be limited to a privileged few. The GNP is not the only yardstick to measure the growth of our nation.**

**Industrialization can democratize consumption and provide for a broad sector of the population. This implies access to a world of products and services in different areas of everyday life: health, housing, farming tools, education and transport to mention few. This emphasizes a need to take serious steps to plan directed design and development programs that will help vast number of population. 12th five-year plan as envisaged by our planning commission included more than photos development sectors 30 sectors for faster, more inclusive and sustainable growth. Each section of this sector is helplessly looking forward to innovative inputs from designers and design planners.**

**In 2007 Union cabinet approved the national design policy. The first item on the list was preparation of a platform for creative design development, design promotion and partnerships across many sectors, states, and regions, for integrating design with traditional and technological resources; however, it remained only on paper! The only exception to this vision document is the formation of the Indian Design Council, which is sadly a nonentity. It has failed to take any tangible action in promotion of this vision document. Neither do they have any funds, nor any active programs to put forward design promotion to various sectors.**

**Prof. Gui Bonsiepe my professor in Ulm wrote on the subject on "Design and Democracy" and I quote**

***" Taking a look at the present design discourse one notes a surprising –and I would say alarming–absence of questioning design actives. Concepts like branding, competitiveness, differentiation, globalization, comparative advantages, lifestyle design, strategic design, fun design, emotion design, experience design and smart design prevail in design magazines and the-all too few books about design. Sometimes one gets the impression that a designer aspiring to two minutes of fame feels obliged to invent a new label for setting herself or himself apart from the rest of what professional services offers".***



**Unfortunately, more and more design has moved away from the intelligent problem solving and has drawn nearer to the, intelligent problem solving**



**More and more design moved away from the NID ( National Institute of Design) IDC (Industrial Design Centre) DOD ( Department Of Design)**





**IDC Products first decade transitory, fashionable, quickly obsolete and just a formal aesthetic play of products of everyday life. For this reason, design today is often identified with expensive, exquisite, not particularly practical, funny and formally pushed, colourful objects. It has failed to reach the original objective: to make a difference between design as intelligent problem solving and styling. Thus life-centres of today pursue exclusively commercial and marketing aims to provide orientation for consumption. This patterns a new – or maybe not that new – social segment of global character. This is in complete contrast to advocates of good design who have pursued socio-pedagogical objectives.**

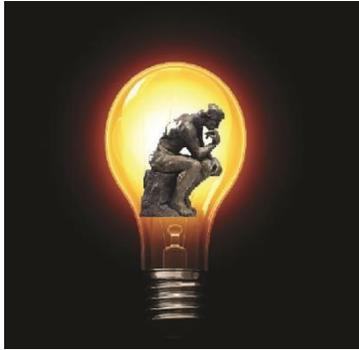
**My training in design school at Ulm in Germany made me aware of the intrinsic nature of design in its principles and methodologies. It has strongly established in my mind the social and humanistic role of**

**design. It has brought me closer to the Gandhian philosophy of simplicity and excellence, the essential elements for good design.**

**'Design as an assistance in Developmental Plans' was the theme of my diploma project under the guidance of Prof. Maldonado. It gave me an impetus to implement some of the ideas I discussed as a prelude to our new educational program back home, first at**

**NID Ahmadabad, and then IDC at IIT Bombay and Department of Design at IIT, Guwahati. In the beginning it was difficult to convince not just the students and other faculty members but also the Government whose prime support for design was for export market. It never occurred to them that it is also a very important tool for improving life of our own people. It took some time to penetrate this approach as IITs are built to give advance technological learning and we were talking about technology to support the basic needs. Our deliberately selected projects to put forth our point of view i.e. our concern for every day needs of the people I believe made some impact.**

**When NID and IDC were established the Indian industrial scenario was not so appealing. Core industries were under Government control, whereas the consumer industry was left to the private sector, which was expected to develop the necessary research and development facilities to cope with the changes to come. Although it had government support through financial concessions, this sector continued to depend on import of product know-how and technology. These ready-made approaches have hindered our own development of innovative culture and led us to an impotent situation.**



**Now Innovation has become suddenly a buzzword in industry, in management education and even in politics. It is very satisfying that with the word innovation comes design thinking. Businessmen often have little to no control over the technological development of the products they peddle. However, using cheap clichés from Bollywood, and icons from mythology, their products are packaged, or shall I say disguised, as innovative products.**

**Here we come to the role of the market and the role of design in the market. Economist Kenneth Galbraith, once the US Ambassador to India and a writer of the book 'Affluent society' analyses the function of the concept of the market that according to him is nothing more than a smokescreen for not talking openly about capitalism. –A term that does not necessarily enjoy a high rating on popularity scale in all social classes and in all countries. Galbraith inserts design in the context of techniques of corporations for gaining and consolidating power. He says and I quote "product innovation and modification is a major economic function, and no significant manufacturer introduces a new product without cultivating the consumer demand for it. Or forgoes effort to influence and sustain the demand for an existing product. Here enters the world of advertising and salesmanship, of television, consumer manipulation and thus leads to an impairment of**

**consumer and market sovereignty. In the real world, producing firm and the industry go far to set the prices and establish the demand, employing to this end monopoly, oligopoly, product design and differentiation, advertising and other sales and trade promotion”.**



**With access to the World Wide Web and liberalization the consumer is now well educated and have enough choices for selection of products. Unless you have enough advantages over other competitive product you have no chance to survive in the market. Design is increasingly becoming a major competitive weapon. More and more number of firms in fact recognizes the importance of design and design driven innovation as a mean to achieve a sustainable competitive advantage. It is heartening to know that the process of design thinking i.e. investigating the problem to its root cause, interacting with the stake holders, the consumer has become a part of their innovative process. Business people realized that there is no more sellers' market. The market driven era is finally given way to the people centred era. Businesses today are built around humans, not merely as customers of commodities. Many of the management schools here and abroad are focusing on how a creative process can be controlled within company. How design in all its facets can become a decisive success factor for company.**

**Firms have also recognized that in today's business dynamics, where innovation has become the basic rule of competition, core capability of managers is their attitude to activate and master the process of innovation. Strategic thinking, vision creation, generation and management of innovation in highly uncertain environments, integration of network of internal and external resources, teamwork, creativity and leadership, are the core skills of tomorrow's managers.**

**Massive liberalization will bring problems not only for our own manufacturing companies but also to our own indigenous designer. To avoid what happened to Designers in Brazil and Argentina after the liberalization, we the designers and the managers must work together to bring forth innovative indigenous products if we have to compete with the home grown international market. Last sixty years or so we talked a lot about innovation, now it is time to start doing something tangible about its actual realization.**

**To conclude this kirtan I would like quote from Prof A.G.Rao's statement**

***" The experiences in the west can only give us leads and unless an approach appropriate to deal with the problems rooted in social, cultural and political structures is developed, the profession would remain a white elephant".***

**I am sure next four days will be interesting and fulfilling endeavour and I wish you all success.**

**Thanking you**



***Lalit Kumar Das pioneered Industrial Design education at IIT Delhi. He has developed a programme that is an excellent blend of design sensitivities and industrial propensities. Very many of his students have distinguished themselves at National & International Design competitions.***

***Lalit graduated in Civil Engineering from IIT Kanpur. Thereafter he did his Masters of Technology in Design Engineering from IIT Delhi and then Master of Art in Industrial Design from the Royal College of Art, London. He has widely travelled and has worked at the Industrial Design Center, I.I.T. Bombay and at the Department of Fine Art, University of Manitoba, Canada and now at Delhi Technological University.***

***At Delhi Technological University he holds the position of Distinguished Honorary Professor and at IIT Bombay, School of Design, as Distinguished Visiting Professor.***

***E-mail: lalitdas@gmail.com***

# **Many Dimensions of Wellness**

*A primer for designers*

*Lalit Kumar Das, Distinguished Honorary Professor*

*Department of Design, Delhi Technological University*

## **Abstract**

*The primer for designers, explores the many dimensions of wellness starting from Physiological, to psychological, to mental, to social and finally aspirational. Each of these dimensions has opportunity for design intervention which is left for the designer to explore. Wellness is an emerging and impending concern that will engage all designers in the decades ahead.*

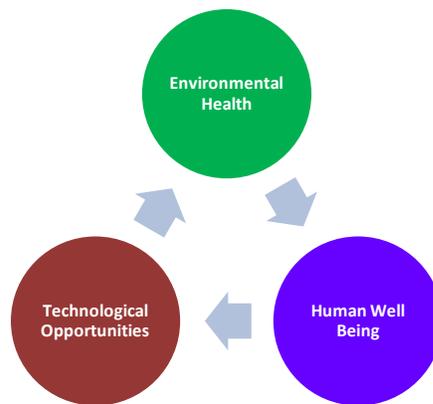
## **Keywords**

*Well-being, wellness, human care*

**Designers by training are creative problem solvers who are engaged in design of product, services, environment, communication and experience. If design is to deliver wellbeing then it becomes essential to understand what human wellness is all about.**

**Wellbeing of humans has been propelling and justifying technological advancement in the last three centuries. While humans generate the knowledge, methods and machines for its advancement, its advancement also relies heavily on the**

**environment for the energy and material resources. Thus, technological advancement has been adversely impacting the environment. This in turn has been impacting human well-being.**



**Design in the 21<sup>st</sup> Century will be increasingly challenged by this triad. It is important for designers to engage themselves with human and environmental wellbeing The symbiosis between humans and environment will be the key driving force in design education and design profession. Humans and environment are immiscibly linked. However here my focus is on human well being.**

**Economic wellbeing is important for people as it enables access to product and services required to fulfil their needs, wants and aspirations. Technology, innovation and design has brought about a proliferation of product, services and opportunities. This brought about tremendous improvement in standard of living. Together with advancements in hygiene and nutrition it increased the life expectancy of the humans. However later in 20<sup>th</sup> Century it become clear that it was accompanied with environmental degradation which had an adverse impact on the ecosystem and people's health. Life expectancy continued to increase but at a higher medical cost.**

## **Physiological Well Being**

**It moved over to physical health through advancement in surgical practices, medicines in particular antibiotics, antiseptics, anaesthesia, drug supplements & delivery systems, management of physiological parameter, diagnostics, hospitals & intensive care units.**

## **Circulatory System & Well Being**

**Circulatory system is at the core of physiological wellbeing. It distributes the resources for wellness and removes the waste by products. The two major circulatory systems in our body are the blood and lymphatic systems. Although the blood system has been studied extensively. The lymphatic system has not been as well studied as the blood circulatory system. It has received much less scientific and medical attention because of its elusive morphology and mysterious pathophysiology. The blood circulation picks up nutrients from the intestines and carries it to all parts of the body. In addition, the blood through arteries, veins and capillaries, carries oxygen from inhaled air to the tissues of the body, and venous blood carries carbon dioxide, a waste by product of metabolism in the cells, from the tissues to the lungs to be exhaled out. In addition, the leukocytes also called white blood cells help defend the body against infection and foreign substances. Disorders in the white blood cells, affect the body's immune response and its ability to fight infection. The lymphatic system serves as one of the body's main vessels of immunity, the lymphatic's primary function is to create immune cells. The system also helps to transfer away fluids from tissue in the body, as well as absorb fat and move that fat to the**

**circulatory system. Its improper functioning is detrimental to good health. Lymphatic system does not have a dedicated pump to perform its functions. It in fact functions when we move our body. Walking, exercising or any other form of body movement helps in the flow of lymph. Sedentary lifestyle is not good for the lymphatic system and therefore it is often advised to move around. Soft massaging is also of great help. Exercising and food, water and fresh air are central to good health. Without it circulatory system cannot perform its function.**



## **Skeleton, Joints, Muscles & Well Being**

**The muscles and skeleton together form a system that gives humans the ability to move in a controlled manner the different parts of body. The muscle-skeletal system serves as a framework for tissues and organs to attach themselves to. It also serves as a protective structure for vital organs. The brain being protected by the skull and the lungs are protected by the rib cage. The muscle-skeletal system provides a structural integrity to the human body. It helps coordinate the body movements. Adjacent bones and muscles are connected to each via connective tissue such as tendons and ligaments. Muscles not only keeps bones in place and also play a role in the movement of bones and together with the sense of balance provides for stable, safe and predictable movements. To allow**

**motion, different bones are connected by joints. Cartilage prevents the bone ends from rubbing directly onto each other. If the space between joints become less than optimal then bones may rub each other causing pain and discomfort. Synovial fluid between the gaps provides lubrication. Glucosamine a naturally produced compound in the body, if reduced onset rheumatism and arthritis. Glucosamine or bone broth as supplements can help overcome deficiency.**

**Though bones are essentially a structural element to sustain forces and loads, they have other functions also. In the long bones of legs and hands resides the red and yellow bone marrow. The yellow marrow found in the marrow cavity stores fat that the body uses during starvation. The red marrow in some bones produces blood cell production. Here all erythrocytes, platelets, and most leukocytes are produced and migrate to the blood to do their special tasks.**

**Another function of bones is the storage of certain minerals and help regulate mineral balance in the bloodstream. When minerals are high, they are stored in bone; when it is low it will be delivered from the bone.**

**There are three types of muscles—cardiac, skeletal, and smooth. Both cardiac and smooth are not consciously controlled. Smooth muscles control the flow of substances within the lumens of hollow organs. Cardiac muscles control the beating of heart and thereby main blood flow. Skeletal muscles are consciously controlled and can precisely move the desired part of the body. Muscles receive and send information through nerves. They are linked to the central nervous system.**

**Ligaments are fibrous tissue that connect the ends of bones together in order to form a joint. Ligaments limit dislocation, or prevent certain movements. They are only elastic and can increasingly lengthen when under tension. They can also lose their elasticity. When this occurs, the ligament may be susceptible to break resulting in dislocation and an unstable joint.**

**The skeleton system, the muscles, and the organs support each other and they are covered and held together by the skin. The skin is protected by a biome that protects and maintains its health.**

**Things can go wrong anywhere in this complex, interconnected system. The many causes of ill-health and unhappiness could be paralysis, fragile and broken bones, arthritis, broken ligaments, sprains and dermatitis, etc. Prevention of disorders here can be an important area of design intervention.**



## **Diet & Well Being**

**In the second phase of scientific health management we have moved towards nutraceuticals. The emphasis is on food supplements, vitamins, prebiotics that can manage disease. Say no to chemicals & pre-processed foods. Organics are the in thing. Strengthening immune systems has become important. Smart watches are**

becoming popular for managing blood pressure, exercise, sleep. Now the emphasis is towards natural and life regimes for managing physical health.

Cuisine & culinary designers are busy dishing recipes that are health giving. Designers are coming up with new cooking systems that cook healthier foods.



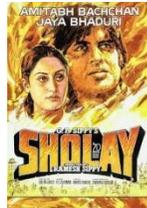
## Endocrine System & Well Being

The role of endocrine systems that releases hormones is becoming important in moment to moment wellbeing of humans. Different hormones have different effects on the shape of the body. Some of these hormones work quickly to start or stop a process and some will continually work over a long period of time to perform their functions. They help in body growth, development, metabolism, sexual function, reproduction, mental processes, etc.

We are beginning to understand the functions of Triiodothyronine (T3) and Thyroxine (T4) released by the thyroid gland. These helps manage growth and metabolism. Then there is insulin released by pancreas for controlling the usage and storage of glucose and thereby energy availability for muscle function and activities. Further we have Oestrogen, Progesterone, Prolactin and Testosterone that help manage reproductive functions in the human body.

Still further we have hormones that govern our mental states. Notable among these are Serotonin which nature's feel-good chemical. It is associated with learning and memory, regulating sleep, digestion, regulates mood, some muscular functions etc. Then there is Oxytocin, Dopamine, Cortisol, Adrenaline. They all bring you into a state of mind.

Laughter, tears, sex, intense activity, taking up challenging tasks, caring, smiling, cuddling can all play an important role in secretions of hormones and refreshing / resetting physiological and mental functioning. Artists, designers, architects, film makers, story tellers can manage our moods and our state of well-being.



## Senses & Cognition

There are five important senses. vision, auditory system, tactile, olfactory. These are essential to learn about the external environment. There are different parts of the brain dedicated to each sensory stimulus. Communication within and among these specialized areas also takes. Multisensory integration brings about a more vivid representation of objects and experiences. Dysfunctionality here can lead to major impairment. In addition to the five senses we also have proprioception, vestibular system, interoception. Proprioception is concerned with a sense of the relative position of one's own parts of the body and strength of effort being employed in movement. A cat wishing to walk through a

whole must know its boundaries and compare it with the size of the hole before it ventures to do so. Vestibular is concerned with the sense of the relative position of one's own parts of the body and strength of effort being employed in movement. This is necessary to maintain balance when walking over a boundary wall. Interoception is defined as the sense of the internal state of the body. It encompasses the brain's process of integrating signals relayed from the body into specific sub regions—like the brainstem, thalamus, insula, somatosensory, and anterior cingulate cortex—allowing for a nuanced representation of the physiological state of the body. This is important for maintaining homeostatic conditions in the body and, potentially, aiding in bodily self-awareness. These together allow us to perform our day to day activities while maintaining the integrated functioning of the body.

Information from the senses is interpreted by the brain. It is pieced together into objects, structures and processes. Relationships are formed. These relationships grow into narratives that guide life. These narratives modulate our interaction with the environment. The narratives we hold determine our interaction with others. The narratives will determine our ability to cooperate and collaborate. In short, our interpretation of ourselves and our environment determines our state of wellness.

Cognition is not confined to the brain in the skull. The guts, i.e. the stomach and intestine too require information processing. What we put in our mouth and swallow will determine the bio-chemical processes required to digest and assimilate the food. The gut's brain or the "enteric nervous system" is located in the sheaths of tissue lining the oesophagus, stomach, small intestine and colon.

Considered a single entity, it is a network of neurons, neurotransmitters and proteins that zap messages between neurons, support cells like those found in the brain proper and a complex circuitry that enables it to act independently, learn, remember. This plays an important role in digestion. There is to and for communication between the brain in the skull and brain in the guts.

The immune system is also a cognitive apparatus. It has to determine what is foreign and harmful to the body and device mechanism to fight and overcome the adversary and remove it through the lymphatic system or tuck it away in the bones.

Wellness and cognition are closely linked. Cognition cannot happen in a stimulus free environment. Interaction is absolutely vital. Over stimulation may be upsetting but under-stimulation is not conducive to growth and wellness. Sterility breed sterility.



## **Sleep & Well Being**

We know very little about the purpose of sleep but it is clear that lack of sleep can have detrimental effect on human health. They must have their daily dose of sleep. During this period a lot of physiological and psychological repair and reconciliation takes place. We also do not know what is the best sleeping pattern for a well-being. Much research is on the role of REM sleep and Deep Sleep. Most mammals and birds show signs of REM sleep. However, reptiles

and other cold-blooded animals do not. Today, gadgets like smart watches are telling us how well we are sleeping. Creative experimentalists are designing sound waves and music to induce sleep.

## **Physiological Care & Well-Being**

We see that there are innumerable vulnerable points for things to go wrong and upset the wellness cart. What we see is merely the tip of the ice-berg. WHO statistics show that 45% of member states have less than 1 physician for every 10,000 population. India would fall in this bracket. On the higher side we have Cuba with 81.9 physician per 10,000 population. Sweden has 50 physicians per 10000 population. Number of physicians or GDP slice devoted to health is not the final measure of physiological wellness. Consequently gyms, spas, yoga centres, alternative healing centres, nutritional advisors propose and promise wellness. There is an enormous opportunity for designers to step in and hold hands with others. However, the designers will have to shed that old consumerist paradigm in design and evolve a new design culture of holistic empathy and care.

## **Prosthesis & Well Being**

A prosthesis is an artificial device that replaces a missing body part, which may be lost through trauma, disease, or a condition present at birth (congenital disorder). Prostheses are intended to restore the normal functions of the missing body part. Amputee rehabilitation is primarily coordinated by a physiatrist as part of an inter-disciplinary team consisting of physiatrists, prosthetists, nurses, physical therapists, and occupational therapists. Prostheses can be created by hand or with Computer-Aided Design (CAD), a software interface

that helps creators design and analyse the creation with computer-generated 2-D and 3-D graphics as well as analysis and optimization tools. There is prosthetic limb for amputees, dental, facial, ocular, breast, heart valve, etc.

There are many research studies that have documented the efficacy of prosthesis both from a functional and psychological viewpoint. Prosthesis is a great leveller. It brings about social inclusiveness.

### **Assistive Technology & Well-being**

Assistive technology provides assistive, rehabilitative and adaptive devices for people with disabilities, impairment or the elderly. People who have disabilities often have difficulty performing activities of daily living independently, or even with assistance. Self-care activities that require assistive technology may cover toileting, mobility, eating, bathing, dressing, grooming, and personal care. Assistive technology can ameliorate the effects of disabilities that limit the ability to perform daily activities. Assistive technology promotes greater independence by enabling people to perform tasks they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to, or changing methods of interacting with, the technology needed to accomplish such tasks. Wheelchairs provide independent mobility for those who cannot walk, while assistive eating devices can enable people who cannot feed themselves to do so. Due to assistive technology, people with disabilities have an opportunity of a more positive and self-sustaining lifestyle, with an increase in "social participation," "security and control," and a greater chance to "reduce institutional costs without significantly increasing household expenses."

**Here designers have been playing a role and will continue to do so.**



## **Psychological Well-being**

**Brain is the seat of Human personality. Personality is about our different ways of being human. How we are all variations on the same themes. How the human nature we all share manifests in different styles of thinking, feeling and acting. Personality is defined as the characteristic sets of behaviours, cognitions, and emotional patterns that may be inherited or evolve from biological and environmental factors. It is ways of responding to a situation. It is a bundle of our cognitive filters, our attitudes and emotions. It is these attitudes, motivations, beliefs and filters that determine sense our well-being. Be it positive or negative. The wellbeing may be short term or long termed. It will determine our sense of security or insecurity. It will determine our greed and fears, our desires and aversions. The type of projects we embark on. The relationships we cultivate. Psychologically we can make an issue out of anything. Or anything can be a non-issue. We can hold memories of non-pleasant experience for ever, or we can let bygone be bygone. We can forgive and forget or we can nurture hatred for ever and let our future course of action be determined by the past happenings and encounter.**

***"Your personality style is your organizing principle. It propels you on your life path. It represents the orderly arrangement of all your attributes, thoughts, feelings, attitudes, behaviours, and coping mechanisms. It is the distinctive pattern of your psychological functioning—the way you think, feel, and behave—that makes you definitely you." – The New Personality Self-Portrait by Oldham and Morris. [2]***

**Each personality type has its own propensity for wellness.**

**Personality has many facets that people talk about when describing a person. Personality is often assessed using a self-report inventory or observer report inventory.**

**The six factors, their facets, and the personality-descriptive adjectives that typically belong to these six groups are as follows: [**

### **Honesty-Humility (H):**

***Facets: Sincerity, Fairness, Greed Avoidance, Modesty***

***Adjectives: Sincere, honest, faithful, loyal, modest/unassuming versus sly, deceitful, greedy, pretentious, hypocritical, boastful, pompous***

### **Emotionality (E):**

***Facets: Fearfulness, Anxiety, Dependence, Sentimentality***

***Adjectives: Emotional, oversensitive, sentimental, fearful, anxious, vulnerable versus brave, tough, independent, self-assured, stable***

## **Extraversion (X):**

*Facets: Social Self-Esteem, Social Boldness, Sociability, Liveliness*

*Adjectives: Outgoing, lively, extraverted, sociable, talkative, cheerful, active versus shy, passive, withdrawn, introverted, quiet, reserved*

## **Agreeableness (A):**

*Facets: Forgivingness, Gentleness, Flexibility, Patience*

*Adjectives: patient, tolerant, peaceful, mild, agreeable, lenient, gentle versus ill-tempered, quarrelsome, stubborn, choleric*

## **Conscientiousness (C):**

*Facets: Organization, Diligence, Perfectionism, Prudence*

*Adjectives: organized, disciplined, diligent, careful, thorough, precise versus sloppy, negligent, reckless, lazy, irresponsible, absent-minded*

## **Openness to Experience (O):**

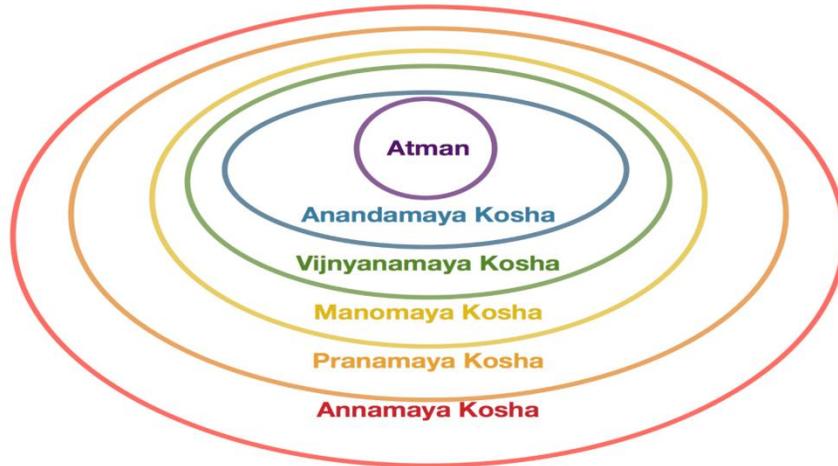
*Facets: Aesthetic Appreciation, Inquisitiveness, Creativity, Unconventionality*

*Adjectives: intellectual, creative, unconventional, innovative, ironic versus shallow, unimaginative, conventional*

**Personality not something that is carved out in stone. Personality can change with physiological biochemistry at different period of our**

growth. Our hormones can affect or responses and this in turn can shape our personality.

## **Meditation, Mindfulness & Yoga**



**Annamaya kosha. This is the gross, physical body. Food creates it.**

**Pranmay Kosh (the life force) is the pranic sheath composed of prana, the vital principle or the force that holds together the body and the mind. Its physical manifestation is the breath.**

**Manomaya means composed of manas or mind. Thinking, feeling and willing. The mind along with the five sensory organs (taste (tongue),smell (nose), vision (eyes), hearing (ear), and touch (skin), is said to constitute the manomaya kosa or "mind-sheath".**

**Vijnanamaya means composed of vijnana, or intellect, the faculty which discriminates, determines or wills.**

**The fifth or the Anandmaya Kosh is the innermost Kosh in close proximity of the Soul.**

**Yoga, meditation and mindfulness is concerned with the union, the synchronization, developing harmony, enabling unfettered flow and interaction among the five sheaths of human body.**

**Over indulgence in any thought becomes a fetter that obstructs the flow of energy. Thoughts that are governed by lust, greed, anger, disgust and attachment are most obstructive and impede wellness.**

**Yoga, meditation and mindfulness has been extensively researched scientifically and have validated its efficacy in enhancing and restoring wellbeing in the subjects.**

**Balance is the essence of wellbeing. It is variously described in various Asian cultures as Ying / Yang, Li / Chi, Shiva / Shakti**

**Yama (abstentions), Niyama (observances)**

**Asana, Pranayama, Pratyahara: Domain of Yoga**

**Dharana, Dhyana and Samadhi is the domain of meditation & mindfulness**

**Awareness is an important underlying thread. It is the most essential ingredient in our quest for wellness**

## **Brain Wave & Well Being**

**Different life activities require different measures of attentiveness, focus, flexibility, resilience and relaxation. The brain is switching from one state to another depending on the requirement of the activity. While it is difficult to continuously monitor what is going on in the brain at the neural level, however researches have been able**

to monitor the electrical activity emanating from the brain. The field of Electroencephalography (EEG) has advanced so much that it is possible to have reliable capturing of brain waves using easily wearable dry electrodes. This has made brain wave studies common place. It has been scientifically established there is a very close one to one relationship between the state of brain functioning and brain waves

**> 40 Hz    *Gamma waves***

*Higher mental activity, including perception, problem solving, and consciousness*

**13–39 Hz    *Beta waves***

*Active, busy thinking, active processing, active concentration, arousal, and cognition*

**7–13 Hz    *Alpha waves***

*Calm relaxed yet alert state*

**4–7 Hz    *Theta waves***

*Deep meditation /relaxation, REM sleep*

**< 4 Hz    *Delta waves***

*Deep dreamless sleep, loss of body awareness*

Ten of thousands of users are using some Rs. 30,000/= devices to practices neurotherapy through neurofeedback that uses real-time

**displays of brain activity—most commonly electroencephalography (EEG)—in an attempt to teach self-regulation of brain function.**

**This can become an important tool in developing wellbeing.**



## **Social Well Being**

**People with good social connections tend to live longer and are healthier than those who don't.**

**Social health can be nurtured by good and positive relationship with family members, neighbours, friends, co-workers, class-mates, etc. Belongingness and social contact can also come from community groups, volunteer organisations, social work groups, hobby groups, etc.**

**Relationships are all important in fuelling positive emotions, whether they are work-related, familial, romantic. Even pets play an important role. Relating with others is important in both good and bad times.**

**Social media has added a new dimension to social wellbeing. People can connect with each other over even though they may be geographically removed. Other people like and comments have become important. Trolls can be devastating. People can get addicted to social media and this addiction can impair wellness.**

## **Aspirational Wellbeing**

**We all aspire to be our best. We also aspire to be something more than we are. We are not omni-potent in our motivations and potentialities. We need help, we need guidance, we need training, we need mentors, we need facilities. Our prospects for fulfilling our aspirations depend so much on the socio-political infra-structure around us. We want recognition for our achievements. We may even want to help attain their aspirations. We want to understand, we want to be understood. We want to aspire; we want to help others to aspire. We want to attain; we want others to attain.**

**Maslow articulates a set of human needs. Physiological and Safety Needs being the most basic. Beyond this are love and belongingness, esteem and transcendence. Researchers have added three more needs. Need for knowledge and understanding, need for aesthetics and need for self-actualisation. These are aspirational needs. In many situations of extreme poverty, physiological and safety needs themselves will be necessary for aspirational wellbeing.**

## **Conclusions**

**There are many dimensions to human wellbeing. An awareness of the many dimensions will enable designers to direct their empathy in better understanding their users and stakeholders. Only through an empathetic understanding, can we appreciate the persona, we are trying to benefit, really stands, what are the bottlenecks and how the persona can be helped to achieve to move forward in their wellbeing.**

**Design is about caring. Without empathetic understanding there can be no caring. Wellness is central to caring.**

## **Acknowledgement**

**The author acknowledges with gratitude, use of images obtained through google search engine for use in this free, zero cost article meant for academic use. The choice of images was largely incidental and meant only to point out further directions for exploration. Thanking all authors for the same.**

## **Suggested Reading**

***An Introduction to the Study of Man by J. Z. Young, Oxford University Press; 1st edition (1971)***

***Anatomica: The Complete Home Medical Reference, by Peter Forrestal (Editor), Global Books, 2001***

***The Pursuit of Human Well-Being: The Untold Global History, Richard J. Estes, M. Joseph Sirgy (Editors), Springer 2017***

***Sustainability, Human Well-Being, and the Future of Education, by Justin W. Cook (Editor), Springer Nature, Switzerland, 2019***



***Dr. Harvinder Singh Chhabra is Chief of Spine Service and Medical Director at Indian Spinal Injuries Centre, New Delhi, India. His expertise is grounded by more than 25 years of clinical and academic experience as an orthopedic surgeon. He is the President of International Spinal Cord Society and Associations of Spine Surgeons of India, Member Secretary of Association of National Board Accredited Institutions (ANBAI) and Spinal Cord Society-Indian Chapter (SCS), Executive Member at Asian Spinal Cord Network (ASCoN) & International Group for Advancement in Spinal Science (IGASS). He is Peer reviewer at various journals. Dr Chhabra has over 107 publications including papers & full-length chapters in the leading textbooks to his credit. In the last few years, Dr Chhabra has been a recipient of some of the major prestigious awards and recognitions like felicitation by Hon'ble Health Minister and ASCoN Star Award 2018 for his immense contribution to the realm of medicine and Spinal Cord Injury service development in India and the wider Asia region. He has also been honored with ASSI Research Awards for Seven consecutive years from 2013 to 2019.***

# **Challenges, Costs & in Comprehensive Rehabilitation of people with spinal cord injury in India- ISIC Experience**

*Dr. Harvinder Singh Chhabra*

**The term Spinal Cord Injury (SCI) refers to damage to the spinal cord which leaves a person with partial or complete loss of sensory function or motor control of arms, legs and/or body for life. In India, there has been a surge of such injuries with increase in high impact road traffic collisions and poor pre-hospital care. This is in tandem with increase in non-traumatic reasons such as tuberculosis or cancer.**

**There is no reliable estimate of global prevalence, but estimated annual global incidence is 40 to 80 cases per million populations (WHO report). In India, approximately 1.5 million people live with SCI. Approximate 20,000 new cases of SCI are added every year and 60-70% of them are illiterate, poor villagers (R Singh). About 10% of all the traumatic SCI receive no proper acute management and around 72% of patients are sent home after acute management without comprehensive rehabilitation.**

**There is a continuous challenge and burden with regard to acute care, rehabilitation services and health maintenance for prevention and management of various complications that arise with SCI. These include lifelong debilitating and even life-threatening conditions like deep vein thrombosis, urinary tract infections, muscle spasms, osteoporosis, pressure ulcers, chronic pain, and respiratory**

**complications. Aside from the physical and emotional recovery, the main issues for individuals with SCI are financial concerns, lack of appropriate accessible housing and transportation, access to adequate personal care supports, and high unemployment.**

**The number of SCI centers and the services available are grossly inadequate. Post-discharge follow-ups, home-care services, community inclusion and vocation are areas in which India lags behind. Not returning to vocation is a result of inadequate vocational rehabilitation, followed by lack of awareness of government benefits, lack of opportunity and psychological factors.**

**Other factors like lack of availability of trained manpower, inadequacy and inaccessibility of services, non-availability of multidisciplinary comprehensive care, lack of a barrier-free environment and financial barriers hinder comprehensive management of SCI and leaves the injured home bound, jobless and a permanent burden to the family.**

**The financial factor leading to non-treatment of ailments in India has doubled. The Socio-economic scenario in India thus poses a big challenge to SCI management. It is expected that a very large percentage of the Indian population find it difficult to access the expenses of SCI management and community integration. The subjects of the lower group are often not even able to reach a tertiary level center. Essential medical coverage for SCI management is unaided to upper lower, lower middle and upper middle socio-economic Indian groups and these strata face maximum financial challenges in all the stages of treatment. One of our surveys published in 2015 in Spinal Cord Journal suggests that**

**financial constraints affected all components of SCI management in all except the upper class.**

**Very often the people with SCI keep pursuing alternative medicine with the hope of a 'cure'. This is especially true for cellular therapies. There had been media hype about the positive outcome of this therapy. People with SCI often spend precious resources to avail such transplantations. In the meantime, they do not pursue rehabilitation in the expectation of a 'cure'. Once it becomes evident that they would not improve in neurology, they become depressed.**

**Mostly, patients reaching our centre do not have proper wheelchairs prescription depending upon person needs and level of injury. For example, a person with injury at lower dorsal level may require wheelchair with least back support. Another problem is with repeated use of catheters which leads to recurrent urine infection. Intermittent catheterization (evacuating urine by inserting catheter in the urinary sphincter) is either not initiated or initiated late which leads to bladder complications. The majority of patients in the LMIC are not able to afford disposable catheters due to the costs involved. Majority of consumers use reusable Nelaton or Foley's catheters because of lack of affordability.**

**There remains a vast imbalance in the availability of specialized spine services between urban and rural areas due to the aggregation of tertiary centers in cities and a lack of a systematic referral system for spinal ailments. Despite much development over the last few decades, there exists a substantial gap between what is "possible" or "needed" and that "actually available" to the common man. We believe that strong family support, awareness and availability of cheaper resources may help in overcoming these challenges.**



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***Dr.Amit Ramesh Dhumale is currently Director Rehabilitation services at Jupiter hospital, Thane Mumbai. He is actively involved in planning & executing inter-disciplinary rehabilitation program for stroke, traumatic brain injury, cerebral palsy, spinal cord injury, Parkinson's disease & other progressive / non-progressive neurological diseases for all phases of rehabilitation (Adult & Paediatric).***

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memorial, Ville Parle***

***Dr. Priyank Patel is an eminent Orthopaedic Spine surgeon. After  
finishing his basic MBBS training in Mumbai and MS training in  
Nashik, he received the Prestigious Spine Foundation Fellowship in  
Mumbai. He has also trained at several international centres of  
excellence in spine like University of Wales, Cardiff, Robert Jones  
and Agnes Hunt hospital, Oswestry, UK, Fellowship in Spinal  
Deformity at Royal Orthopaedic hospital, Birmingham, Uk,  
Fellowship in Minimally Invasive Spine Surgery, Chicago, USA,  
Fellowship in spine Oncology, bologna, Italy. He is attached to  
several hospitals in the city like Jupiter/ Lilavati / Breach Candy and  
many more. He is also involved in various teaching and philanthropic  
activities of the Spine Foundation, Mumbai. Dr. Priyank  
Patel understands the impact of spine related disorders and believes  
in a conservative approach to the problem. With almost 10 years'***

***experience in the field, Dr. Priyank Patel has various national and international presentations and publications to his merit. He attends various conferences and workshops to keep him updated in newer technologies and skill set in spinal surgeries. Minimally Invasive Spine Surgery and Spine Tumour Surgery are his special interests.  
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# **Saloni Merchant- Factors That Led To A Miraculous Recovery**

*Dr. Priyank Patel, Spine Surgeon*

*Dr. Amit Dhumale, D.N.B. (PM&R), D Ortho*

**A 16-year-old girl who had fallen off a 15 feet high wall leaving her paralysed waist down, is now able to walk & run independently. The fall had led to a spinal fracture & paraplegia. Timely surgery & rigorous neuro-rehabilitation at Jupiter hospital for over 2 months helped her finally recover fully.**

**Saloni had a complete 3 column fracture in the mid dorsal spine, which resulted in translation, flexion & rotation of spine. As a result of this the spinal cord got compressed. The injury was very severe which led to complete paraplegia below level of D6. When they saw me she had been in this condition for over 48 hours. Given her age we wanted to give her the best chance of recovery. The first step was to realign the spine & stabilise it with pedicle screw- rod system and at same time decompressing the nerves. The next step was to optimise her medically & start rehabilitation. Since we wanted to start rehabilitation as soon as possible, we used minimally invasive techniques that she could start rehabilitation within 24 hours of surgery.**

**Saloni underwent a comprehensive inter-disciplinary coordinated rehab program including conventional therapys as well as advanced rehab technologies in the form of robotic, sensor based, computer aided & virtual reality rehabilitation. Rehabilitation is an important**

**part of the patient journey to recovery after a medical setback in life so as to live an independent life.**

**Apart from this I would like to share my thoughts on what attributed to a miraculous recovery in Saloni's case:**

***1) I really appreciate Dr Priyank Patel not only for his surgical skills but the faith he put in me & my rehab team. I was the first person he called when he came out of the operating room as he told me that she needs a good rehab program to compliment the surgery. There is an immense need to spread the awareness about rehabilitation amongst healthcare professionals.***

***2) The faith that the family put into us. Saloni has excellent family support. Her parents were extremely cooperative & understanding.***

***3) Team approach & team spirit in the rehabilitation team is always crucial to a successful rehab process.***

***4) Access to state of the art advanced rehabilitation technology.***

***5) Last but not least, regular rehab counselling of patients & her family. This was a devastating incident not only for the patients but the family as well. The parents were shattered & at times seemed to lose hope & think about the worst. Rehab counselling assured them that they are not alone in this struggle. We advise our patients to concentrate on things their disability does not prevent them from doing & don't regret the things it interferes with. It's important to have an emotional connect with the patient & their family.***

**In the end me & my rehabilitation team are happy that we are a part of this family's most memorable experience. Their smile says it all as**

**they told me that they had never imagined that they could be happy again. There is nothing more satisfying than that.**



***Saloni on her feet once again From L to R: Dr. Priyank Patel, Saloni Merchant, Dr. Amit Dhumale***



***Chandra Rao. I have been in a wheelchair for most of life, 62 years now.!***

***I was fortunate that my Spinal Cord Injury happened in England when my father who was in the Indian Army was posted to England for a 2-year course at the Royal College of Military Science. I was treated in the best hospital at that time for Spinal Injuries, under Dr Ludwig Guttmann.***

***My education was resumed when my father got posted to Delhi and I recovered completely after battling pressure sore for 3 years and after 4 operations.***

***After school I completed B. Com (Hons) from Delhi University, and Chartered Accountancy from a medium sized Accountancy Firm. When I did my CA, I was only the second women to qualify from Delhi and there were only 38 women CAs from all over India!!***

***The professional qualification enabled me to get a direct officer entry into Central Bank of India and I finally resigned after being a Chief Manager.***

***Email- chandrao@yahoo.com***

# **Quality of Life of Living with Spinal Cord Injury in India: Rehabilitation Design Challenges and Solution.**

## **Accessibility of Home from Spinal Cord Injured Person's Perspective:**

*Chandra Rama Rao*

*After a person suffers a Spinal Cord Injury and the family finds out that she will be spending the rest of one's life in a wheelchair the impact of all the hurdles to everyday life hits one very hard. More so when the person is brought home from the hospital and it is realised that nothing in the home is convenient for the wheelchair user.*

It starts with the entrance to the home. Obviously. There will be steps and daily entry and exit will entail help. A Ramp will be a cheap and permanent solution, but this may not always be possible due to space constraints. But where this is possible it should be gently sloping. According to UN standards on Barrier Free Environment requirements the inclination should 1:12 and the width of the ramp should be at least 1 metre. It should also have railings on both sides. If one cannot build a ramp due to the position of the house /flat or lack of requisite space

The alternative is to have a small hydraulic lift which is powered by a generator set and is compact enough to be installed outside. The cost varies with the specifications. The manufacturers/ dealers in India can be accessed on the internet.

**Another alternative is a stair lift in case the house is a duplex house and the stairway is within the house. Again the most appropriate will depend on the person who has to use it. Her level and extent of disability and the costs involved.**

**Once in the house I would like to touch on some major issues.**

**Doorways.** Doors necessarily need to be wide enough to let the wheelchair in.

**Minimum for comfortable entry (without grazing ones knuckles!) is 30 inches Where the door is not wide enough then the Chowkat (the framework of the door) may have to be removed and a thinner one inserted. A sliding door maybe feasible too. Which way the door opens is also relevant, there has to be enough space for the wheelchair to manoeuvre and get in safely.**

**Doors leading into bedrooms and bathrooms need to be wide enough. My own experience has been that in most houses the door leading into the toilet is smaller. In many houses it is just 23 inches and the bathroom is also very small. Of course once the house is built it may not be possible to change the specification of the size of the bathroom and even the placement of the toilet, wash basin and bathing areas. How this can be made more accessible and convenient is something an interior designer/ architect/ occupational therapist will have to see and suggest alterations.**

**But it is necessary to ensure that the floor is level and the washbasin has space underneath for the wheelchair user to approach and slide under the wash basin.**

**Another important issue is that bolts and locks on doors have to be reachable. Generally, bolts are placed at the top and at the floor level. Both these points are not reachable for the wheelchair user. Ideally it needs to be fixed at a level of 30inches to 36inches high so that it is reachable. Self-locking doors are not a good idea as it will require a key to open the door, especially if the wheelchair person has limited use of hands and fingers. It may also prevent entry from outside if the wheelchair user falls down or is unable to transfer on wheelchair and open the door.**

**Positioning of the doors is important for the free movement of the wheelchair furniture needs to be placed such that there is adequate free space available for moving within the room.**

### **Electric Switches and Plug points:**

**In almost all houses the convention has been to place switches near the door so that lights can be switched on as one enters the room. The plug points are invariably placed just about 4inches to 6inches above the floor level in corners. Both these practices are quite inconvenient for everyone and more so for a wheelchair user. It is a mystery to me why plug points are placed so low and in corners. These are inaccessible to wheelchair users as well as old people. And dangerous for babies who love to crawl and explore every nook and cranny.**

### **Bathrooms:**

**I have noticed that due to space constraints they are becoming smaller and smaller. For a wheelchair user it has to be at least 8 feet by 5 feet to enable movement in the bathroom. The placing of the**

wash basin, western style toilet and bathing area also have to be convenient. The toilet should not be placed in the corner it is difficult to approach the toilet in that position. I find the best position is right in front of the door. Of course in an existing house this may not be possible as the sewage and pipe lines would have already been laid according to layout. However, if a new bathroom is planned then a very careful thought has to be given to the placement and grab bars planned in advance. Floor mounted toilets are more stable and firmer for wheelchair users. The height of the toilet should be 17inches to 18inches high. A very low toilet is quite inconvenient for a wheelchair user to get on and off. Commode seat risers are also available in India and online.

Washbasins should be wall based so that the wheelchair can approach as near as possible and slide underneath, there should not be any cupboards underneath the washbasin. Switches and Plug points need be reachable.

The floor should be flush with the bedroom. Generally, bathrooms are made about an inch or so lower, ostensibly to prevent water from flowing into the bedroom. But this is a hindrance for the wheelchair user and could also lead to the overturning of the wheelchair while exiting the bathroom in wet conditions.

The taps and hand showers should be within reach. Any plug points for geysers should also be reachable. Normally they are placed high at 6 or 7 ft. A sliding door is the most convenient for the bathroom. It also maximises the available space and is easier for the wheelchair user to close and open the door. A Reacher can be placed in the washroom to safely switch on/ off geysers and switches as electric gadgets need to be free of water spray.

## **Kitchen:**

**In many houses kitchens are small and out of necessity shelves are placed high on the wall. Below the counter tops also cupboards are built. This of course makes it quite inaccessible for the wheelchair user to access the provisions from the shelves and get near enough the counter top to be able to do anything. For the wheelchair user to cook the kitchen does need several changes. The counter top should be no more than 30 inches high. A part of it should also be cupboard free so that the wheelchair can slide underneath for working. The position of the kitchen sink may also need to be adjusted so that the wheelchair user can wash his/her hands. Here also there should not be any cupboard underneath the sink. The tap should be reachable from the wheelchair. While it will be impossible to have everything within reach of the wheelchair user's reach, some shelves have to be made reachable from the wheelchair. Plug points and switches also need to be placed at a comfortable height.**

**Conclusion: The wheelchair user should have easy access to the entire house. For this all the rooms should be at one level and the furniture so placed that the wheelchair user has enough space to manoeuvre. People must understand and realise that disability can strike anyone at any age. Spinal cord injury and consequent paralysis is a permanent disability as of now. It can strike anybody most often the cost & effort of building ramps is borne by the person's family everywhere.**

**I only request that Architects, designers, planners, rule makers and rule enforcers understand this. Concepts of Universal Design need to be an integral of our buildings so that the houses, offices and**

**public places are accessible, safe, and liveable throughout one's life starting from birth to death, encompassing temporary and permanent disability phases also.**



***Anupama is associated with Nina Foundation for more than a decade. Over the years she has been a core team member for various events and activities of Nina Foundation. She played a pivotal role in conceptualization and the successful launch thereafter of Project Nirmaan – a unique multi-disciplinary Out Patient Department for economically challenged friends with spinal cord injury from urban slums and rural areas.***

***A science graduate, her logical left brain steered her to a career path as a Computer Software trainer and she eventually owned a firm for software development. Post that, she took a break from her professional life to raise a family. While heading out from the break, it seemed like the right side of the brain took over and Anupama has been at her creative best since then - an artist that works with different materials and paints.***

***The push and pull of the left and right brain continues to lead her on to new experiences and exciting adventures.***

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***with spinal cord injury across the length and breadth of India. She has been Nina foundation's core team member for rural camps, home visits and providing assistive technology.***

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# **Quality of Life of Spinal Cord Injured in Rural India**

***Rajshri Patil, Anupama Ganesh***

**Spinal cord injury is the most devastating disability and leads to a complete change in the lifestyle of the injured and also the family. Especially so if the person injured was the breadwinner for the family. This is the truth whether the person with spinal cord injury is from a rural or urban setup. But this change is fraught with more challenges for those living in rural areas. There are no rehab centers or centers for reskilling options, no physiotherapists or assistive technology. There are no jobs or alternate enterprises for becoming independent.**

**Through our interactions with rural friends with spinal cord injury a very scary pattern emerged. Along with lack of proper infrastructure and basic facilities, our rural (and sometimes even urban) friends were also dealing with lack of information on how to deal with the post-injury changes in life. Sadly, some of our friends paid the price for this lack of information with their lives.**

**A typical scenario. After a traumatic spinal cord injury (road accidents, fall etc.) the patient is taken to the hospital, operated and sent home after a few days with a urine bag. Most of the times the patient and the immediate family members who are also the primary care givers, do not get any guidance on how to deal with life after the injury. They don't get proper information on bladder-bowel management, skin care, physiotherapy etc. In some cases, they are not even aware or refuse to believe that this is a permanent disability without any cure.**

**Let's take a look at the most common and easily avoidable situations that were fatal in some cases.**

## **1. Skin care.**

**While in hospitals, patients have air beds to avoid bedsores and pressure sores. The nursing staff cares for the patient. After discharge they come home to a very different setup – rudimentary sleeping arrangements and untrained family members as care givers. They may not have a proper bed. Even if the family is affording, the erratic electricity in rural areas would mean no airbeds. They may not have (or are unaware of) appropriate cushions to sit on. All this can cause bed sores and pressure sores. In case of remote villages medical care may not be available. Bedsores develop very quickly and can be difficult to heal. If proper care is not given they can get infected and in some cases it can lead to death.**

### **Simple Solution:**

- ***While in hospital the situation at home of the patients should be assessed and they must be guided accordingly.***
- ***The primary care givers should be educated on***
  - ***why the bedsores occur and how they can be avoided by***
  - ***importance of proper skin care like***
    - ***keeping skin dry and clean***
    - ***moisturize the skin at pressure points with coconut oil***
  - ***identifying skin irritants like buttons, wrinkles on clothing or sheets***
  - ***how to inspect the skin daily for signs of sores***

- *shifting and turning at regular intervals to relieve the pressure*
- *proper hygiene to be maintained post bowel & motions evacuation.*

## **Bladder-Bowel Management**

Depending on the level of injury the bladder and bowel may be partially or fully affected but incontinence is a reality. If not cared for appropriately it can cause severe complications. Every person with spinal cord injury suffers from a Urinary Tract Infection (UTI) at some time or the other. An untreated UTI can lead to infection in kidneys and can cause kidney failure.

### **Simple Solution:**

Before discharge the patient and the care giver should be educated on:

- *Proper management of bladder-bowel system.*
- *Well-balanced diet.*
- *Various methods of emptying bladder like in-dwelling catheter (IDC), selfcatheterization (CIC), etc.*
- *Steps they can take to minimize the chances of infection like adequate water intake, regularly voiding the bladder completely, cleanliness of equipment etc.*
- *Identifying & being aware of the symptoms of UTI.*
- *Importance of seeking proper medical care.*
- *Most rural homes have Indian toilets which are impossible to use post spinal cord injury. Folding commode chairs & shower chairs offer both hygiene and dignity with less burden on the care givers.*

## **Physiotherapy**

**A good exercise regime is something that every person with spinal cord injury must follow. Regular exercise helps to maintain good muscle and bone health.**

**It also helps reduce spasticity. It also helps them to be more independent and improve their quality of life.**

### **Simple Solution:**

- ***Before discharge, it is important to explain the role that regular exercises will play in the lives of the spinal cord injured.***
- ***They should be made aware that daily exercise routine is a lifelong process and lack of exercise can lead to problems like muscle wastage, stiff limbs etc.***

## **Pests**

**In the rural areas we have seen incidents of rats and ants eating away patient's body parts (toes, testes) during the night. Due to lack of sensation they do not feel them and only observe it visually the next morning.**

### **Simple Solution:**

- ***Use pest repellants.***
- ***Elevate the bed.***
- ***Keep the bed away from the walls and windows.***
- ***Do not keep any eatables near the bed.***
- ***Clean the bed immediately after meals.***
- ***Wear socks.***

## **Mental health**

**The sudden change in life from being active and independent to someone who is completely dependent on others for every small need is very traumatic and a very strong support system is needed at this critical time. Sometimes they are not even aware that a spinal cord injury is a permanent disability. Once the family and the person with spinal injury settle into daily life the gravity of the situation hits. Simple tasks like cooking, washing clothes or visiting a temple becomes impossible. Another worrisome factor is neglect and abandonment. Some families are so poor that they cannot give proper care even if they want to. Depression can creep in. Care givers are not able to handle the stress. If the person affected was the breadwinner of the family, then they also face severe financial burden.**

**Sadly, we don't have a Simple Solution for this one.**

- *Along with all the solutions listed above the spinal cord injured and the family members should go through some counselling sessions to understand the gravity of the situation and to prepare them for the life ahead.***
- *They should be introduced to support groups and organizations/NGOs like Nina Foundation whose mission is to serve the spinal cord injured community. They need to be constantly in touch by phone for solving issues in real time.***
- *Connect them to other friends with spinal injury preferably in that area who can help and guide them. Peer counsellors play a very important role in sharing and motivating them.***
- *They should be made aware of practices like yoga, meditation etc. to deal with the stress.***

- ***Families should ensure that the social contact is not broken. Simple things like talking & meeting friends, going out of the house, attending school/college and functions helps immensely.***
- ***Technology has made it very easy to keep in touch with people. Keeping in touch with peer counsellors or being part of a support group is very easy due to WhatsApp and other social media.***
- ***Rural employers must be broad minded and accept friends with spinal cord injury for jobs and work. It is very important to be financially independent thus become confident too.***

**As part of its initiative "Project Nirmaan", Nina Foundation has innovated a "Hope Kit" for the friends with spinal cord injury. It contains some basic items which are needed on a daily basis like a mackintosh, a urine bag, catheters, jelly, Dettol soap, mirror for skin inspection, coconut oil etc. This kit should be handed over to the spinal cord injury patients at the time of discharge from the hospital.**

**To summarize the following things should be done at the hospital level:**

- ***Hope Kit.***
- ***FAQs booklet in local languages where most common problems faced by a spinal cord injured are listed along with the solutions to tackle those problems.***
- ***A copy of this booklet is handed over and explained to the patient as well as the primary care givers.***
- ***List of doctors, physiotherapists, charitable trusts etc. in the area with addresses and contact details.***
- ***Connect them to peer counsellors/mentors, support groups, NGOs like Nina Foundation before discharge.***

- ***Occupation therapist / social worker to visit their home and assess the layout, requirements and modifications.***

**We are aware that the solutions offered above is not going to make problems disappear for our friends with spinal cord injury and their families. But they will be better equipped to face the challenges.**

**Issues / problems listed above are just a few of the challenges faced by rural friends with spinal cord injury. There is another demon which needs to be slayed – superstitions and the “Baba”s who promote quackery. But that’s a story for another day.**



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# **Living with Paraplegia: A qualitative study on Rehabilitation Challenges in India**

*Nalina Gupta*

**Demographics of spinal Injuries in India differ from that of the developed countries, in context to the gender, type and mode of injury. Road traffic accidents and the falls are the major causes of spinal cord injury (SCI) in India and there are a much larger number of males who sustain SCI, and people with paraplegia, and complete injuries.<sup>1</sup>**

**Due to lack of structured health care delivery system and very few specialised spinal injury centres in India<sup>1</sup>, SCI victim is taken to any of the hospitals available in the vicinity and there is often a delay in initiating the comprehensive management. Patients are often discharged prematurely once their vertebral lesion is managed and they are advised to continue exercises at home rather than being referred to a definitive spinal or rehabilitation centre.<sup>2</sup> The probable reasons for their early discharge from the hospitals are non-availability of bed, financial constraints, lack of rehabilitation facilities, low priority to rehabilitation services by doctors and hospital managers, and lack of awareness about the importance of rehabilitation including physiotherapy in professionals, patients and their families.<sup>2</sup> Such neglected cases get predisposed to complexities such as pressure sores, contractures, deformities as well as psychosocial issues, influencing the overall rehabilitation outcome.<sup>2</sup> The major challenges in India are lack of infrastructure and trained man-power.<sup>3</sup>**

**Patient centred care has gained its importance recently. It also becomes really important to understand the lived experiences of people with SCI/paraplegia. Thus, the present article focused on the experiences, rehabilitation challenges and expectations of people with paraplegia.**

**Various organizations/institutions/private clinics/societies specializing in spinal cord injury (SCI) rehabilitation or maintaining the database of persons with paraplegia were contacted. Inclusion criteria was adults with level T6 and below, complete injury, duration of at least six months' post-injury, and community dwellers. Contact details of fifty-two participants were thus obtained. All the persons with paraplegia were first contacted telephonically to provide information regarding the research and to seek consent. Eight individuals could not be contacted due to a disturbance in telephone lines. Out of forty-four participants, twenty participants were excluded due to non-availability/busy schedule, having lesions at the cervical level, or having no/poor network connection. After getting the consent of twenty-four (n=24) participants telephonically, demographic details were collected to ensure inclusion criteria. Information regarding the online interview and ZOOM software for online discussion/meeting was also provided.<sup>4</sup>**

**Interviews were scheduled based on participants' convenience/availability. All the participants were sent informed consent form and demographic details form through their mail ids, which they had to fill, sign and send them back. Based on their convenience/time availability, participants were grouped into six small groups of two to four participants and two individual**

interviews. Their meetings were scheduled/ arranged on ZOOM software for online discussion/meeting using an open-ended format. Outline of topics was used to guide the interview. Topics outlined were regarding their expectations of care after the injury, met/unmet expectations, information regarding their basic skills, daily tasks, community re-integration, and their suggestions to improve the standards of care after SCI in India. Data saturation occurred after interviewing twenty participants. The term "Data saturation" is used in qualitative research as a criterion to discontinue data collection. Data saturation is the point when no new information or a code is emerging from the interviews.<sup>5</sup> Recorded interviews was transcribed into texts and analysed using ATLAS.ti software for qualitative data analysis.<sup>6</sup>

Various themes emerged were related to lack of knowledge regarding spinal cord injury among general public, inadequate care at the accident site, lack of education regarding SCI provided to the patients and families in the hospital, inadequate rehabilitation/physiotherapy facilities in the hospital, lack of guidance or reference for physiotherapy after discharge, lack of facilities/relaxation for exercises for people with paraplegia in the education and employment centres.<sup>4</sup>

Management of an SCI victim begins from the site of accident and continues life-long. In the present study, one of the important themes which need serious consideration is knowledge of SCI among general public. Participants quotes related to this theme were

**Participant 1a: "I had no knowledge what spinal cord injury is"**

***Participant 1a: "The person who lifted me, made me sit first. When I told this to my doctor, he told me that this may have increased my injury. Knowledge should be there how to manage a person injured on road, and how to shift him in an ambulance."***

***Participant 5a: "We did not know what SCI is; this subject is new for us"***

***Participant 2c: "I was not able to understand anything. I did not know what will happen. I thought it's a simple problem, it will get solved."***

***Participant 1b- "Due to lack of knowledge, our expectations were not realistic/ practical."***

***Participant 4a: "I did my rehabilitation in a specialised centre and there actually I was able to know the complete scope of my injury... like how will I recover, whether I will recover or how long I will take to recover. I had complete idea, so I did not keep much hope to it."***

**Almost all the participants had no knowledge regarding SCI before their injury. There is a need to create awareness of SCI and shifting of a victim with SCI from the site of accident in India.<sup>7,8</sup> Hoardings (a large board in a public place to display), pamphlets or use of media to create awareness and knowledge regarding SCI, its prevention and transportation of spinal cord-injured victim are few of the measures that could be adapted.<sup>9</sup> Most of the participants were even not given adequate education in the hospital regarding their injury, recovery and further management post-discharge except the ones who were in SCI specialised centres.**

**Lack of structured health care delivery system, very few specialised spinal injury centres<sup>1</sup>, lack of rehabilitation facilities, low priority to**

rehabilitation services by doctors and hospital managers, and lack of awareness about the importance of rehabilitation including physiotherapy in professionals, patients and their families<sup>2</sup> are some of the reasons for inadequate rehabilitation and comprehensive management. Quotes related to this theme were

**Participant 1c:** *"I did not get good first treatment as its' not that known here. They made me lie on bed for one month and I had pressure sores."*

**Participant 1a:** *"I would like to say that doctors did not tell me about rehabilitation whether I should do it or not. They did not tell how to care for ourselves. They said physiotherapy is important, and get it done."*

**Participant 1d:** *"Since the time, I have learnt basic skills such as rolling from my friend, there are many changes which have come to me. Initially, I used to be tensed (pareshan), now I do most of the things by myself. Initially I used to shout if I had to roll, now I do it by myself. My initial 6-7 months were very bad. I did not have any knowledge and have not seen such cases nearby."*

**Participant 2:** *"We must be told what we can do based on our level. Wheel chair skills must be taught at most of the centres."*

**Participant 4a:** *"Most of the people are not exposed to good rehab centres and training. There are only few places." "I have a good wheel-chair, so I can do most of the things. But others don't have that, so they cannot do it.*

*So, availability of a good wheel-chair is also a main thing."*

***Participant 6a: "My wheel chair is of old type. It was given to me. I have not bought it. But there are many problems with the wheel-chair. There is no folding system. Arm rests cannot be taken out. That's why there is a problem."***

***Participant 8a: "In villages, government should open specialised centres. Life gets spoilt for the one who lives in a village."***

**In the present study, there was a difference in people with paraplegia who were rehabilitated in a specialised centre from the ones who got treated in a local hospital, in context to education regarding their injury, comprehensive management and their expectations post-injury. Thus, it becomes really important for a health care professional to provide clarity about patients' recovery or prognosis, so that they do not have unrealistic expectations.<sup>10</sup> Patient education and education of the health professionals are two of the most important aspects of SCI rehabilitation. Elearning resources<sup>11,12</sup> can be tried for their feasibility in India. Rehabilitation professionals must have knowledge regarding various organisations dealing with wheelchairs in India, so that mobility of persons with paraplegia is not hampered.**

**There is a decline in community re-integration in India.<sup>13</sup> Probable reasons could be unsuitable alternatives in work-place, lack of relaxation for work and exercises at work-place and/or inaccessibility. Quotes related were**

***Participant 1b: "My Company was giving me options but I did not like that much. Also, I felt that job will occupy more time and I won't have much time for physiotherapy. So, I opted to resign."***

**Participant 1c: "I have done MCA. I do some work online. If I go for a job, I have to leave exercises. That's why I am not working."**

**Participant 1d: "I take tuitions at home and it's a very good option for us and we can spend our time nicely."**

**Participant 3a: "Accessibility is not easy, there is problem everywhere. In trains, person accompanying you will help. Else if possible I go in my car and get my work done. Problem will remain in accessibility."**

**Participant 3b: "I have my own company. When I have to meet other people, they are not that flexible. They may not come at the place I tell them. If I have to go to their office, that's not accessible for me. That's problematic.**

**If I go there, and its' at first floor, then I feel how to go. If my event is at open grounds, I have problem with uneven ground/ ground that is not levelled."**

**Participant 4a: "Physiotherapy centre is little far from here, around 1.5-2 km from here. After coming back, we cannot go there as we are really tired. If we get it in hostel, we can do that. Otherwise we cannot do that."**

**Participant 4b: "We don't get time because of classes. We are out from 8 am and come back at 6-7pm. Then we don't have energy to get exercises done."**

**After SCI, there is lower return to work rate because either the person does not go back to his/her pre-SCI work status or he/she may not be hired. However, there are available rights of employees in India that they should be made aware of.<sup>14</sup> Lower return to work**

rate could be due to inaccessibility, transportation issues and lack of disability-related accommodations at work site.<sup>11</sup> Flexible working hours and job sharing are some of the programmes being encouraged by government in some countries.<sup>12</sup> There is a need to encourage job accommodations for these individuals.<sup>15</sup> Telework, working at a remote place using technologies, may be an option for persons with SCI in India and could help overcome issues of accessibility, transportation and health limitations.<sup>12</sup> Educational participation must be enhanced, and there should be strategies to overcome accessibility issues. At the same time, education and rehabilitation must be brought together.<sup>12</sup>

To summarize, there is a need to create awareness regarding SCI in India. Education of the people with paraplegia/SCI, and health care professionals are the two most important areas that needs to be taken into consideration for SCI rehabilitation. Rehabilitation continues life-long and community re-integration must be encouraged.

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# **Designing Occupational Therapy Program With Virtual Reality and New Trends for A Good Quality Of Life for Indians with Spinal Cord Injury**

*Dr. Chitra Kataria (Chief of Rehabilitation Services)*

## **Introduction:**

**Spinal cord injury is a devastating and life threatening injury. Based on their causes, spinal cord injuries can be divided into two different groups: traumatic spinal cord injuries and non-traumatic spinal cord injuries. The incidence as well as the prevalence of spinal injuries has been on the rise with the incidence rate being estimated to be from 15 to 40 cases per million worldwide. In those cases, the most common level of injury is the cervical spine, which results in patients being paralyzed including upper limb and lower limb. In Indian setting, the major cause of spinal cord injury is fall and road traffic accidents. The low socio-economic status and younger age group has a major financial, social and psychological impact as majority of the patients are the primary earning members of the family. Spinal cord injuries are highly disabling and concentrated in young adults, so they bring great pain to the affected individuals and their families. In addition to the considerable burden for the affected individuals and their families, society must bear the cost of healthcare treatments, rehabilitation and lost productivity. In certain instances, Spinal Cord Injury may render a person dependent on caregivers, with family members often forced to take on the role for a variety of social and economic reasons. Costs associated with Spinal Cord Injury are higher than those of comparable neurological conditions**

such as dementia, multiple sclerosis and cerebral palsy. The complications of Spinal Cord Injury (e.g. scoliosis, hip dysplasia, pressure sores, autonomic dysreflexia, and the need for intermittent catheterization and bowel management strategies), have a tremendous impact on quality of life, as well as on the financial resources. According to the World Health Organization (WHO), quality of life (QOL) is the perception of individuals concerning their position in life, cultural context, and system of values attributed to objectives, expectations, standards and concerns. This definition includes six main domains: physical health, psychological state, level of independence, social relationships, environmental characteristics, and spiritual pattern. Individuals having paralysis of both upper and lower limb (tetraplegia) have limitations in upper limb function leading to dependency in activities of daily living (ADLs), which reduces the quality of life.

These individuals will have varying levels of difficulty in performing activities of daily living (ADL) such as upper body dressing, grooming, and self-feeding, as well as limited mobility skills. Individuals with injuries below cervical level generally retain hand function, which aids in the performance of ADL, but continue to have deficits in trunk control and balance and in walking. These functional expectations also vary depending on whether the injury is complete or incomplete.

The spinal cord injury rehabilitation team revolves around the patient and family, helping to set up long term and short term goals for recovery of SCI individuals which includes many skilled health professionals like Physiotherapists, Occupational Therapists,

**Psychologists, Psychiatrist, Social worker, Orthotist, Respiratory therapists etc.**

## **Role of Occupational Therapists:**

**Occupational therapists evaluate a wide range of life skills needed to do function at home, at work, in school, in the community, and during leisure activities. The Occupational Therapy (OT) service in the Spinal Cord Injury Centre begins at acute admission and continues through to discharge into the community and also offers ongoing outpatient support. The main areas of OT intervention are:**

**Daily living skills:** for example- training and practice in self-care and domestic tasks such as washing, dressing, feeding, drinking, grooming and housekeeping. We also offer assessment for appropriate equipment and the opportunity to practice skills in our independent living assessment unit.

**Bed mobility and functional transfers:** training and practice in bed mobility and in getting to and from the bed, wheelchair, shower chair, toilet, bath, stair lift, sofa, car and other transfers for daily living.

**Wheelchair, posture and cushion requirements:** trial and assessment for a wheelchair (manual and/or powered) that allows for maximum independence. Identification of appropriate pressure relieving cushions. Posture assessment and identification of correction/support systems required. Liaison then takes place with each patient's local wheelchair service for provision of equipment.

**Hand therapy:** maintaining range of movement, oedema management, assessment and training of functional potential, splint provision to prevent deformity, maintain aesthetics and replace function.

**Communication aids:** for example- trial of equipment to aid communication such as telephone adaptations, writing splints, computer keyboard hand splints, mouth sticks, environmental control units. Occupational Therapists also refer to ASPIRE<sup>1</sup> for computer assessments/advice and for accessing assistive technology devices e.g. eye blink computers.

**Community living skills:** advice on returning to work, returning to driving, training and practice in advanced wheelchair skills (slopes, rough terrain, stairs), arranging driving lessons, assistance with establishing routines and problem solving.

**Environmental modifications:** assessing and identifying home/work/school adaptations in cooperation with the community team.

**Vocational support:** when the time is right, occupational therapists analyses previous job roles and current skills and advice a return to vocation with a plan.

**Problem solving:** Occupational therapists are excellent problem solvers and help the individuals with spinal cord injury to overcome with their problems.

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<sup>1</sup> <https://www.aspirelaw.co.uk/assistive-technology-spinal-injury>

**Researchers have investigated the effects and possibility of various treatment options to perk up upper limb strength and function in SCI individuals. With physiotherapy, occupational therapy comprises the foremost components of rehabilitative intervention including strengthening/endurance exercises, range of motion (ROM)/stretching exercises, and ADL training. Occupational therapists may adopt or amend specific contents of the therapy based on the level of injury, severity of injury, and functional expectations with the goal of facilitating motor recovery of the upper limbs and optimizing functional independence.**

### **Emerging Technology:**

**Technology is one of the most powerful tools that can be provided to people with spinal cord injuries and many new technologies are emerging and improving at a considerable rate, which is a hopeful sign. New technologies have joined the goals of independence for people with spinal cord injury. In last two decades, there is a shift in treatment and assessment approaches for the individuals with spinal cord injury. Complementary treatments given to the individuals with spinal cord injury in turn help to improve the quality of living. One of the new trending technologies is virtual reality (VR) in rehabilitation of SCI individuals. VR is a computer-based, innovative, interactive, multisensory simulation environment that occurs in real time. It presents users with opportunities to connect with what appears to be real world objects and events. The rehabilitation periods for tetraplegia are long, expensive, and exhausting. As a rehabilitation complement, VR has shown several motivating factors, such as perceived control, curiosity, exploration, competition, and social interaction and motivation is a key to success in overall**

rehabilitation. It provides a more attractive and engaging treatment for individuals with tetraplegia within the perspective of therapeutic goals and decreasing therapist support. VR use does not replace conventional rehabilitation; rather it adds a dimension of enjoyment by offering an opportunity for socialization and leisure. It acts like simple biofeedback as the individuals with SCI see how they act in response to specific situation like a simple reaching-aiming movement, such as putting a glass on a shelf, is represented in the artificial scenario and was represented by a virtual glass and shelf and painting a wall, cleaning table shelf; these types of games are there in the virtual reality which engage the individuals in the virtual environment. VR helps to improve balance of SCI individuals, enhances upper limb movement through neuroplasticity and increases confidence to survive in real life. It allows individuals to know about their progress within the game's scoring system and monitor their performance on a day to day basis and hence improvise their standard of living.



*Virtual reality games for SCI rehabilitation*

Some new trends seem to be emerging like wearable or wheelchair mounted sensors are becoming popular, which will expand the rehabilitation in the natural environment, robotic and intelligent systems are able to transform the quality of life and independence of

people with SCI in years to come. Environmental factors are modified for home and vocation for individuals with SCI under guidance of occupational therapist. Environmental factors include modifications in home and vocational environment i.e. ramps for wheelchair, obstruction free environment, broad doors of toilets for wheelchairs, modified cars to increase independence etc. Surface magnets can be used to increase the independence of self-feeding in a person with decreased hand function due to SCI with immediate results. To facilitate the intensive training process, therapeutic technologies have been developed, such as exoskeletons, functional electrical stimulation (FES), and robotic rehabilitation devices.



## **Gait and Balance Assessment and Treatment in Virtual Environment**

### **Conclusion**

All these new technologies and new trends in occupational therapy are emerging for SCI individuals consequently improving their

**quality of life and provide standards of living to spinal cord injury individuals, family and to society too. So virtual reality and these new trends should be used as adjunct therapy in addition to conventional rehabilitation to improvise the quality of life of SCI individuals.**

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***Air Commodore Nitin Sathe is a helicopter pilot of the Indian Air Force with 35 years of commissioned service to his credit. During his career, he has been a part of many a life threatening and lifesaving mission, both in India and abroad. He has flown almost all the helicopters on the IAF inventory and has a total of 5500 hours of flying experience. When the tsunami of 2004 ravaged the islands of Car Nicobar Islands, he volunteered to go there for the rescue, relief and rehabilitation efforts and stayed there for a year battling against all odds to bring back the islands to normalcy. Long thereafter, he decided to pen down his experiences and came out with his first book titled „A Few Good Men and the Angry Sea“ released in 2014. Egged on with the success of his first effort, he went on to write a biography of his batch mate, Flying Officer MP Anil Kumar- A MiG-21 pilot who became a quadriplegic due to an accident at the age of 24. Defying all odds, Anil Kumar went on to live a meaningful life for 26 years after the tragedy and this biography takes you through his life and reads like a Stephen Hawking story. This motivational book titled „Born to Fly“ and released in Dec 2016, has been recommended by NCERT for additional reading by children. It also has very recently been awarded an award for the best novel in the***

***„non-fiction“ category for 2016. The book is now being translated into 8 vernacular languages including Braille to improve its reach.***

***His third book is a bouquet of 19 short stories which was launched in Sept 2018 at Delhi. These short stories that have been written from real life incidents and happenings that will bring to life the episodes, trials and tribulations of men in uniform, mainly focussing on the life and flying adventures of a helicopter pilot carrying out a multitude of missions.***

***Air Cmde Sathe is presently posted as the Senior Instructor at the Defence Services Staff College at Wellington (Nilgiris), India.***

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# **Happy Landings, Empee**

**- Air Commodore Nitin Sathe**

**Reheat.**

**Afterburners on.**

**Rolling for take-off.**

**In the wee hours of the morning of May 20, 2014, my friend and course mate, "Empee" got on his way into the blue skies. Having been literally tied down to a wheel chair for a half of his life, he was finally free - to do as he liked, to do what he liked best, to fly high in the sky.**

**When he took off for his final flight, Empee had spent 50 years and 15 days on this planet. The writing was on the wall; we had been told by the doctors just short of his 50<sup>th</sup> birthday. He had the deadly blood cancer and there was no way out. But more deadly than the disease that claimed his life was the accident that made him a quadriplegic.**

**In early 1988, Empee had graduated top of his class as a fighter pilot. He had taken to the cockpit like a natural. But he was as studied as he was instinctive. He spent a lot of time preparing and for his sorties and analysing his performance thereafter. He was also known for reading voraciously.**

**His wide knowledge in the field of aviation made him a sort of „Gen-master“ of his squadron. Friends and seniors sought his help if they**

were to understand some intricate aspects of aerodynamics or the latest in navigation systems.

On 28<sup>th</sup> of June 1988, Flying Officer MP Anil Kumar, a strapping, promising young fighter pilot met with a freak motorcycle accident in Pathankot, an accident that transformed his life forever and took him from being "airborne" to a "chair borne" warrior. For 26 years, Empee was paralysed neck down and confined to a wheelchair. But a warrior he remained nevertheless. Incidentally, "Airborne to Chair borne" was the title of his personal account of how he fought with life and his quadriplegia, a memoir that launched him into the field of serious writing.

Now that Empee is gone, all there is to do is cherish the memories he left behind - Empee in a colourful *lungi* and a matching shirt, up and about early. Empee having breakfast in bed with his favourite *mall* songs or glued to the news on TV. Empee being wheeled to his computer by the window, painstakingly researching and writing his articles. Right across the fields from Empee's window in the Kirkee Paraplegic Home, fighters getting airborne at the Air Force base while visitors wait to meet Empee. They see him first through this window, he nods his head and the pencil in his mouth drops into his lap. The wheelchair is brought out in the corridor and a few chairs for the visitors. Empee insists on a particular placement of his chair so that he can keep an eye in the sky for the fighters.

Some visitors are ill at ease to meet him for the first time but the warmth and confidence he exudes melts away all the inhibitions. Empee has a way of putting everyone at ease with his wit and humour. He has a variety of visitors. - fellow paraplegics to batch-mates to young students of school and colleges, not to forget his

**„school-types“ from Sainik School, Kazhakootam. He gets along like wild fire with all of them, expressing his views on any topic thrown at him. Once you know him, you want to hold on to him, return to meet him again and again, such is his magnetic charm. I visit Empee in Kirkee every time I am on annual leave in Pune.**

**One day, I find him in a frenzy, feverishly tracking his correspondence with the Indian Air Force and the Government of India. A cadet involved in an air accident in the final stage of his training and paralysed waist down, is to be boarded out and sent home with no benefits as per the policy in vogue. But Empee is not one to back down. He fights the established norms and demands a humane view for the plight of the cadet. Finally, the cadet is granted commission as an officer on a wheelchair. Empee's victory is the first such case in the history of the Armed Forces in India. Empee makes us so proud.**

**His discipline, his perfection and his dogged determination in fighting for what is rightfully due make him a loved, yet feared inmate at the paraplegic home. All inmates turn to him to resolve their problems and issues and he is the de-facto leader of the home. Through his constant engagements with the management, he ensures that the good quality of life promised to the inmates is delivered in practice.**

**Empee is a stickler for perfection and his demands for order in the smallest things - such as his cupboard - makes us pull our hair sometimes! One day, Empee wants me to read one of the articles that he has written. I am made to go to the place and given perfect instructions - “look in the left pile of magazines near the window,**

**the third one from the top, page 72-to 74. And after you read it please keep it back in the same place."**

**So well researched and grammatically correct are the articles he sends his publishers, that editors have nothing to do but upload them on the website. Empee also makes it a point to remember little details that mean something to you. He can remember the date day and time that he met you, what you were wearing, what the weather was like on the day, he remembers your birthday and anniversary the names of your children. I, like many of his friends, treasure the signed-by-mouth card that I receive on for my birthday without fail, every year.**

**It is 2014. In a special corner of the ICU reserved for him, Empee is celebrating his 50<sup>th</sup> birthday in style. He has decided the guest list, presided over the preparations, given explicit instructions to everyone as to how his day is to be celebrated. He has finalised the menu - cup-cakes from Monginis, samosas from his favourite shop in Kirkee market, no non-veg and tea/coffee. He has made a guest list, calculated the costs and reconciled them with his budget, all from the ICU. Someone suggests he invite a certain senior officer. "If we call him he will come with his entire entourage and that will be the end of my party!" quips Empee, ever witty as well as practical. This is the last time that we are to see him as we have known him – sharp, alive and kicking. Just a little later, we, his friends are to see him slip in and out of coma. Sometimes, he opens his eyes and we find in them, the same recognition, the wit and the humour as if he is picking up on a conversation from where he left off. When he is coherent, he argues with the doctor that he should be at his computer as soon as possible. "You see all this running around for**

**chemo has resulted in a whole lot of correspondence piling up on my computer", he says and we wonder if he has grasped the nearness of death. "I can come at the time that you ask me to and can go back to my room immediately after that...", he continues. Then, as we fear his loosening grip on reality, he adds without skipping a beat. "I would like to die in my own bed. I hope you know that." Empee's pet line comes to mind when Empee breaks his earthly shackles. "The greater the difficulty, the sweeter the victory." He was born to be free, the almighty put him to a hard test and here too he passed with flying colours. Happy landings, Empee!**

**Live Life to the Fullest!!!!**



***Sunita Sancheti is a successful entrepreneur running her family business, counsellor, motivational speaker, traveller, sportsperson and a transformation coach guide.***

***In the year 1987, at the age of 16 Sunita's world came crashing down when a medical negligence which resulted in a spine injury leaving her confined to a wheelchair thus restricting her progress due to lack of infrastructure in India.***

***Rehabilitation in UK in 1996 gave her a new lease of life making her an independent, self-motivated, powerful change maker with a resolution to change life of the disabled by improving accessibility in India having tasted a disable friendly environment in UK.***

***She started assisting her father and brother in running the family business, and taking care of taxation thus taking the family business to new heights and continues to do so.***

***In 2000 she met like-minded people and started working with them under the banner of ADAPT (Able Disable All People Together). Where she started working on making places accessible for persons with disabilities. She has audited at least 25 places of public visit,***

***education institutes, work places and also tried making public transport accessible.***

***Sunita is a mentor closely associated with Nina Foundation and counsels persons with Spine Injury that could happen due to various reasons, sports, accidents, terrorist attacks, medical issues, falls thus paving the path to lead a normal life.***

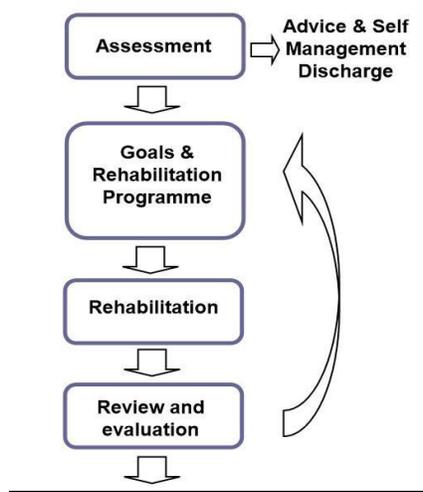
***Email- sunitasancheti@gmail.com***

# An International Rehab Program That Redesigned My Life

*Sunita Sancheti*

I used to do vigorous physiotherapy at home after I came back from Bombay Hospital -Mumbai, it kept me active, but I was not independent in my day to day routine. Our family friends mentioned about The National Spinal Injuries Centre at Stoke Mandeville Hospital which is one of the designated Spinal Cord Injury Centre They have a team of highly skilled healthcare professionals who provide specialist advice, assessment and rehabilitation to improve the quality of life for clients (they do not call the person patient) with a long-term condition.

They see people with all different conditions which lead such as Neuro rehabilitation, stroke, Parkinson's, multiple sclerosis etc. At the reception there was a poster, I was looking at it and trying to understand.



Then was my time for assessment and I was getting little nervous.

## **Interaction with General Physician Dr Gardner**

***Dr Gardener:*** - Hello young lady, what gets you to UK from India

**Me:** -Heard lot about this rehab centre. I want to get independent, do my routine and lead a so called normal life.

***Dr Gardener:*** -Very happy that your answer is that you want to get independent. Many clients come to us saying that I want to go home walking.

**Me:**-I have understood in past nine years that being independent is the only way to move ahead in life.

***Dr Gardener:*** - You will get best rehab here but before that let me do proper assessment and I also need to understand your requirements and your routine. Tell me what all do you want to learn and we will have a team assigned for you. We work with you to identify your priorities and goals. Then we set action plans to achieve your goal. We work with you in the most appropriate setting be that clinical, at home, your workplace or in the community.

**The team includes:**

- ***Clinical Psychologist***
- ***Occupational Therapists***
- ***Physiotherapists***
- ***Supported by administrative staff***

**The Journey of my rehab began, a proper journal was made which mentioned all the things that I wanted to learn which included all**

**types of transfers, bathing, dressing, managing your bladder and bowel timings, staying fit and keeping your weight in control. They prepared a proper chart which was given to the teams and it stated how the progress has to be monitored. The goal plan is discussed by the team and family members.**



***Rehab at UK***

**Once I achieved few targets they asked me about how would I go about managing my own expenses I was blank as I knew that I have no qualification to my name so how would I work and rather where would I work. They asked me my likings and they suggested few jobs that I could do, I told them about how India has inaccessible infrastructure. They suggested to work at an office as that would be accessible and change my interest of work.**

**While they were training for bathing, dressing and managing my daily activities they gave me a wheelchair which they felt would make things easy for me and I understood importance of a well-designed wheelchair as per your requirements, height, weight and**

posture. They also had a modular kitchen which is designed to suit a wheelchair user's requirements, where in you are taught to cook few dishes and wash your own vessels.

We had aqua sessions, outdoor visits to railway stations, banks and many more public places and they made us walk on roads and trained us how to use curb cuts.

The Infrastructure in UK was so disabled friendly, and made me realize how convenient life could be with the right facilities. I realised that it's the designing of the infrastructure that makes your life or breaks your life when it comes for persons with disabilities or senior citizens.

This thought kept coming back to my mind as I was on the flight back to Mumbai. At that moment I had a dream of making my city disable friendly .... however, the challenge was that I had no clue how would I go about fulfilling my dream.

They always say where there is will there is a way.

Challenge of finding a job came to an end when I started doing a part time job at a chartered accountant's office, but my passion for working on making my city accessible was always in my mind.

In year 2000 at ADAPT (Able disable all people together) found few likeminded people and we started working on making Mumbai barrier-free.



*With loving family*

**While I was working on all these aspects of access I met Dr. Prof Ketna Mehta and got to know about Nina Foundation which serves Persons with Spine Injury. She is a great mentor and a leader and under her guidance I learnt how to counsel our fellow team members on issues related to bladder bowel management, skin management, and other issues.**

**I have gone through multiple surgeries and also had fracture but that has not stopped me from growing in life. I have taken part in many activities such as dance, fashion shows, treasure hunt. I have travelled a lot.**

**Through Nina Foundation I have got chance to interact with many people with spine injury and guide them how important it is to be fit and active in their day to day life. It's very important that we lead a so called normal life by attending family functions, being part of some sport, yoga, dance therapy or follow any type of hobbies. We**

**have had basketball camps which has created a team which has reached to international level. Rehab expo gave us an opportunity to connect with many more people with spine injury and helped us change their lives. Seminars and conferences give you a broader way of thinking. Happy that I am contributing in betterment of many more people with spine injury and the credit goes to the rehab which made me independent and my family who supported me at each and every step of my life.**



***Shri N. D. Dharap is 92 years old and is paraplegic due to spinal cord injury for the past 61 years (since 1959).***

***Always smiling, cheerful, homely, kind & happy, is loved by his family, relatives, neighbors, friends and all of us at Nina Foundation-Recipient of the 1<sup>st</sup> Rockstar Award by Nina Foundation in 2009.***

***Dr. Ketna L. Mehta interviewed him to share his wisdom of living a full life despite a spinal cord injury in India for so many years.***

***Email ID- satishdharap@gmail.com***

## **Interview with Shri N. D. Dharap Kaka**

### ***Interview:***

**Q1. – Please give us a brief background about yourself and how you became a paraplegic?**

***A1. - I am a B.Sc. Tech from UICT, Mumbai. I was working as a factory inspector in Kolhapur. My wife and one year old daughter were in Pune. I came to Kolhapur from tour and while I was opening the door of my room on the ground floor, the overhanging balcony of the first floor came down on me and I got buried under the debris with severe head, lung and spinal injuries and I got paraplegia at L1. I had to undergo two and half years of hospitalization and physiotherapy. Finally, I learnt to do some day to day activities with great efforts using crutches and calipers, but got confined to a wheel chair since 1959 till date. Both my legs have neither any power nor any sensation. However, even after this, I think I lived my life very successfully.***

**Q2. – What philosophy has made your life so happy and meaningful?**

***A2. – The word `philosophy' in the question makes it look like a tough question. You are not offered a life by your choice. You have to accept it and live it as successfully as you can. Suppose you are eating Idli-Sambar, and you are suddenly asked a question `Are you physically disabled?', you will be fumbled and surely reply `Why? What is the point?' So long as you are not talking about your handicap, you are not disabled. Thus a man can be happy and disabled, both, simultaneously.***

**Q3. – What are the problems that spinal cord injury has imposed on you in the past 61 years and what would you suggest to others ?**

***A2. – It is now 61 years since my disability. Memories of my `Able Life' are fading fast. No doubt, the life of a disabled or physically challenged person is a hard one. True that it is not chosen by him. But it is equally true that in most of the cases, nobody else is responsible either. All said and done, you have to face it with courage and magnanimity.***

***To explain it further, I will give instances in my life to show how I faced my problems.***

**1. *Throughout my life, I am staying on the first floor of the building without an elevator. Everyday, I had to go up and down while going to office. But I took it this way. My calf muscles are getting stronger. Later, when I toured extensively in India and abroad, I never complained about climbing.***

**2. *The door of the bathroom of the block where I stay, is such that a wheelchair cannot enter in. So I developed a technique of transferring from one chair to other, kept in the bathroom.***

**3. *I was working in Government Laboratory in VJTI Premises, which was near to our house and I had no option but to take a cab daily from home to office and back every day. The toughest of the problem was when I was transferred on promotion to the New Administrative Building opposite Mantralaya in Fort. The option of taxi every day, would mean that I would be working for the taxi driver. So, I took a soft loan from the Government. of Maharashtra, purchased a three wheeler Vespa Delivery Van, modified it with the help of my friend, to make it hand-controlled. I learnt driving the same. I fought with the R.T.O. for almost over a year to get it***

*approved for driving by a disabled driver, obtained a driving licence. Mine was the first three wheeler approved by RTO for driving by an Disabled person on the streets of Mumbai. Later this became a precedent and now a person with disability can get a licence for driving a specially modified vehicle.*

*Enough of this long story, let me now narrate some lighter instances.*

**4.** *I was a guest at my cousin in Nagpur. I went there for the first time. It was evening when we were sitting in his gardens. Later we went inside and while I was changing my clothes, I noticed that one of my leg was completely covered and bitten by red ants and they were running helter skelter. A doctor was called for him this was a very peculiar case. What had happened was that one of the wheels of my wheel chair had trampled the habitat of Ants (Varul), while we were sitting in the garden. As I had no sensation on my legs, I could not feel the biting of the red ants. Luckily for me, all the wounds healed without any special treatment.*

**5.** *Next time it was the rat which was responsible for the damage. During winter, I slept with my socks on. A small rat had entered our house. He entered one of the socks and bit all the toes. It was removed and killed later (the rat!). This time also, the wounds healed without any medication. Thank God, what else! The lack of sensation is the problem.*

*Well, for any paraplegic person, normally, Bed Sores, Pressure Sores and Urine Infection are most common problems, and if not controlled in time, can become serious. I used to read a lot and I was well aware of this. Hence, I took maximum care and took all the necessary precautions to avoid or keep these problems in control all along for so many years.*

**Q4. – Can you please share with us the special role played by various people around you during all these years.**

**A4. – Now I must add something about my family members.**

***First about my father. I have already mentioned that we were not very rich. But my father stood like a `Rock of Gibraltar' behind all of us. After all he was head of our family. My mother was, that way, very sensitive. Her eyes watered when the news was bad or even when it was good. Now, both of them are no more.***

***Now about my wife Vasumati. There are three important V's in my Life.***

***– Vasumati (my Wife), Wheel Chair ( which had added to my mobility) and Vespa (Three wheeler), which made my job possible. Now, I am 92. I think without Vasumati, I would be a quadriplegic.***

***My two daughters – Uma & Shama, are both married and well settled in their lives. Nothing to worry. My son Satish and grandson – Mihir, are both M.Tech from IIT Mumbai and are running a successful business in Satara, manufacturing gear boxes. My other grandson is working in Godrej. He is also an engineer. His wife is a professor in Ruia College. My Daughter-in-law was working in Central Bank of India.***

***We are all well educated (Graduates) in our family. Whenever any decision on family matters are taken, a lot of free and fair discussion takes place with all the concerned members in the family. Since everybody is consulted, it helps in keeping everybody happy.***

***I have a number of friends & relatives in my life, but the stress of city life makes it difficult to keep contacts. Thank god, mobile***

**phones are invented. I wish all my friends & relatives on their Birthdays & Marriage Anniversaries. In fact, it is my hobby.**

**My employer was `Director of Industries, Govt. of Maharashtra.' I am really unconditionally thankful to them for providing me pension at as late age as 92. No other employer would have done this. In the fast life of Mumbai, I cannot say that I am maintaining contacts with all my friends.**

**I think, I have a balanced and successful life in spite of the severe disability – Paraplegia.**



**With his better half, Vasumati**

**Q5. – How would you describe yourself – emotionally, spiritually, Intellectually etc. ?**

**A5. - This is the toughest question of the lot. It deals with me straight. I think I am very sensitive. Small instances in life create deep impressions and disturbances. Yet I do not like to make a show of it. I keep it to myself, deep, in a cupboard. I love reading books pertaining to `Advaita Vad' of Adyaguru Shankaracharya. Also I think there is no God who controls our lives. I believe in Big Bang and the expanding universe.**

**Q6. – Why are you so loved and respected by everyone ?**

**A6. - I think, others, who love me, respect me, will be the right persons to answer this question. In Addition, there may be some who dislike me or avoid me. So I will not know if any such persons are there or not. However, it is better to be under impression that people like me and respect me. It feels good.**

**Q6. – As a veteran, what guidance and advice would you like to give to**

**To 1.5 million friends with Spinal cord Injury in India?**

- **To Govt. of India?**
- **To Wheel Chair Manufacturers?**
- **To Doctors?**
- **To Automobile Manufacturers?**
- **To Family Members etc?**

**A6. – I feel that the scope of this question is very vast and I do not know if I am qualified enough to give advice to everybody. One thing is sure. My life with a spinal cord injury extends over more than 60 years which is quite unique. Instead of advice, I would like to give my suggestions as under :**

**My suggestion to 1.5 million friends with spinal cord injury –**

**You are not the only one who is suffering. Everybody thinks that his problem is toughest. Problems are of various types – Financial, health, relatives etc etc. There could be grave problems even in the life of other non-disabled people. One should never feel that he is selected to suffer by God. Much depends on how you react to it. Think of your abilities rather than counting your inabilities and start**

*making good use of your abilities. There is a case of Kunti in Mahabharat, who requested God to Flood her with Problems. Please never see your problems through a magnifying glass, at least not under the microscope.*

### **My suggestions to Government of India**

*The physically disabled persons are like your own children. They may not be coming to the voting booths to vote for you. Yet, while framing policies, see that you are not doing injustice to them. Their number is never insignificant. Here, I would like to point out that it is not only spinal cord injury persons who have restricted mobility, even any other person, after a certain age, does face difficulty in moving around. If Government makes it mandatory to have ramps and disabled friendly Toilets in all public buildings, markets, theatres, schools, colleges etc., many more people can come out of their homes and roam around like everybody. Every person will have to face this situation in their old age.*

### **My suggestions to wheelchair Manufacturers**

*The manufacturers of wheel chairs should visit international exhibitions and see the latest wheel chairs being manufactured world-wide and the facilities being incorporated. They should incorporate any small changes in the design in their products. It is noteworthy to see how Korean Wheel Chairs have captured the market. People with disability will always go for any new feature that will reduce problems in their lives. Wheel-chairs manufactured for disabled sports persons playing in international competition is a separate subject worth exploring.*

## **My suggestions to the Doctors**

***Doctors who are treating Spinal Cord Injured persons have to be more sympathetic to their patients. Doctors should also explain the probable problems that could be faced by them lifelong and should educate the near one's of how to handle these typical problems.***

## **My suggestions to Automobile Manufacturers**

***Automobiles which can be driven by disabled person is still a novelty in India. The vehicles which could be driven by people with different types of disabilities, is a field where some work is needed to be done. If Modified vehicles are put on road, such vehicles will need a special marking or colour code that the other drivers will be more cautious while negotiating with such vehicles. In U.S., there are separate and more convenient parking places reserved for such vehicles.***

## **My suggestions to family members**

***Involve and love your family member who has spinal cord injury in all activities at home, and other functions and make it possible for participating as a whole family.***

***Be supportive in their dreams and keep communicating like before.***



***With his family***



***Anupama Ganesh is associated with Nina Foundation for more than a decade. Over the years she has been a core team member for various events and activities of Nina Foundation. She played a pivotal role in conceptualization and the successful launch thereafter of Project Nirmaan – a unique multi-disciplinary Out Patient Department (OPD) for economically challenged friends with spinal cord injury from urban slums and rural areas.***

***A science graduate, her logical left brain steered her to a career path as a Computer Software trainer and she eventually owned a firm for software development. Post that, she took a break from her professional life to raise a family. While heading out from the break, it seemed like the right side of the brain took over and Anupama has been at her creative best since then - an artist that works with different materials and paints.***

***The push and pull of the left and right brain continues to lead her on to new experiences and exciting adventures.***

***Email: [foranupama@hotmail.com](mailto:foranupama@hotmail.com)***



***Bhavna Umarshi Chheda is a Peer Mentor at Nina Foundation. She also counsels patients at the Nina Foundation OPD which serves socially & economically poor friends with spinal cord injury from urban slums and rural areas. When she was 24 years old Bhavna suffered a spinal cord injury at level C3-C4 due to a car accident.***

***She is a core managing committee member of Nina foundation for all their events . She is an angel champion for rehabilitation of friends with spinal cord injury. She also co-ordinates with various vendors and suppliers of assistive devices and the recipients to ensure smooth and timely transactions.***

***A Commerce graduate, Bhavna was a topper during her school years and has won the Best student, Best Captain and Best Writer trophies. She has completed a Certificate course in Jainology. Bhavna is an avid reader. She loves interacting with kids and gives tuitions in Mathematics.***



***Madhu Singh is Head of Nina Foundation OPD which serves socially & economically poor friends with spinal cord injury from urban slums and rural areas. She is a Peer Counsellor and co-ordinates with a multi-disciplinary team comprising of spine surgeons, urologists, physiotherapists, assistive technologists, orthotists, Trustees, other Peer counsellors as well as collaborators AIWC (All India Women's Conference) team members. Madhu is young, energetic, reliable and a creative friend with spinal cord injury which was caused due to a fall from***

***her village terrace in Benares when she was barely two years old. She has been paralyzed and disable waist down since then. She is completely independent and is the primary care giver managing the health and wellbeing of her aged parents solo in Mumbai. A real role model for a woman with permanent disability.***

***She is a core managing committee member of Nina foundation for all their events .***



***Dr. Ratna Vora is associated with the Nina Foundation OPD as a Physiotherapist.***

***She has participated in Nina Foundation's medical camps at Sultanpur (UP) and***

***Jalna (MH) for the local friends with spinal cord injury. Ratna was nominated by Nina Foundation to attend the WHO-Motivation India workshop for Wheelchair skills.***

***Ratna has completed a Master's degree in Physiotherapy (Orthopaedic and Sports medicine) and is currently working as Onco-Physiotherapist at Tata Memorial Hospital, Mumbai.***



***Dr. Ashish Dubey*** is associated with Nina Foundation OPD as a **Physiotherapist.**

# **Project Nirmaan- A Free OPD in Mumbai for Patients with Spinal Cord Injury by Nina Foundation**

***Ms. Anupama Ganesh ,Ms. Madhu Singh ,Dr. Ratna Vora ,Dr. Ashish Dubey ,Ms. Bhavna Chheda***

**Spinal cord injury, whether traumatic or non-traumatic, most of the times results in a permanent disability of the most devastating nature. In 2012 WHO (World Health Organization) has declared spinal cord injury as the most devastating injury in the world!**

**A spinal cord injury can be caused by an accident, fall from height, bullet injury, adventure sports, diseases like Tuberculosis or Tumour in the spine and others. The spine impacts the functioning of the entire body. In Spinal Cord Injury the patient usually loses control over their body movement and most likely have medical complications such as chronic pain, bladder and bowel dysfunction, increased susceptibility to respiratory and heart problems. They become Quadriplegic (paralysis neck down) or Paraplegic (paralysis waist down). This significantly changes every aspect of life.**

**Rehabilitation of Spinal Cord Injured is the Key for a Good Quality of Life.**

**According to International Statistics, India stands second with the number of Spinal cord injury patients. The total number of spinal cord injury patients is approximately 1.5 million. Fresh cases every year are almost 20,000+. There are only 28 Rehabilitation Centres in**

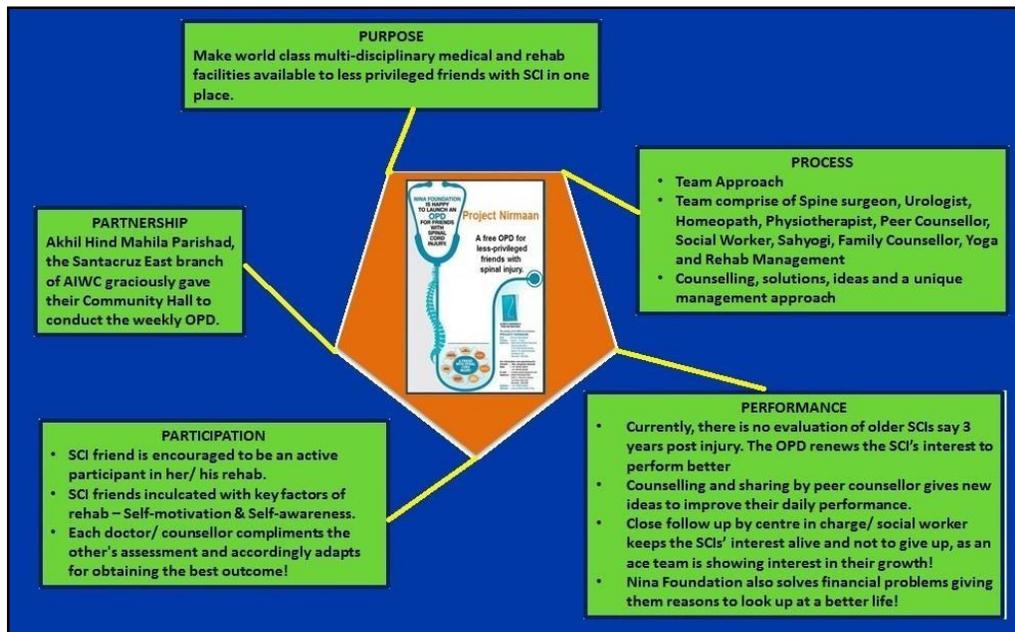
**the entire country with a provision of 900 beds only. In India there are only 2 world class rehabilitation Centres-*Indian Spinal Injuries Centre (ISIC)*, New Delhi and *Christian Medical College (CMC)*, Vellore. Mumbai is still awaiting a world class Rehabilitation centre.**

**For the past nineteen years, Nina Foundation has worked relentlessly to spread hope and optimism amongst the spinal cord injured. Nina Foundation's ethos is to 'give the Best to the poorest' - be it highly expensive and qualified doctors, counselling or treatment! Its innovative Project Nirmaan is a free non-residential once-a-week OPD (Out Patient department) launched in March, 2014 in collaboration with the Santa Cruz East branch of AIWC (All India Women's Conference). Through this venture, Nina Foundation's ace multi-disciplinary team assess, counsel and treat friends with spinal injury – all under one roof, in a single visit. They also help with diagnostics, transport, assistive technology, home modifications, home physiotherapy and guidance to care givers.**

**Nina Foundation's vision of giving hope to live to our friends with spinal cord injury is achieved at the OPD through personal one-to-one attention and time investment by top class doctors. The team of experts at the OPD also includes Peer Counsellors – friends with spinal cord injury who have struggled and self-learnt how to face life at home, at work place and in society. They interact with the patient and offer solutions which are doable and unique thus improving their quality of life! But the edge and the key difference at this OPD is homoeopathy consulting. *Project Nirmaan - An overview***

**A spinal cord injury patient would have spent over Rs. 20,000/- as consultation fees only, plus almost a month for appointments, cost of travel, foregoing a day's salary by the family member for every**

appointment plus all the effort. At the Nina Foundation OPD, they get assessed by the entire team under one roof in a single visit.



Many patients coming to the OPD are from an economically challenged background. Some of them have not seen a doctor for years due to financial and accessibility issues. The family members / caregivers tend to overprotect the patient. They are also at the receiving end of the anger and frustrations of the patient and need guidance and counselling.

The OPD has helped the older SCI (3+ years post injury) to perform better by renewing interest in rehab. Counselling & sharing by peer-counsellor gives new ideas to improve daily performance. Seeing another friend with spinal injury living an independent life also gives hope. Follow-ups by OPD team keep them interested in their rehab. Privileged friends with spinal cord injury are also seeking the facilities of this weekly OPD. Medical & psycho-socio-economic

**needs of hundreds of friends with spinal cord injury have been addressed since inception.**

**Before the OPD was launched there were a lot of naysayers who tried to discourage the team by saying it won't work at all but the Nina Foundation team persevered. Today Project Nirmaan OPD continues to answer multiple needs of less-privileged friends with SCI & instil optimism, hope and positivity in their lives.**



***The AIWC Santa Cruz (E) team***



***Shivakumar Nagarajan (Shiva) is Director and Founder of Bionic Yantra. Shiva has over 22 years of experience including stints at CRISIL, Citibank, Microland group and TCS. In his last role, he headed IP incubation globally at Capgemini. He has experience in product strategy, sales and execution. He is an alumnus of IIM Lucknow ('97) and NIT Surathkal ('95)***

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# **New innovation for spinal cord injury rehabilitation: *Design & Impact***

***Shivakumar Nagarajan***

## ***Spinal Cord Injury – a tough challenge!***

**Spinal Cord Injury (SCI) is a devastating condition that has affected around 5,00,000 people in India and many more globally. A significant proportion of SCI suffer from quadriplegia (paralyzed neck downwards) and paraplegia (paralyzed waist downwards). Most of them are unable to perform their activities of daily living, which puts lot of pressure on their caregivers. SCI injuries mostly occur as a result of industrial accidents, road traffic accidents, falling from trees and construction site mishaps. Another unfortunate statistic is that most victims are young (below age of 40) and face a tough challenge for the rest of their lives.**

## **Ambulation is key to a virtuous cycle**

**While a detailed presentation of all the benefits of walking is beyond the scope of this article, here is a brief recap of problems faced if one is *unable to walk*. Blood circulation is poor, bones suffer from osteoporosis and muscles can waste away owing to lack of use. Further, owing to no movement, pressure sores and bed sores can develop on the body, which are often more painful and expensive to treat than the primary condition itself. In addition, a large proportion of the SCI injured do not have bowel and bladder control, no sensation below the injured area and sexual activity is very**

difficult, if not impossible. Their loss of dignity owing to full dependency on caretaker leads to very low motivation and in some cases, depression. All of this can be reversed or at least ameliorated using a new innovation, that is presented below.

*This innovation focuses on rehabilitation (recovery) of the body post an SCI. It is known that brisk exercise can assist in some functions coming back (owing to neuro-plasticity) but many patients find it too tough with their own effort (manual therapy) to reach the neuro-plasticity threshold. Powered (robotic) rehabilitation with a fall-safe mechanism can help tremendously in such a scenario.*

## **Current state of rehabilitation solutions**

### ***Manual rehab is tedious and offers poor outcomes***

And of course in manual rehab, therapists had to lift and hold patients making it very tedious and making the therapy quite subjective. It takes roughly 3 times longer than robotic rehab to achieve the same outcomes (if at all).

### ***Existing robotic rehab does not eliminate Fear of fall***

While existing Robotic rehabilitation solutions using exoskeletons are nice, they do not prevent fall. Patients and therapists worry about further damage when trying to do therapy / rehabilitative exercises. This is particularly true for fragile users such as SCI patients, for whom a fall is often catastrophic and possibly life-threatening. Naturally, almost all therapists focus their attentions on preventing fall rather than on therapy.

## Manual LRT



## Robotic LRT



### ***Existing robotic rehab is Not hands-free***

Next was not being able to use their hands. As a corollary, fragile patients were also kept away from early intervention since using crutches, walker etc. needed balance and strength, thereby depriving them of the benefits of early intervention.

### ***Existing robotic devices are quite uncomfortable to wear / use***

Able-bodied people may not realize it but post injury / disease, the patient's body itself can undergo some changes (deformation) and need to conform to the standard body shape. Many brilliant engineers had unfortunately not understood this aspect and hence many of the contemporary devices did not have a "good comfortable" fit for patients. It was too loose or tight or clumsily wrapped thereby leading to loss of therapy time. These are just a few instances of requirements. Several more are listed below.

## Manual Rehabilitation

Tedious to undergo, Poor Outcomes

Protocols are inconsistent

No Session-Level Measurement

## Current Robotic Rehab

Not Hands free & Not Fall-Safe

Excludes weak upper body patients

Needs 2-3 Therapists to supervise

## The Innovation: REARS (Robotic Exoskeleton Assisted Rehabilitation System)

Enter Robotic Exoskeleton Assisted Rehabilitation System or REARS. REARS consists of 2 robotic sub-systems - a mobile robot (also called body weight support or BWS system) and a wearable robot (also called exoskeleton). The BWS is in the shape of a frame (around a user) having 4 wheels. A harness is suspended from a hook at the top of the frame. This harness is strapped around the torso of the user.

REARS is a unique combination of a Mobile Robot (BWS) and Wearable Robot (Exo) with common control system and power

### Intent Detection

Exoskeleton drives gait – detects intent via head tilt and foot sensors

### 1 Device : Multiple conditions

Software protocols for specific diseases are configured for patient, using robots as channels

Body Weight System (BWS)  
Mobile Robot



Exoskeleton  
Wearable Robot

### “Patient Follower”

Patient following mobile robot enables constant unloading while walking by detecting patient CG

### Fall-Arrest mechanism

100% fall-safe is enabled via detection of fall via CG drop velocity triggering fall-arrest mechanism

The second sub-system is the Exoskeleton or wearable robot which powers the legs of paralyzed patients. The exoskeleton enables

previously wheelchair bound persons to stand and walk, while the BWS prevents them from falling.

### ***What is the innovation?***

The BWS and Exo have a common control system – so the exoskeleton powers the walk while the BWS follows the patient (patient does not pull or push it). This is much more complicated than it sounds – given that it involves 2 robots with human inputs / feedback loop, the device is quite unique and even has a patent. Both the robots have to be designed to work together (starting from gait, power mechanism, sequence of operation and many others) – you cannot simply connect one Exo to a BWS and expect them to work together.

### ***Why is it so unique?***

The exoskeleton powers the (paralyzed) legs of the user to make them walk in a human-like fashion, while the BWS follows the patient to prevent fall. Note that the patient does not pull or push the BWS – it is robotically synchronized to the exoskeleton and hence follows the patient. There is no risk of fall and yet no tedium felt by therapists / doctors.

How does it help an SCI patient?

It helps in 7 ways

#### ***1. Early intervention (owing to fall-safe walk)***

It enables early mobilization of patients (since fear of fall is eliminated) enabling effective use of the golden hours of

rehabilitation. More granularly, patients can be made to stand / walk as early as the day after their operation without any fear of fall.

## ***2. Walking with unloading weight***

On-ground walking with weight unloading is a unique feature offered by this device. Fragile patients who cannot bear their full body weight can be unloaded (as per what the therapist recommends) and gradually reduced as their body heals and is able to bear more weight. This kind of calibrated unloading while walking on the ground is not possible with other exoskeletons.

## ***3. Enabling access to robotic rehab for those with weak upper body / hands-free rehab***

Given the safety harness and no need to use hands for balance, patients with very weak upper body strength (even up to SCI C5/C6) can utilize this device for rehabilitation. This addresses fall-safe walking for those who are not strong enough to hold crutches, don't have enough balance or are very fragile.

## ***4. Enabling access to robotic rehab for those with spasticity***

Patients with spasticity are usually excluded from using exoskeletons on the ground since a sudden spasm can lead to loss of balance with catastrophic consequences. This risk is elegantly eliminated since the safety harness protects against fall.

## **5. Objective measurement – boosting motivation**

REARS is an IOT device and provides a detailed report (using sensors to record data) on locomotion parameters (distance walked, speed, stride length, range of motion of knees, stride symmetry etc.)

at the end of each session which enables the therapist to know the efficacy of the exercises and more importantly the patient to know whether there is real progress. The incremental day-to-day progress goes a long way in motivating patients. The evidence of improvement (however small) boosts motivation.

## ***6. Therapy with Comfort and Dignity***

A winch is present to lift patient from wheelchair to standing position and held by the harness. When moving, nobody needs to hold the patient, as they are held safely by the harness. To make it comfortable for patients, the batteries, computer and heavier motors are all in the frame of the BWS, thereby making the exoskeleton very light for the patient to use. The device has sensors on the BWS that detect intent to move forward to trigger a forward step as well as hip, knee actuators on the Exo to initiate a step consistent with the user's gait. This enables the patient to feel that he/she is exercising rather than being treated by a medical device.

## ***7. Hope of much better outcomes***

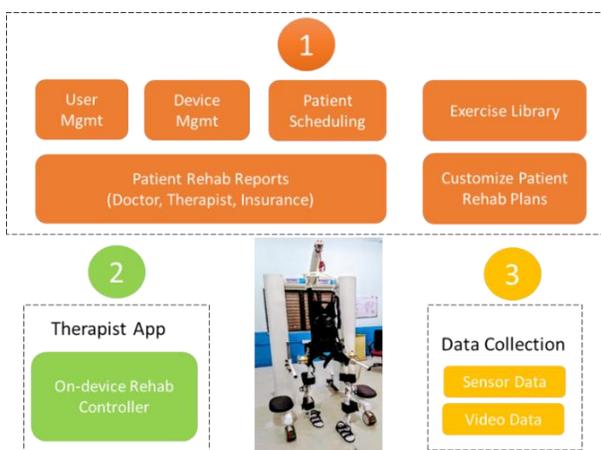
This early intervention and on-ground walking (as compared to treadmill walking) is superior since the patient's natural walk is encouraged (where a patient could start walking slowly, stop, start again, walk faster and then again reduce speed etc.) – all of this is not possible in a treadmill walk. Hence it gives an opportunity for the body to heal as much as it can.

This innovation holds the promise of being a much faster and effective rehabilitation system and hence prevent many (especially those with recent injuries, milder conditions) from getting to a wheel-chair. Even walking with a crutch, walker etc. will be a

significant upgrade rather than only ambulate using a wheelchair. Early try-outs by patients at a hospital are quite encouraging.

## The software platform

While the hardware is impressive, the software offers more features. The software will be utilized to change the behaviour of the hardware, as desired by the therapist / doctor and in that regard, the hardware will be a channel to deliver software driven therapy.



The software consists of sophisticated algorithms that provide the right power / torque to the specific patient to enable maximum rehabilitation (for that medical condition). As may be evident, this is niche medical knowledge. The know-how on

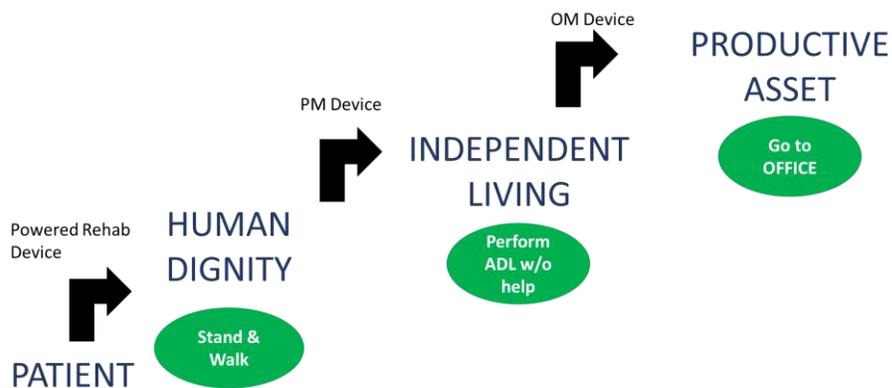
what exercises are relevant for a person of certain injury type and demographic profile (age, gender, lifestyle) using robotics is not common knowledge, and Bionic Yantra has access to this, thanks to its collaboration with one of the leading rehabilitation hospitals in the world.

This implies the therapy can be customized for each SCI patient (their exact level of impairment, metabolic state, gender, age and other parameters). This is possible using AI/ML algorithms that enable "mass-customization".

## Product Roadmap

Bionic Yantra's mission is to transform patients to productive assets of society. It is intended to do this via a 3-step process.

Step 1 is rehabilitation, which essentially is to enable the body to recover as much as it can and in a much faster timeframe. This is the purpose of REARS. After rehabilitation, some patients may happily walk back home but some may still need assistance to walk at home.



Step 2 is to build a Personal Mobility Device (PMD) that allows SCI patients to perform the activities of daily living (bathing, grooming etc.) independently at home. This would both reduce the pressure on the caregiver and increase self-worth of the wheel-chair bound. This would enable some simple (simple function but technically not that simple) manoeuvres like transfer to a chair, commode and a cot.

Step 3 is to build this Office Mobility Device (OMD) that can allow them to move outside their home to an office and thereby become productive assets of society.

REARS (step 1) is ready and plans are afoot to build the PMD (step 2) next year.

## **In conclusion**

**Good design comes from understanding customers (users) needs deeply. Bionic Yantra's REARS is an innovation that attempts to significantly change the rehabilitation scenario using robotics – especially for SCI patients.**



***Pragya Ghildial is senior Yoga Therapist at Indian Spinal Injuries Centre, New Delhi, India***

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# **Yoga for people with Spinal Cord Injury**

***Pragya Ghildial***

**Yoga is the key to sound health, vitality and a clear mind. Yoga is the science of right living, and should be incorporated in daily living. It works in all aspects of person: physical, vital, mental, emotional, physic and spiritualistic yoga will help increase strength, flexibility, and muscle tone, aid mobility and self- esteem. Yoga also helps in control weight and aid digestion. Research into the effects of SCI yoga practices is currently underway with promising results. According to the medical scientists, yoga therapy is a successful because of the balance created in the nervous and endocrine systems which directly influences all the other systems and organs of the body. People with physical disabilities will off course, not be able to do many of the yoga asanas, but some great benefits can be derived from the breathing techniques and meditations and the mental aspects of yoga. A healthy body image implies the real acceptance of all parts of the body, even the not-so-happy parts. It is only then that one gains the emotional strengths to make physical and emotional changes if one wishes to.**

**SCI yoga is designed keeping in mind the physical limitations of people confined to the wheelchair, while helping them to carry out these exercises any time and any place they choose. They are many benefits to practicing wheelchair yoga. Not only will you start feeling stronger, healthier but your muscles, joints, and tendons, as well as your vital organs will start functioning better and with more vitality. Brings down stress and enhances powers of relaxation.**

**SCI yoga also helps you to gain spiritual, physical, mental, benefits. If you are depressed about physical condition, you will begin to feel calmer, more in control of your life and generally begin to experience a sense of well-being that will aid you in overcoming day to day limitations.**

**When practicing wheelchair yoga, you will not feel stiff or lack of energy. In fact, some of the more positive effects of wheelchair yoga include increased muscle and mental strength, decreased levels of anxiety, nervousness, and stress. You will sleep better, feel stronger and experience a surge in confidence and self-esteem levels.**

**The exercises, postures, and movements are selected carefully during wheelchair yoga sessions and the emphasis on comfort, ease, and simple poses for every wheelchair bound individual. More and more physiotherapist recommends yoga as a supplementary physical therapy to patients who are SCI**





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# **“Aquatic therapy to improve Quality of Life in friends with spinal cord injuries – Our AquaCentric experience”**

***Dr. Brinda Merchant (PT) & Dr. Amit Kohli (PT)***



**Aquatic Physiotherapy** refers to evidence based and skilled application of physiotherapy, in an aquatic environment. It is administered by a physiotherapist trained in aquatic therapy.

Perceived as an effective therapeutic modality, aquatic therapy is shown to be extremely beneficial in persons with spinal cord injury.

Spinal cord injury leads to physical limitations and consequent reduction in physical activity. This is associated with conditions such as diabetes mellitus, obesity, poor cardiorespiratory function and

poor quality of life. Land based exercises often get tedious, repetitive and strenuous with age. An aquatic environment ensures more variation, leading to greater efficacy of treatment.

When compared to swimming, aquatic therapy aims to improve vertical function (standing based function) of an individual, to achieve functional goals for daily living.

**Benefits of aquatic therapy for persons with spinal cord injury include**

- *Improved muscle strength and endurance*
- *Improved mobility*
- *Better postural control*
- *Enhanced aerobic capacity (stamina)*
- *Reduced joint pain*
- *Decreased muscle fatigue*
- *Improved cardiorespiratory function*
- *Improved cardio metabolic risk profile*

The therapeutic benefits of aquatic therapy relate to the fundamental principles of hydrodynamics:

- *Buoyancy*
- *Viscosity*
- *Hydrostatic pressure*
- *Thermodynamics*

**Human body being less dense than water is subjected to buoyancy of water, rather than force of gravity which dominates on land. Gravity loads the body, whereas buoyance off loads the body. Immersion in water up to the chest level, would result in 70% of less loading. Consequently person feels lighter and therefore experiences decreased joint stress and more mobility than on land.**

**Water allows stability of trunk without relying on use of upper limbs as is often the case during land-based exercises. Postural stability in standing is enhanced as water acts as a supportive medium. This when combined with movement strategies promotes better alignment and postural control while standing.**

**Viscosity or drag force refers to resistive force provided by water to movement, providing natural resistance and increased sensory stimulation. Muscle strengthening is hence facilitated as the body needs to work against viscosity. Force can be altered with use of pool equipment like resistance jets, diving fins, kickboards and pool noodles.**

**Hydrostatic pressure is pressure exerted by water on body during submersion. Hydrostatic pressure assists in resolution of oedema, increase in joint range of motion and tone modulation.**

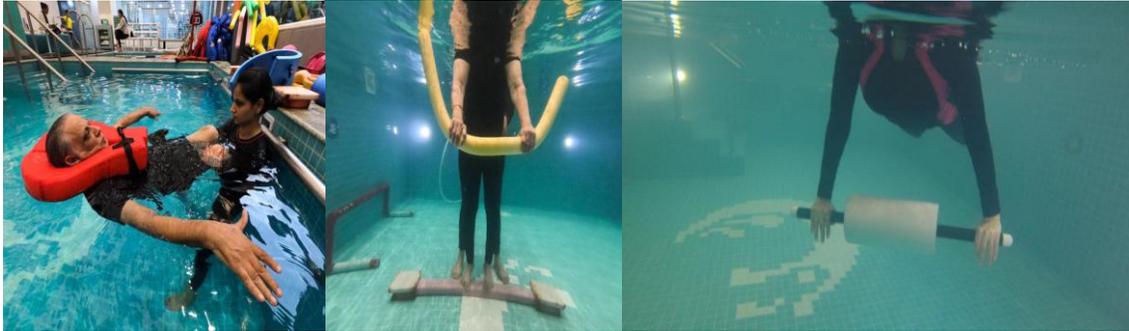
**Warm water in aquatic therapy pool promotes pain relief, muscle relaxation, enhances circulation and general comfort. Ideal temperature for therapeutic pools is 32.5 degrees Celsius, which is thermo-neutral for the human body. However in conditions like pregnancy and multiple sclerosis, a cooler pool temperature of 25-28 degrees Celsius is required.**



**Aquatic therapy interventions for persons with spinal cord injury** comprise of techniques which utilize physical properties of water. These include Water Specific Therapy (WST), Bad Ragaz Ring Method (BRRM), Aquatic Strengthening, Functional training and Clinical Ai-Chi.

**An important factor for deriving functional benefits is having skilled aquatic therapists design a treatment programme customized as per individual's functional ability and limitations.**

**Depending on individual needs, frequency of session may be 3-5 times a week with session duration of 45 minutes.**



### **Case in point 1**

**60-year-old male spastic quadriparesis wheelchair bound since 2018, associated diabetes mellitus, and hypertension was referred for aquatic therapy. An aquatic therapy plan was formulated with focus on trunk control, muscle strengthening and functional gait. Frequency of sessions is 4 times a week. Six months post therapy, person walks independently with walker within his house.**

### **Case in point 2**

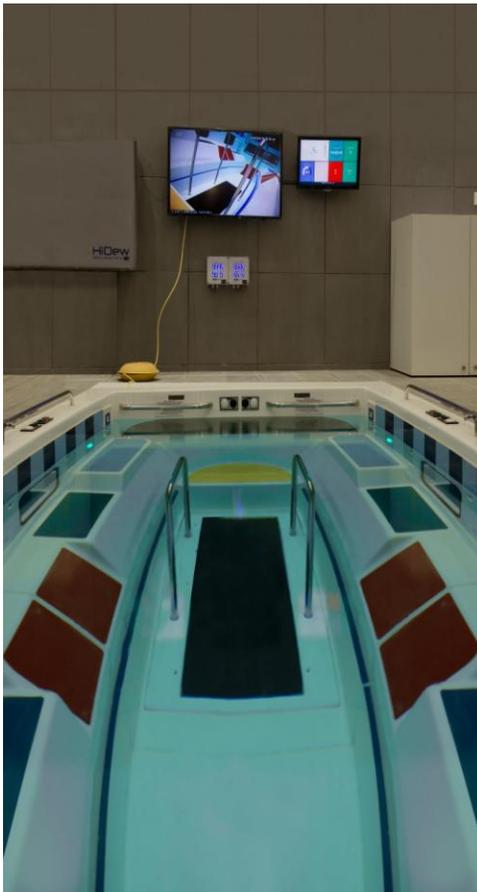
**23-year-old male with spastic paraplegia since 2014, was using a floor reaction orthosis and walker prior to start of sessions. Walking was limited due to less endurance. Therapy goal was independent walking with elbow crutches. Aquatic therapy plan was formulated with focus on endurance and movement control apart from optimizing energy expenditure. Frequency of sessions is 5 times a week. One-year post therapy, person has improved postural alignment. He walks independently with crutches and ankle foot orthosis.**

**Aquatic therapy pools** are designed to meet functional goals and for enhancing recovery from paralysis. Improved standing based is a primary therapeutic goal. Hence pools are adapted to facilitate therapeutic activities while standing. It is ideal to have incremental pool depth ranging from shallow to deep for treatment interventions. Side rails are an essential feature to provide requisite support. Pool staircase has an anti-skid surface with side rails for safe entry and exit.

**Special features include:**

- ***Underwater Treadmill:*** Invaluable for gait training, underwater treadmill allows individuals to practice walking patterns which mimic land patterns. The speed of the underwater treadmill changes in small increments allowing persons to safely progress at their own speed.
- ***Underwater Cameras:*** These enable real time monitoring of gait and movement patterns without looking down, so that corrective feedback may be provided by the physiotherapist immediately
- ***Electronic pool hoist:*** Persons with spinal cord injuries may frequently have mobility issues that which make entry and exit difficult .Electronic pool hoists are used to facilitate entry and exit, making pool safe accessible for persons of all ages and abilities, eliminating need for ladders or steps.

- **Resistance Jets:** Variable speed resistance jets allow physiotherapist to adjust the level of water pressure and vary resistance offered by water, thereby altering exercise intensity.
- **Deep-tissue Massage:** In pool, high pressure massage hose allows deep tissue release, reducing the amount of muscle soreness and promoting a faster recovery.
- **Height adjustable drop in platforms:** These are sturdy, on slip surfaces above level of pool floor. Sitting based exercises and other strategies of water specific therapy (WST) are facilitated using pool platforms
- **Underwater stationary cycle and elliptical trainers:** These are designed for improvement of cardiovascular endurance.



**Aquatic therapy equipment comprises of water dumbbells, foam rollers, resistance band, boards, floatation vests, neck collars, pelvis rings and snorkels.**

**Pool surroundings are required to be accessible in terms of design. Pool deck, changing room and wash room facilities are wheelchair accessible, with wide doorways and adequate room for wheel chair manoeuvring. Anti-skid flooring is installed in all areas. Wide benches need to be provided. Hand rails are installed at strategic locations**

**Trained support staff assist with safe transfers. Nursing personnel assist with assessment of vital parameters, bladder management and wound dressing.**

**Precautions are taken in case of co-existing lung or heart conditions, ear infections, open wounds, inserted lined / tubes and unregulated bowel/bladder incontinence. Aquatic exercise should not be attempted in case of uncontrolled seizures or conditions classified as medically fragile. It is important to seek medical clearance prior to start of therapy.**

**In conclusion, evidence based aquatic therapy is proven to be an efficient tool for rehabilitation of persons with spinal cord injuries, providing opportunity for neurological recovery and functional goal attainment.**

## **FAQs**

### **Is it necessary to know swimming?**

*It is not at all necessary to know swimming to avail aquatic therapy. Person is supported by therapists and where necessary floatation devices like neck collars and rings are used.*

### **May I enter the pool if I have bladder/bowel incontinence?**

*Yes, waterproof diapers along with containment briefs are used. However diarrhoea and loose, watery stools are an absolute contraindication.*

### **Will only aquatic therapy intervention suffice for therapy?**

*While aquatic therapy is proven beneficial for improving parameters like strength and endurance, it is most efficacious when combined with land based therapy. Dosage of aquatic and land sessions is recommended by physiotherapist.*

### **Will aquatic therapy help with transition to land function?**

*Aquatic therapy is utilized to ease transition of functional skills on land since physical properties of water help improve strength, endurance and balance create. It's going ahead, and it won't stop here."*



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▪

# **Inclusive Fashion Design**

*Sunita Sancheti, Madhumita Sancheti, Namrata Iyer*

**SWIP started off as an idea in the corner of Namrata's classroom. It grew from wanting to make a garment that had some sense of story, that helped someone in society - and not just be a common mass produced garment created for profits.**

**To see how it has grown into a real, tangible product that has the potential to make someone's life easier, gives the team so much hope with how powerful and important fashion can be.**

**The Fashion Industry has had a reputation for being non - inclusive, unsustainable and extremely rigid with the kind of people they represent. However, this age old tradition is changing, slowly, but readily. One of the quieter problems they exude is being non inclusive towards Persons with Disabilities, an untouched, unspoken of sector that requires intervention, for the clothes we wear are primarily designed for the standing body, and a lot changes when we sit.**

**Since Namrata had never had any interaction with Persons with Disabilities, she felt like she was walking straight into ambiguity; a very nerve wracking state to be in. After spending hours researching on paraplegia through medical text books and TED Talks and conducting long interviews with other paraplegics, she realized that there is a reason why she takes 3 minutes to change whereas a person with paraplegia takes 10 minutes or more for the same task.**

**And the reason does not lie in the disability. It lies in the inaccessibility and ignorance of the design.**

**This is when she met Sunita and Madhumita after which, they participated in AD - DRESS together. Sunita is a Disabilities right activist and a national level badminton player, among many other things and Madhumita has an education in marketing, but has continued to pursue yoga and fashion design through small exhibitions that she organizes.**

**Madhumita has also been designing for Sunita for the past few years and in the process she has had certain revelations as to how garments fall on the body differently while sitting. Small details like the importance of the right fabric, functional features, and easy wear are at the top of her mind when she designs. However, above all, she keeps in mind the final look, making sure the person always looks stylish and felt comfortable.**

**After their first few interactions, Namrata was also briefly enlightened about small things that affect us while being seated. When sits, the back of the pants become loose, tight on your thighs, and even run up a little from ankles. The pocket at the top of the pants lose function, and blazers are often unbuttoned. All these examples are proofs that the clothes we wear are designed for the standing body.**

**To cater to most of these problems, SWIP has short sleeves and drapes on like a shirt, which makes it very easy to put on, without much lifting of the hands. The hip measurements are larger -**

accounting for the thigh expansion when sits and the back runs higher than the front. The length is adjusted to be longer and it fits on as a half elastic, half band at the waist. There are pockets at knee level, so that they can actually be used while one sits.

They have also accommodated zippers on the side of the garment for easy pulling on, which also doubles for easy catheter usage. Finally, the fabric of choice is Tencel - a natural and biodegradable fabric obtained from wood pulp, thus making it sustainable comfortable.

It's important to note how this garment is a wardrobe staple and can be layered with other accessories like scarves or blazers or even jewelry. It's been consciously made to be styled in several different ways, and does not limit the user. It's a classic that could also give the illusion of a jumpsuit.

As a mentor, Sunita felt these features were important. She strongly felt the market did not cater to her needs in specific, and there are many things young designers were not aware about regarding the problems of persons with disabilities- by the mere reason of it not being written or expressed anywhere. The advantages of this garment are small - faster dressing, less strain on certain body parts and functional features like pockets in the correct spaces. One may even miss out on them once worn; but that's the beauty of the garment - it feels exactly like any garment from the store, but caters to the smallest details one thought of as problems in oneself rather than the garment. The goal is to make it feel as easy and accessible as possible, and perhaps not even remember that it is an 'adaptive garment' in specific.

**AD- DRESS was a competition by Ekansh Trust anchored by Anita Iyer, which is working to promote adaptive clothing in India, organized the event to bring attention to the need to design for the differently abled and to encourage young designers to come up with new solutions. The NGO is currently working to sensitize clothing manufactures to the issue. Ad-dress held a runway show for its 15 finalists, shortlisted from a group of 50, which included students from the National Institute of Fashion Technology. The fashion event showcased the final product of collaborations between teams of fashion designers, their mentors, and muses with one of the 21 disabilities recognized by the Government of India. The teams were tasked with creating an outfit that both catered to the specific needs of their muse and also showcased design prowess.**

**By the end of it, it was a very encouraging state to be in - to have completed a garment as such, and even be recognized for SWIP got a 'SPECIAL MENTION AWARD'. There were definitely a lot of setbacks on the way - some functional, and some by the nature of creating something new, but the blend of the team made it possible within the stipulated deadline.**

**They came to a couple of realizations by the end of this project. "We understood that every time we make a change, we learn, we grow. We make mistakes, question ourselves, our skills and ignore one part for another. We feel sheepish for not getting it right and yet, we grow.**

**We've been asked time and again, how this project is going. And to be honest, we don't know how to describe my answer. It's beautiful to create. It's going ahead, and it won't stop here."**



***Salil Chaturvedi is a writer and poet, based in Goa. He sustained a spinal injury due to a road accident in 1984, when he was sixteen years old, and he has been using a wheelchair ever since. He has written on the experience of disability, often using humour to draw attention to societal apathy towards disabled persons. He has represented India twice for wheelchair tennis. In 2009 he sailed a boat from Mumbai to Goa to highlight the importance of access for disabled persons. He was awarded the Super Idol Award by IBN7 in 2012. His fiction and poetry has appeared in various anthologies in India and overseas, and his writing has received various accolades. He is also a Trustee of Score Foundation, an organisation that works for the empowerment of visually impaired persons.***

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## **'So, You Want to Drive?'**

*Salil Chaturvedi*

**'Yes, Sir,' I responded to the doctor's question with enthusiasm, but at the same time being careful not to say more than the necessary.**

**'How do you drive?' he asked, still looking at the form.**

**'Quite well, Sir,' I said with a hint of pride. 'I've been driving for the past twenty years and no challans!'**

**He looked up from the form and fixed me with a stern gaze. I suddenly felt unsure of myself. I could feel a hole emerging in my stomach. After a long, cold stare he said slowly, 'How do you drive with just your hands?'**

**'Oh,' I said, understanding now, 'It's quite easy actually. I can also swim with just my hands,' I added helpfully.**

**'Does this look like a swimming pool to you?'**

**'No, Sir.'**

**'Then why are you talking about swimming here, huh?'**

**'Sorry, Sir. I meant that the car is modified, so it's easy for me to drive. What they do is fix a device on an automatic transmission...'**

**'This won't do,' he cut me short. 'Why are you smiling?'**

**'I'm not smiling, Sir,' I said defensively and with earnestness.**

**'In this picture,' he said sternly again, pointing at the form. 'Why are you smiling in the picture? This won't do. You are a disabled person. You will need a new picture for this form. A be-weepy.'**

**'Be weepy?' I asked, not sure what he meant.**

**'Yes, a be-weepy. How many emotions can you do?**

**'Sir, I can do happy and angry,' I said, feeling flustered. I suddenly felt I was in school again, facing the Principal.**

**'No, no. You need a be-weepy. You need a full body picture. This is only till your chest. Do you look disabled?' he asked, thrusting the form in my face. 'Take a new picture and fold up your trousers so your legs can be seen. And look sad. We need a be-weepy.'**

**'Weepy?' I asked to be sure.**

**'Huh!' he said dismissively. I knew it wasn't going very well.**

**'You want me to be weepy, Sir?'**

**'No, no. The picture has to be in a be-weepy format. You people don't understand anything. Stop wasting my time. I have many patients to see. This is a government hospital, not a fancy private hospital where I can have long talks on the weather with you.'**

**'Sir, I am not sure I understand. If you could please...'**

**'Be Weepy, Be Weepy ... A Bichara Viklang Picture,' he said, capitalising the first letters of the words as he spoke.**

**'Oh ... a B.V.P.' I said, understanding finally dawning on me. 'Yes, a**

**B.V.P. Now come back with two post-card size and two passport-size BVPs. This is a medical board, not a joke. Don't take it lightly. When you are back, I'll have to do a big test on you. Only then the Medical Superintendent will sign. You must understand I'm trying to help you.'**

**'Right, Sir,' I said, reaching out for the form.**

**I came out of the doctor's office feeling like a freshly deflated balloon. I perked up a little thinking that this experience would help in getting the emotion right for the**

**B.V.P. I immediately told myself not to perk up otherwise the picture would come out all wrong.**

**This was my second day at the government hospital, facing a Medical Board so that I could get a form filled to claim the Excise Duty exemption on the new car that I wanted to purchase.**

**Some of the doctors had been quick about the examination, like the ophthalmologist who had asked me to read some letters from a distance and had promptly signed the form. But, the urologist had been somewhat different.**

**'Why are you here?' he had asked when I had entered his cabin. It was a small cramped room with about seven young medical interns who were there to learn and absorb the workings of a government hospital. They were all dressed in light green coats and they were all girls.**

**'Sir, I want a new car and...'**

**'So what can I do if you want a new car?' he said. 'This is not a showroom.' 'I need your signature on the form, Sir.'**

**He took the form and studied it. 'Now see,' he said to the interns in his best complaining voice, 'This person needs to drive a car and I have to check his testes. Twenty years as a specialist in a government hospital and this is what they expect me to do! I will also have to poke my fingers and check for piles and fistula,' he said, clearly unhappy with the situation. 'All because this gentleman wants to drive.' The girls twittered *en masse*.**

**The doctor took me behind a screen and asked me to unbutton my trousers. As I undid the trousers he asked, 'How many cars do you have?'**

**'Only one, Sir. It's now fourteen years old and I need a new one. I just want this medical form so I can claim the exemption...'**

**'Which one are you buying?'**

**'I was thinking of a mini-SUV, Sir. I like to travel with my wife.' I named the model of the car.**

**'Good choice,' he said, brightening a little. 'My son bought the same car. Good mileage it gives and very comfortable. The ground clearance is also quite good for Indian roads.'**

**I knew all this already, so I said, 'Sir, the testes?'**

**'Oh, forget the testes. You test drove the car, no?'**

**'Yes, Sir.'**

**'Okay, button up your trouser and enjoy,' and he had packed me off.**

**I returned to the hospital after an hour, having gone to a photographer and clicked the B.V.P., but the Orthopaedician had left for the day.**

**The next day I landed up at the doctor's OPD early in the morning. It had been raining heavily and there were very few people in the queue. I entered after only a half-hour wait. I showed the doctor the form and the desired B.V.P. He examined the picture and seemed satisfied with my sad expression. He nodded his head and signed on the form and handed it over to me. I took the form and waited hesitantly.**

**'You can go now,' he said.**

**'Sir, the big medical examination?' I asked with surprise.**

**'Oh, yes,' he said.**

**He reached out his hand towards me and said, 'Shake my hand.' I took his hand and shook it.**

**'All fine,' he said. 'You can go.'**

**As I wheeled myself out of his cubicle he called out, 'Listen, if you need any further help in the future, we will do whatever is required, okay? We are here to help you.'**

**I nodded and wheeled myself out of the office. I caught a glimpse of myself in a mirror hanging near the door. I was smiling. I rushed out before the doctor caught me in the act.**



## **Letter from the Chairman's Desk**

**By Sunil Bhatia PhD**

**One day I was going by my car along with friend who was automobile engineer in United States of America and has very long experience. My vehicle developed some snag and refused to start. My friend came out of the car and inspected the engine after opening the bonnet and made some actions for correcting that mistakes but nothing worked. I allowed him to satisfy with his knowledge but nothing concrete was coming out and vehicle was in same state. At last I thought for calling company mechanic but felt problem is not serious and it would take long time for him to visit and my alternate thought for call for some local arrangements. I called a roadside mechanic who took no time and rectified whatever mistakes and advised "I have made temporary arrangement and do not stop car anywhere otherwise same problem will surface. Visit proper workshop for permanent solution." I paid his charges with thanks and looked at my friend as nothing has happened.**

**While driving the car I was thinking about formal trained engineer who was trained under close learning environments under the proper supervision and informal trained mechanics who has learned in open environments shear from his observation, experiences that have come after trial and error not has any sort of formal training has his own asset of knowledge. Society's major progress is because**

of unorganized sector that is nothing but informal people who have learned from their own resources and majority of time with their own experiences. Its natural next step of progress of any new field is to acquire the stability for progress that time trained and formal group of people with standard format of knowledge manipulates and takes charge. A new area progresses as long it is not formalized. Reason is that collective minds of every walk of life works for solution from their past knowledge for whatever unforeseen problem surfaces, where in formal sector everything is standardized and collective minds are uniform and diversity in thinking is missing for trained in solving in standard format so everyone thinks alike and does not contribute a solution that is lying somewhere in other walk of life but continues to lives with ignorance. ` Is it good for society for diversify thinking for collective minds or unify minds in standard format of thinking alike for progress of the society? It is human nature for adopting standard format for show must go on but disturbances of creative people shakes the society for next level and in due course of time it adopts the new normal. Why do accept new norm as our way of life is mystery? Formal trained minds are limited in number where informal sector is huge and cannot be defined by any specific boundary. Beauty of trained mind is that their basic foundation is laid by outcome of group of informal people's knowledge. It is something like my friend who was automobile engineer with standard knowledge and more relying on outcome of diagnostic tools for attacking the problem for solution and other side road side mechanic in absence of any proper diagnostic tools relying on his basic intuition based on past experiences .Our intuitions of natural instinct are buried under result of diagnostic tools. Formally trained minds lives in under impression that rational knowledge is

**better compared to intuitive knowledge. In other words we can say who is trained as driver of vehicles believes that master of vehicle and forget that vehicle has come to the existence in this present state because of continuous efforts of informal groups minds. Wright brothers have designed the airplane but problem was designed and kept alive by informal group by designing plane with dough by mother as toy for diverting the attention of crying infant later on paper plane or mythological or fantasy stories or performing arts. It is ancient game of communicating by using thread tied both end with empty earthen glass for talking as well listening as a toy and later the same solution surfaced by picking up by Graham Bell for design of telephone (It is the first instrument that has received lots of attention while designing the instruments by keeping in mind the human body function in best manner.) Who has designed knot is still mystery but sure that it was designed by informal mind .But nobody was sure that extension of knot would give us various option for use in different styles by informal group and has led to ladder, button and zip and helped in weaving, embroidery, crochet and various types of glues, welding for joining, nut bolts, rivet etc.**

**When I thought about contribution of informal hero who did lot for progress of society and died unsung, unnoticed, unwatched and we are thankless people who never acknowledged those designed knife, knot, comb, mirror, management of fire etc. Before the formal announcement of area of science as well its sub area like physics, chemistry, mathematics people who were framing their own problems and finding the solutions in due course of time clubbed with various numerous related problems solutions that accumulation of knowledge of certain level took the shape of specific area of science. It was the formal trained person who designed ink,**

pen and even alphabets fonts but scientific minds of Waterman designed the pen of next level and revolutionized the writing skill. Journey of writing with holding small soft rock on hard rock of different color or stylus on soft material as writing instrument or stem or quill pen or brushes dipped in color pot and ultimately to modern sophisticated pen looks interesting. Similarly it was the informal designer who thought of designing wheel and later on scientific minds picked it up to next level of manual to animal driven transport automobile and various applications. How come the idea of rope or thread struck in the mind of ancient people but it was prove the reason of laid down the foundation of present modern world by our informal people. Shoes are designed for meeting the functionality of not to be hurt because of rough terrain of earth. It is my idea not based on any scientific findings that idea of shoes came from the nest where birds lay the egg for raising offspring. Birds designed the nest with arranging small tinder in such a way it formed a shape where eggs can be kept safely for hatching as well there should be opening for exit as well entry of mother, places in branches of tree where it can stay in any adverse condition of weather and it should not be easily spotted by enemies. Humans imitated the designed for shoes as nest are designed with tinder quickly switched to skin of dead animal for covering their feet by tying with rope and later shifted to proper use of stitching technology and later experiences added preferences of soft dry skin for upper and sole was designed for hard skin and filled with hay for softness. Basic designed remained same but hay is replaced with socks for softness. Some area shoes were designed with papaya or palm leaf but problem was it had very short life not strong enough as dead skin.

**Volcanic activity produced the unusual black material that could attract specific metal and believed it has some soul and another natural phenomenon was thunder and as it was surfacing it was generating fear among the humans because of loud sound as well lightening. It was the Faraday's mind that was with his own theory and not based on previous findings has combined the two natural phenomena that helped in progress in unexplored world of electromagnetic field. Faraday has experimented with humble beginning with whatever means and knowledge was available but formal trained mind took that small beginning to giant leaps in present times where he himself will refuse to recognize his discovery.**

**One day I was walking and it is common practice in my locality of encroachment of path reserve for pedestrians for earning by displaying some items that is in need for people and a two wheeler passengers were stopping for buying helmets to meet the legal requirements not for their safety. I found an illiterate young boy was arranging various helmets for showcasing for drivers attentions by using emptied boxes and bamboo sticks in such a manner it was designed as step wall for resting two bamboo sticks for shelving various helmets for sale. The way he designed the shelves for displaying was marvelous temporary but stable design and can be easily dismantle in no time for packing as business hours over. As I walked further I noticed people of illiterate class were pumping out ground water by using mechanical hand pump and at the outlet that was bent pipe downward toward ground was fixed with used broken mineral water plastic bottle by removing bottom at outlet for channelizing water to fall on kept pot not spillage outside and waste. That was indigenous technology designed by local people who were**

**aware about problems as well solutions. Who has thought of using pulley and chain for lifting the heavy items for loading in transportation it has complete scientific experiment?**

**I have found that only area of medical sciences where formal training has excelled and informal practitioner are still in category of experiences and intuition where formal trained people moved much ahead and can find reason of it not relying on intuition but completely based on scientific findings. Ancient people were not guided by any leader and everyone in community was free to take their own decision and problem solution was addressed by group of people in easy comfortable environment. They were not under any emergency situation of market driven and after great consultation and discussion they looked at environmental factors and if sustainability was missing factor whatever it might have best solution they were discarding and looking for another solution. In modern management we call this exercise brainstorming and facilitation management. In surgery I have noticed that although there is leader but leader surgeon always welcome suggestions of others who are assisting and believed in facilitation management that may be reason formal trained people in fact practicing the informal way of working. When looked at potter who belongs to informal group worked on standard tools designed by again informal group but has liberty of shaping as per his choice in fact can create new ideas.**

**Women are master in experimenting for creating the uniqueness out of nature of caring, it might be biological inbuilt natural system of attraction of others. Same sex women were left with either to adopt or look for better means of attraction of others and that proved**

**reason of progress of next level and we called creativity. This whole exercise is performed by informal trained with minds of average growth and limited knowledge, later on refined ideas incorporated in that acts by formal trained people joined as society gradually turned it into standard format after trial and error techniques in those actions. These trained personalities take those actions to next level that was beyond imagination of group of people who initiated these ideas. Women have initiated the idea of coloring their faces parts of lips, eyes and check for attraction of others but refinement came as trained group of people joined this actions.**

**Design of ponds are natural because wherever a place that has little depth rain water will stay but best part is humans designed the artificial ponds for making life liberated and less dependent on natural ponds and it has come to the reality with design after acquiring knowledge of digging by tools . Before the design of artificial ponds people used to stay around natural resource of water for meeting their needs but artificial ponds changed the concept of meeting water requirement so thought process and life styles . It was safer from flood; no chance of displacing because of flood of river .Later on formal trained minds took to next level of designing dams for meeting water requirements.**

**Women are responsible for designing the concept of agriculture for reliable source of foods unlike hunting where probability was high of not getting killed animals for food because she is herself nature and has inbuilt character of compatible with nature for meeting the challenges of lowering the failure of hunting was real foundation of community that later took the shape of modern present society. How come idea of intoxicating the mind struck with artificial means is still**

mystery but their designed products of liquor, cigarette for smoking or opium and other items are still prevailing in our society. Why do we need intoxication in our lives? It is still unknown why did fill tobacco leaves rolled under another leaf for smoking by burning one end for smoke. Who has informed that lung filled with tobacco smoke or liquor in stomach helps in intoxicating the minds. Similarly informal trained women have designed various techniques of cooking and no one is able to design new method of cooking apart from prevailing of roasting, frying and boiling .Informal designers have shaped our culture and preferences and it is difficult for modern person comes out of that culture. Who has thought that tiny mustard seed has that tiny oil can be extracted to that much oil we can use for cooking of frying. Certain items are cooked better in higher temperature and how the idea of cooking in oil that can retain high temperatures best for cooking. I can understand roasting because it was natural next level after discovery of fire but frying is still mystery for me. Boiling or roasting can be think accidentally achieved because of geyser or presence of fire .But frying completely man made design from extraction of oil from tiny seeds to heating the oil in container for cooking .Chefs are busy in innovation of food tastes but no one has ever discovered any new cooking techniques but using the same age old practice. I am not questioning modern tools these are still doing same aged old ancient practice of roasting, frying and boiling. Why do not formal trained minds look for other options of cooking and still relying on boiling, roasting and frying and unable to design new techniques of cooking? Design of chimney came to the existence for keep the fire alive and not to die because of smoke and it was designed by informal minds. The beauty of ancient wisdom was the basic concept of art of design is still

prevailing in chimney and nothing new has surfaced by formal minds. Later on various types of chimneys are designed keeping for good health as well smoke free areas but basic concept remains the same. John kay has designed the flying shuttle for faster weaving but who has thought of initial stage by arranging the threads in warp and weft by tools in for proper stability and durability of fabric? Who has designed loom that perfect tool for weaving? How come idea of designing pit-treadle loom with pedals for operating heddles has come? Is it not formal minds? A modern person with formal trained minds contribution is using the same techniques of weaving but in faster manner.

One day in absence of scissor I wished for breaking the thick thread in two parts. First I tried to break by pulling the two end and it did not work. Then I rolled the two ends on my palm and tried to break with sudden jerk. It also failed then I looked for some sharp end where I can rub for cutting and noticed a corner of wall and I rubbed against and it worked. How come the design of scissor struck in their minds for effortless cutting by pressing the two sharp ends by pressing one against another is mystery for me but I feel like to salute the minds of informal minds those thought of such useful design for laying the foundation of our modern world. Informal minds quietly innovated and made our life simple and never shout at the top of the roof for their achievement where formal trained minds demands as a right for more gains out of meager contribution.

I always salute the people who are earning quietly without disturbing the social fabrics and contributing for progress of society unwatched unnoticed without complaining and acquire partial or complete knowledge of formal or informal from whatever means

with them. Where ever I look I find these type of people are surrounding me and I am completely dependent on their works inspite of I am trained and has formal training with best resources. Carpenter, plumber, meson, glass fixing worker, tailor, housekeeping job workers and others are not formally trained but knows their jobs by joining as assistant to senior person or by trial and error method by applying their common sense and my life will be harsh if they do not presence on my call for support . A small idea of discovery of alkaline soil of river bank soaked overnight after applying on dirty clothes helps in better cleaning of dirty clothes has led to detergent industry for washing of body with toilet perfumed soap, cleaning of soil utensils and washing of dirty clothes and many more applications. Best part is that when ever any products designed by formal trained designer develops any snags we visit these informal group of people for getting our malfunction of products rectified and mostly it comes true and succeed in their attempts. They are master of earning their livelihood and contentment is biggest asset for survival.

*Common among commons (informal selfless action for mind's happiness) is opening a window of infinite possibilities and lays the foundation of systematic innovations for falsehood of special among special (formal selfish action mind's for selfish gains) for progress. A journey of selfless to selfishness is the dynamo of the progress of society- Dr. Sunil Bhatia*

I am thankful to Prof Dr. Ketna Mehta is a socially conscious Indian, Editor, writer, thinker, author, researcher, inspirational speaker and management curator for accepting our invitation .Sometime we appreciate the idea of raising the problem and makes us aware what

**exactly problem is and that helps in search of best solution. She has done justice to this issue by raising the specific problem from many angles and perspective.**

**LAMBERT Academic Publishing has published book "Design For All, Drivers of Design" author Dr. Sunil Bhatia of Design For All Institute of India and it is available on [www.morebooks.de](http://www.morebooks.de) one of the largest online bookstores. Here's the link to it:**

**<https://www.morebooks.de/store/gb/book/design-for-all/isbn/978-613-9-83306-1>**

**This book is dedicated to our esteem readers, contributors and well wishers.**

***Merry Christmas and prosperous New Year 2020***

***With Regards***

***Dr. Sunil Bhatia***

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## Forthcoming Issues

### WOMEN DESIGNER YEAR 2020

#### January 2020 Vol-15 No-1 (INNAGURAL ISSUE)

**Onny Eikhaug is the founder of Innovation for All AS and President of EIDD Design for All Europe, a network comprising of 36 members, consisting of both design institutions, innovation centres and academia. She was for more than 13 years Programme Leader at Design and**



**Architecture Norway, responsible for promoting the Centre's activities in the fields of people-centred, inclusive design as a strategy for innovation. She was Programme Leader for the Innovation for All programme promoting inclusive, people-centered design as a practice and an effective tool for innovation in both private and public sector.**

**She is committed to sustainable, people-centred design and is focused on demonstrating the potential of this approach as a powerful and profitable strategy for innovation. A key aspect of this is presenting and implementing effective methods that can easily be**

**adopted by any organization or enterprise. She writes, publishes, lectures, facilitates workshops and curates exhibitions both in Norway and internationally, and works closely with designers, education, industry, research and government using real projects and other knowledge transfer mechanisms to achieve this. She advises and coordinates people-centred inclusive design projects within business and public sector applying and testing new tools and methods for user research and involvement. She is responsible for the books *Innovating with people –The Business of Inclusive Design*» and *Innovating with People - Inclusive Design and Architecture* as editor-in-chief and author.**

**She holds an MBA from the Norwegian School of Economics and Business Administration. She has a broad executive experience in international marketing, sales, innovation, product development and design management in the fields of personal products, ergonomic lighting, and contemporary furniture having worked for companies such as Unilever and Luxo across Europe and the US. She was also Managing Director of a Norwegian Graphic design company.**

**She was in 2015 appointed Inclusive Design Champion Award by an international jury at HHCD Royal College of Art, London at the Include conference.**

## **February 2020 Vol-15 No-2**

**Sharmistha Banerjee is an industrial designer with an experience in working in collaborative innovation and sustainable product design. Currently I am working as Assistant Professor at Department of**



**Design, Indian Institute of Technology Guwahati. My area of PhD research is Design for Sustainability in the arena of agricultural equipment design. I did my bachelor in Industrial Design from IIT Guwahati and a master in Integrated Product Design from Technical University of Delft, Netherlands.**

**I have co-founded the Sustainability and Social Innovation Lab at Department of Design, IIT Guwahati. The lab focusses on creating systems for sustainable human consumption and production through a complete revamp of the consumption structure with our design interventions. We are part of the global network on sustainability, the Learning and Education Network in Sustainability (LeNS) consisting of 150+ global universities. Currently a large part of our sustainable product-service development projects are in the domain of agriculture.**

**At IIT Guwahati I teach courses like System Design for Sustainability, Usability Engineering, User Research Techniques, Product Detailing, Interaction Design, Product Design, Design Management, Plastics and composites and Design Semantics. I have also developed a MooC course on System Design for Sustainability which had more than 600 subscribers in the academic year 2018 - 19. In the past few years, I have worked in India, Bangladesh and Netherlands with companies like Philips, Infosys, MIDCO, VU Medical University Amsterdam, Conpax Verpakking, Beat Belly, Botanische Tuin Delft, ACC Ltd, educational institutes like IIT Guwahati, MIT Institute of Design Pune, IDC, IIT Bombay and L'Ecole de Design (Indian Operations), Nantes-Atlantique, France and NGOs like International Development Enterprise Bangladesh.**

## **March 2019 Vol-15 No-3**

**Archana Bade Shrestha completed her Bachelor in Architecture in 2008 from Khwopa Engineering College, Bhaktapur, Nepal. I have completed my MSc. in Urban Planning in 2013 from Institute of Engineering, Pulchowk Campus, Lalitpur, Nepal. After completion of B. Arch I worked in a private consultancy named Tekton Consultancy, Lalitpur, Nepal for 5 years. Currently I am a full time faculty working as senior Lecturer in Khwopa Engineering College. I take design studios (housing + residential design), Vernacular Architecture, Building Construction-II, A- cad, Interior Design as the course subjects. My field of research is in analyzing the socio-economic status of Apartments in Urban areas of Nepal.**



## **April 2020 Vol-15 No-4**

**A Doctorate qualification in the fields of: interior architecture, architecture and urban design Dr Dolly Daou has 18 years experience in: teaching, research, quality assurance, and leadership, specialised in multi-disciplinary design projects. Currently the Director of Design Lab: New Eating Habits at L'École de design Nantes Atlantique, France. Previously, the Director of the Association of Interior Designers in the MENA region, an external reviewer to many international educational quality assurance agencies and the Program Director of Interior Architecture and**



**Master of Interior Design at Swinburne University of Technology, (Australia and Hong Kong). Also, was the Treasurer of the Board to the Interior Design Educator Association (IDEA) for Australia and New Zealand. Author of co-edited book Unbounded on the Interior and Interiority.**

## **May 2020 Vol-15 No-5**

**Having been a wheelchair model from an early age, Samanta has always felt frustrated by the lack of luxurious clothing available for disabled people. Working as an advocate for inclusion within the fashion industry, Samanta has decided to join forces with some of the most innovative emerging designers to develop her brand, 'SB' – a**



**unique line of clothing based on the principle that "its not about being disabled, but about feeling beautiful and comfortable whilst in the sitting position".**

**Born in Brazil, Samanta moved to London 10 years ago and has since dedicated her life to improving the lives of people living with disabilities. She hopes that her collection will open people's minds and hearts. Samanta is a former Brazilian no. 1 wheelchair tennis player winning a doubles silver medal at the ParaPanAm Games in Rio de Janeiro in 2007 & representing Brazil in three World Team Cups.**

**"We must be seen to exist" – Samanta Bullock**

## **June 2020 Vol-15 No-6**

**Debra Ruh is a Global Disability Inclusion Strategist, Market Influencer, internationally recognized keynote speaker, published author, branding expert, successful entrepreneur, and an exceptional mother. Debra is host of popular program: Human Potential at Work (Audience in 84 countries).**



**Debra Ruh received her call to action when she was told by so-called "experts" that her daughter, Sara, who was born with Down Syndrome (Trisomy 21), would never walk or talk. She refused to accept the prognosis and perception of this condition. Driven by her unshakeable faith in the power of human potential and the love for her daughter, Debra was determined to dedicate her life to create a path to empowerment and the success for all those with disabilities.**

**Debra had built a multi-million-dollar firm focused on ICT accessibility. Debra was convinced that "the real disability is being unable to see human potential" formed Ruh Global Communications. This new firm focuses on Global Disability Inclusion Strategies, Digital Marketing, and Branding among many other services.**

**Debra consults with Multi-National and National Corporations and the United Nations. Debra is now internationally renowned global keynote speakers and travel the world inspiring and advocating for governments and corporations to include people with disabilities.**

**Debra Ruh is an active public figure she was invited to address the United Nations General Assembly at the Conference of State Parties 9<sup>th</sup> session (COSP9) by the President's office of the UN on May 13, 2016. More recently Debra was selected as the North American representative for the United Nations (UN), International Labor Organization's (ILO), Global Business and Disability Network (GBDN). Additionally, in 2018 the U.S. State Department selected Debra Ruh as a global speaker and ambassador for the United States when visiting foreign nations and speaking on inclusion and disability. Selected as a Global Goodwill Ambassador in 2018.**

**Debra is a recognized global influencer, frequently interviewed by various media outlets and she has gathered a significant presence on many social media platforms, with over 300,000+ followers across all mediums. Co-founder of the award winning #AXSChat the second biggest tweet chat in the world with a reach in the billions. Debra was also named in the "Top 5% of Social Media Influencers" and "Top 0.1% of people talking about Disability Inclusion and Accessibility" by KLOUT. Named #15 in Digital Scouts Top #100 Global Digital Influencers in Sept 2018.**

## **July 2020 Vol-15 No-7**

**Jani Nayar , Executive director of the SATH (Society for Accessible Travel & Hospitality), a tireless advocate and effective educator on travel & disability.**



## **August 2020 Vol-15 No-8**

**Maria Luisa Rossi, Chair and Professor, MFA Integrated Design** Maria Luisa's work at the College for Creative Studies Graduate Studies brings her entrepreneurial, globally-focused, and empathetic cultural approaches to the next generation of designers. She focuses on the seamless capacity to deal with the tangible and intangible aspects of people's experiences. At CCS she is preparing & quot; facilitators & quot; capable of addressing global-local grand challenges, focusing on social innovation. Her projects are concentrated on research, co-creation and people-centered processes.



Maria Luisa's professional career has been independent and international. She attended the premiere master's program in industrial design at the Domus Academy in Milano, thanks to a European Scholarship she won from designing the first wearable computer. The project was featured in the prestigious Domus magazine and gave her a lot of visibility around Europe and the design world. The wearable computer project "The Walking Office" can be found in the Henry Ford Museum Permanent Design Collection.

Following her studies, she founded the design consultancy Iavicoli & Rossi, working on various models varying from interior architecture to tableware.

**Maria Luisa's interdisciplinary attitude, design strategy knowledge, and business acumen brought her to be hired in the team that launched the new Graduate Program at CCS in Detroit, where she set standards of excellence for MFA Integrated Design.**

**Her effort to provide meaningful teaching experiences is validated by a successful alumni job placement in corporations and design consultancies. Throughout her career, Maria Luisa has conducted workshops and lectures in Singapore, Los Angeles, Mexico City,**

**Istanbul, Ankara, São Paulo, Shanghai, Gratz, Brasilia, and Taiwan. Her specialties are Design Strategy, Experience Design, Scenario Design, Service Design, Interdisciplinary approach, with an in-depth knowledge of American, Asian and European culture and markets.**

# New Books



ISBN 978-613-9-83306-1



Sunil Bhatia

## Design for All

Drivers of Design

Expression of gratitude to unknown, unsung, unacknowledged, unstarred and selfless millions of heroes who have contributed immensely in making our society worth living, their design of comb, kite, fireworks, glass, mirror even thread concept have revolutionized the thought process of human minds and prepared blueprint of future. Modern people may take for granted but its beyond imagination the hardships and how these innovative ideas could strike their minds. Discovery of fire was possible because of its presence in nature but management of fire through manmade designs was a significant attempt of thinking beyond survival and no

doubt this contributed in establishing our supremacy over other living beings. Somewhere in journey of progress we lost the legacy of ancestors in shaping minds of future generations and completely ignored their philosophy and established a society that was beyond their imagination. I picked up such drivers that have contributed in our progress and continue guiding but we failed to recognize its role and functions. Even tears, confusion in designing products was marvelous attempt and design of ladder and many more helped in sustainable, inclusive growth.

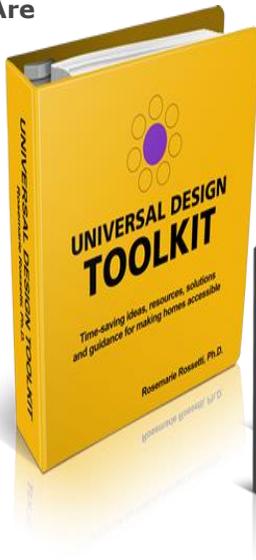
[www.lap-publishing.com](http://www.lap-publishing.com)

it is available on [www.morebooks.de](http://www.morebooks.de) one of the largest online bookstores. Here's the link to it:

<https://www.morebooks.de/store/gb/book/design-for-all/isbn/978-613-9-83306-1>

# The Ultimate Resource for Aging in Place With Dignity and Grace!

Are



you looking for housing options that are safer and more accommodating for independently aging in place? Do you want to enjoy comfort, accessibility, safety and peace of mind – despite your disabilities, limitations and health challenges? The help you need is available in the Universal Design Toolkit: Time-saving ideas, resources, solutions, and guidance for making homes accessible.

This is the ultimate resource for individuals and professionals who want to save time, money and energy when designing, building, remodeling or downsizing a home. The Universal Design Toolkit will help you take the steps to design homes for your clients or yourself while eliminating the costly trial and error challenges you'd inevitably encounter if faced with this learning curve on your own.

Rosemarie Rossetti, Ph.D., teamed with her husband Mark Leder in creating this unique Toolkit. They bring ten years of research, design and building expertise by

serving as the general contractors for their home, the Universal Design Living Laboratory – which is the highest rated universal design home in North America.

Within the Toolkit's 200 richly illustrated pages, you'll find: Insights that distinguish *essential* products, services and resources from the *unnecessary*.

Proven, realistic tips for finding the right home.

Home features you need to look for. Nothing is assumed or left out.

Handy home checklists and assessments.

Interview questions to help you hire industry professionals with knowledge and experience.

Photographs that provide a frame of reference to inspire, clarify and illuminate features and benefits.

Valuable resources to save you time, money and energy.

Helpful sources of funding.

Space planning dimensions for access using assistive devices such as wheelchairs and walkers.

And so much more!

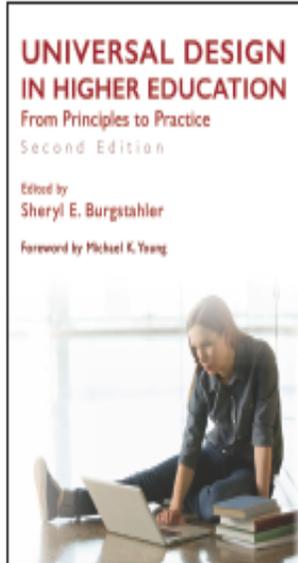
If you want useful, dependable advice and easy to implement ideas from respected experts who know the ropes, you'll love Rossetti and Leder's perspective. As a speaker, author and consultant who uses a wheelchair, Rossetti has helped hundreds of people design their ideal homes. Now her comprehensive Toolkit is available to help and support you!

Get the Universal Design Toolkit now to start your project!

**"Fresh, comprehensive, and engaging, *Universal Design in Higher Education* is expertly written, thoughtfully crafted, and a 'must-add' to your resource collection."**

—STEPHAN J. SMITH, EXECUTIVE DIRECTOR, ASSOCIATION ON HIGHER EDUCATION AND DISABILITY

**Harvard  
Education  
Press**



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## UNIVERSAL DESIGN IN HIGHER EDUCATION

From Principles to Practice, Second Edition

EDITED BY SHERYL E. BURGSTAHLER • FOREWORD BY MICHAEL K. YOUNG

This second edition of the classic *Universal Design in Higher Education* is a comprehensive, up-to-the-minute guide for creating fully accessible college and university programs. The second edition has been thoroughly revised and expanded, and it addresses major recent changes in universities and colleges, the law, and technology.

As larger numbers of people with disabilities attend postsecondary educational institutions, there have been increased efforts to make the full array of classes, services, and programs accessible to all students. This revised edition provides both a full survey of those measures and practical guidance for schools as they work to turn the goal of universal accessibility into a reality. As such, it makes an indispensable contribution to the growing body of literature on special education and universal design. This book will be of particular value to university and college administrators, and to special education researchers, teachers, and activists.

**SHERYL E. BURGSTAHLER** is an affiliate professor in the College of Education at the University of Washington in Seattle, and founder and director of the university's Disabilities, Opportunities, Internetworking, and Technology (DO-IT) and Access Technology Centers.

**"Sheryl Burgstahler has assembled a great set of chapters and authors on universal design in higher education. It's a must-have book for all universities, as it covers universal design of instruction, physical spaces, student services, technology, and provides examples of best practices."**

—JONATHAN LAZAR, PROFESSOR OF COMPUTER AND INFORMATION SCIENCES, TOWSON UNIVERSITY, AND CO-AUTHOR OF *INSURING DIGITAL ACCESSIBILITY THROUGH PROCESS AND POLICY*

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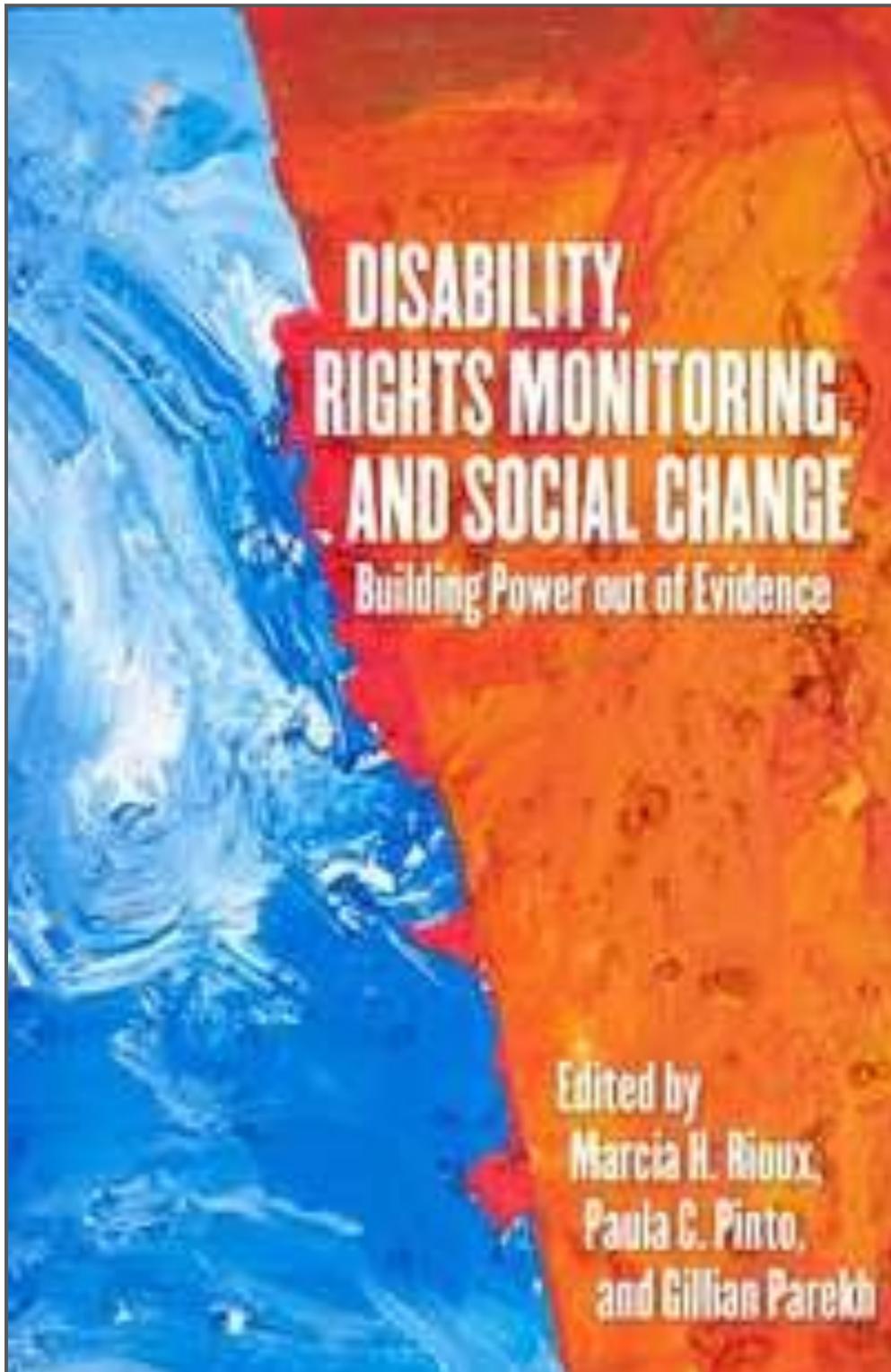
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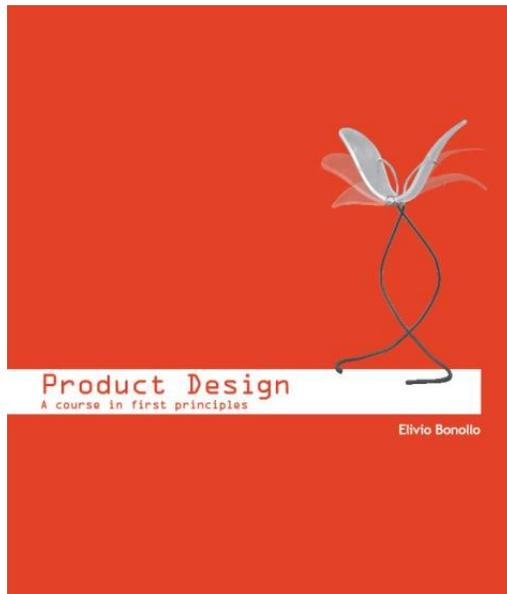
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**Disability, Rights Monitoring and Social Change:**



## New Update: ELIVIO BONOLLO (2015/16) PRODUCT DESIGN: A COURSE IN FIRST PRINCIPLES



Available as a paperback (320 pages), in black and white and full colour versions (book reviewed in *Design and Technology Education: An International Journal* 17.3, and on [amazon.com](http://amazon.com)).

The 2018, eBook edition is available in mobi (Kindle) and ePub (iBook) file versions on the amazon and other worldwide networks; including on the following websites:

ePub version: [www.booktopia.com.au](http://www.booktopia.com.au)

<https://www.booktopia.com.au/ebooks/product-design-elvio-bonollo/prod9781784562946.html>

mobi (Kindle versions): [www.amazon.in](http://www.amazon.in)

[https://www.amazon.in/Product-Design-Course-First-Principles-ebook/dp/B07FNV2F4L/ref=sr\\_1\\_1?ie=UTF8&qid=1532999395&sr=8-1&keywords=Product+Design%3A+A+course+in+first+principles](https://www.amazon.in/Product-Design-Course-First-Principles-ebook/dp/B07FNV2F4L/ref=sr_1_1?ie=UTF8&qid=1532999395&sr=8-1&keywords=Product+Design%3A+A+course+in+first+principles)

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**READING HINTS:** ePub files can be read with the iBook app on Apple MacBook/iPad devices; ePub files can also be read on Desktops PCs, Laptops and Surface devices using readers such as the Microsoft *fredaePub* reader. The Kindle (mobi file) reader is flexible and suitable for reading the eBook on PCs; Kobo readers can also be used to read ePub files on MacBook and iPad. All formats are very interactive with very good navigation.

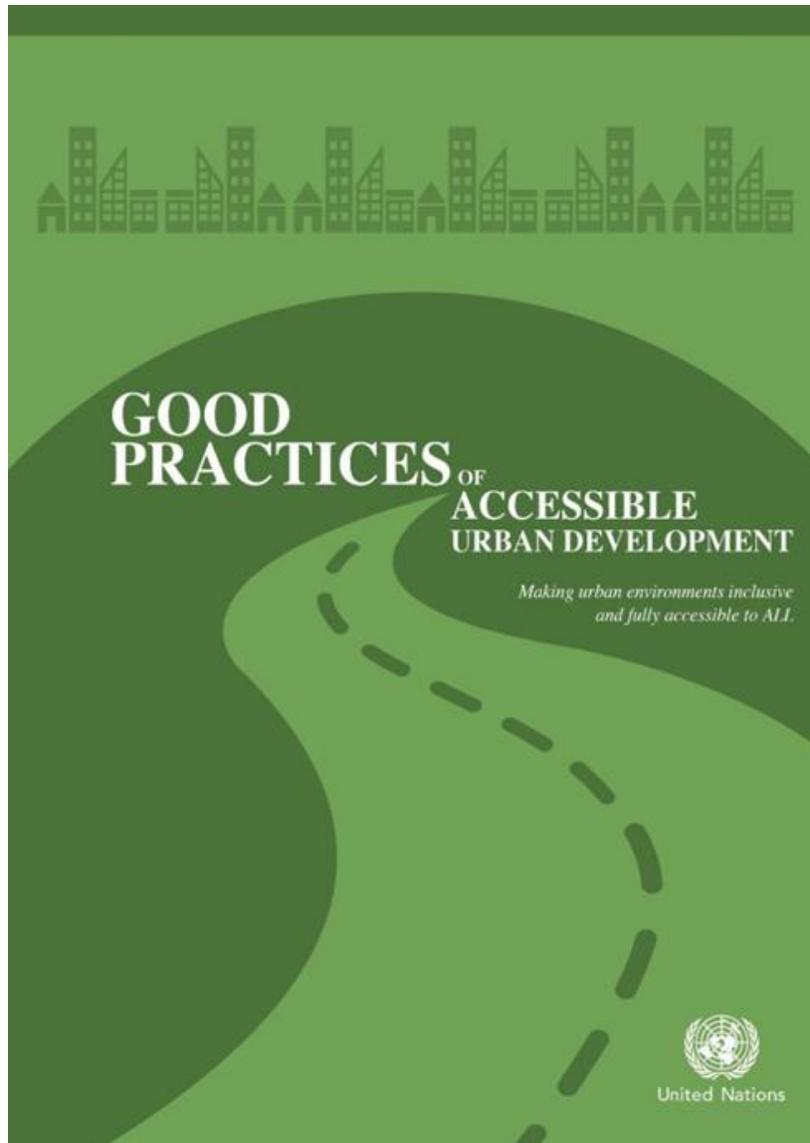
DEBRA RUH

INCLUSION



BRANDING

Revealing Secrets to  
Maximize ROI

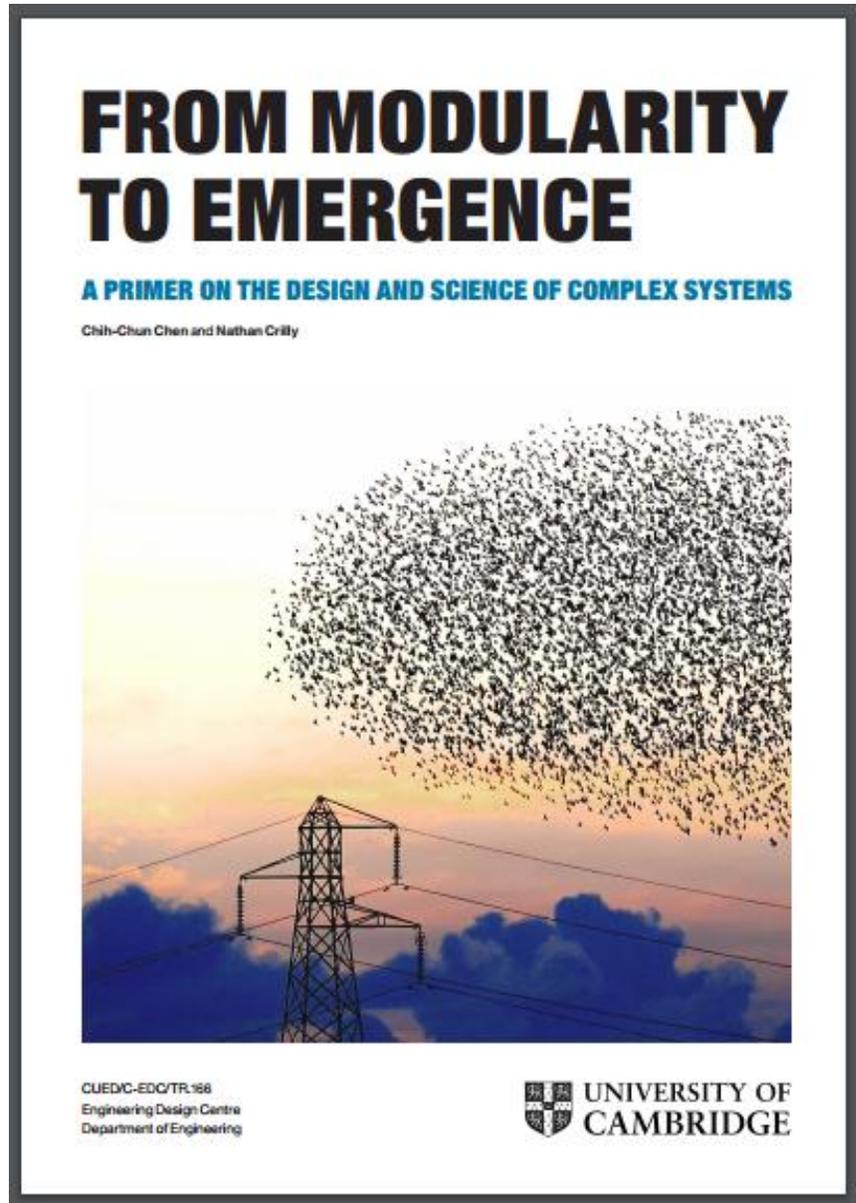


**In light of the forthcoming United Nations Conference on Housing and Sustainable Urban Development (HABITAT III) and the imminent launch of the New Urban Agenda, DESA in collaboration with the Essl Foundation (Zero Project) and others have prepared a new publication entitled: "Good practices of accessible urban development".**

**The publication provides case studies of innovative practices and policies in housing and built environments, as well as transportation, public spaces and public services, including information and communication technology (ICT) based services.**

**The publication concludes with strategies and innovations for promoting accessible urban development.**

The advance unedited text is available  
at:[http://www.un.org/disabilities/documents/desa/good\\_practices\\_urban\\_dev.pdf](http://www.un.org/disabilities/documents/desa/good_practices_urban_dev.pdf)

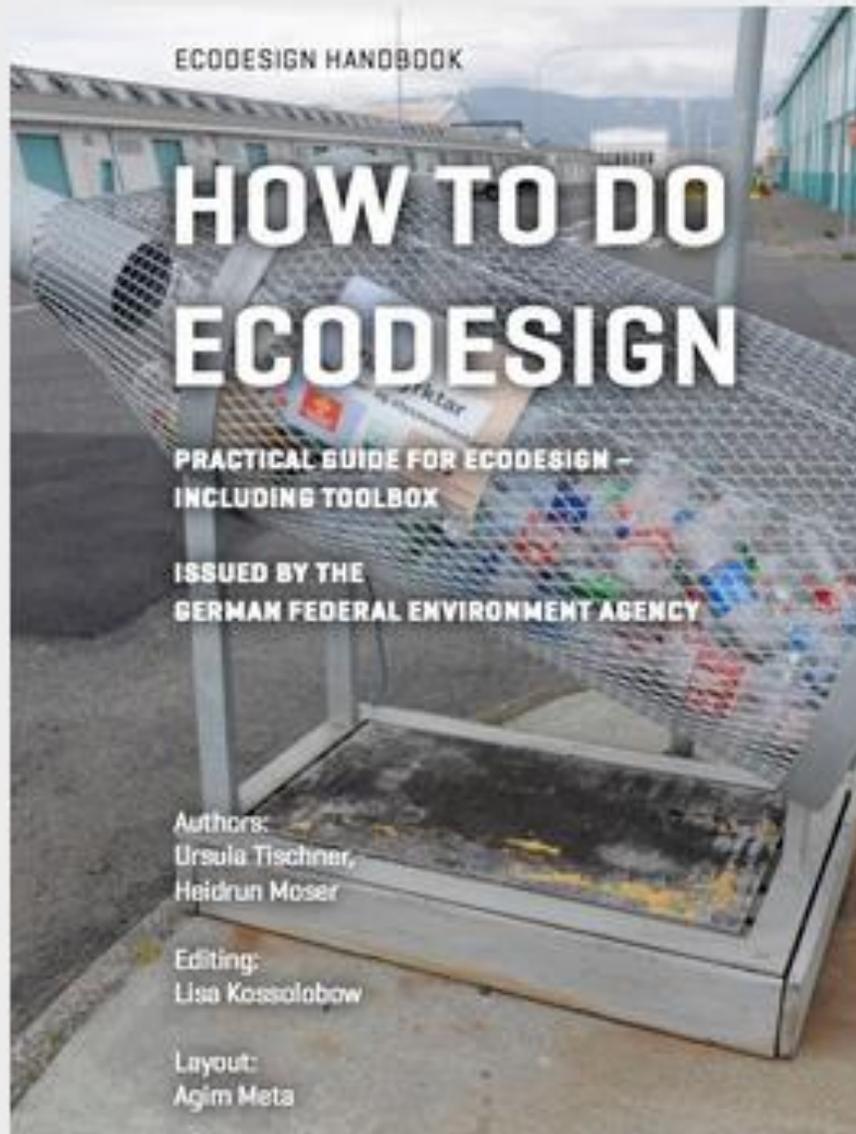


Dr Chih-Chun Chen and Dr Nathan Crilly of the Cambridge University Engineering Design Centre Design Practice Group have released a free, downloadable book, *‘A Primer on the Design and Science of Complex Systems’*. This project is funded by the UK Engineering and Physical Sciences Research Council (EP/K008196/1). The book is available at URL: <http://complexityprimer.eng.cam.ac.uk>

# Changing Paradigms: Designing for a Sustainable Future



# **New iBook / ebook: HOW TO DO ECODESIGN**



Practical Guide for Ecodesign – Including a  
Toolbox

Author: Ursula Tischner



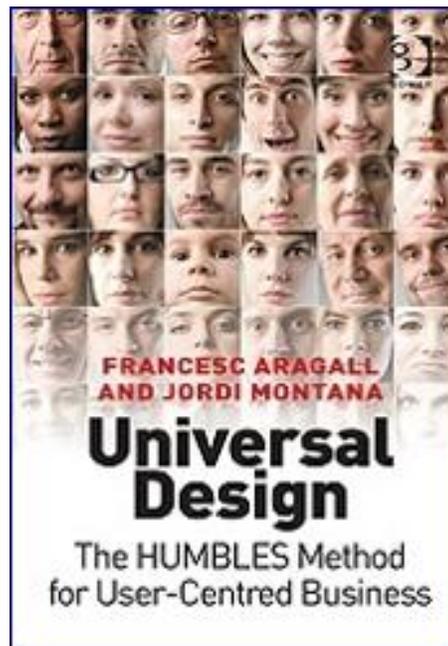
Amar Arnason and Sigurjón Baldur Hafsteinsson

# DEATH AND GOVERNMENTALITY

Neo-liberalism, grief and the nation form



## Universal Design: The HUMBLE Method for User-Centred Business



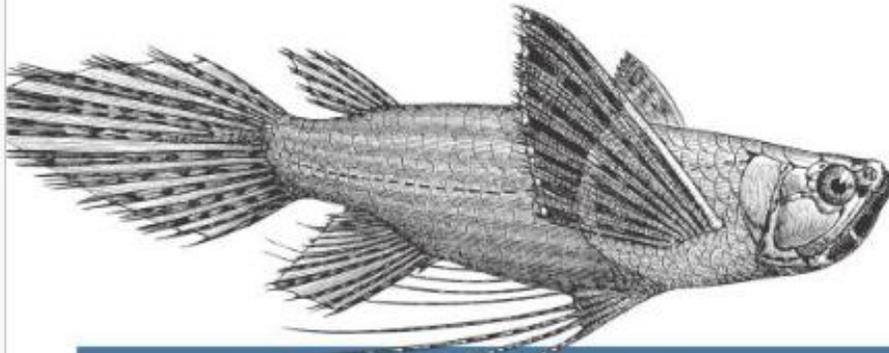
“Universal Design: The HUMBLE Method for User-Centred Business”, written by Francesc Aragall and Jordi Montaña and published by Gower, provides an innovative method to support businesses wishing to increase the number of satisfied users and clients and enhance their reputation by adapting their products and services to the diversity of their actual and potential customers, taking into account their needs, wishes and expectations.

The HUMBLE method (© Aragall) consists of a progressive, seven-phase approach for implementing Design for All within a business. By incorporating the user's point of view, it enables companies to evaluate their business strategies in order to improve provide an improved, more customer-oriented experience, and thereby gain a competitive advantage in the marketplace. As well as a comprehensive guide to the method, the book provides case studies of multinational business which have successfully incorporated Design for All into their working practices.

According to Sandro Rossell, President of FC Barcelona, who in company with other leading business professionals endorsed the publication, it is “required reading for those who wish to understand how universal design is the only way to connect a brand to the widest possible public, increasing client loyalty and enhancing company prestige”. To purchase the book, visit either the **Design for All Foundation website**

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# Engineering for Industrial Designers & Inventors

FUNDAMENTALS FOR DESIGNERS OF WONDERFUL THINGS

I have a new book that presents fundamental engineering concepts to industrial designers that might be of interest to you. This is the link:

**[https://www.amazon.com/Engineering-Industrial-Designers-Inventors-Fundamentals/dp/1491932619/ref=sr\\_1\\_1?ie=UTF8&qid=1506958137&sr=8-1&keywords=engineering+for+industrial+designers+and+inventors](https://www.amazon.com/Engineering-Industrial-Designers-Inventors-Fundamentals/dp/1491932619/ref=sr_1_1?ie=UTF8&qid=1506958137&sr=8-1&keywords=engineering+for+industrial+designers+and+inventors)**



# News

1.

## **India Design Council launches initiatives to support design**

**The India Design Council on Thursday launched two initiatives, Design Education Quality Mark (DEQM) and Chartered Designs of India (CDI), to support and set standards for the design profession. The DEQM will benchmark design education programmes on predetermined standards and will accord a quality mark to institutions that meet the standards. The mark will be granted to institutions that undergo a review process and meet or exceed the expectations for quality and standards as prescribed in the Quality Code. It will communicate that an institution has a guaranteed minimum level of quality and standards and has undergone a third-party and neutral review process. The mark, which includes a trademark-protected logo, will help students choose the right design programme and aid prospective employers to understand the standing of the design institute. In 2007, India became one of the few countries to adopt a National Design Policy (NDP) and the government in March 2009 announced establishment of the India Design Council. The CDI is an institution that will establish and uphold the professional standards of design practice in India. "The need for a Quality Code was felt as there has been an exponential growth in the number of institutions providing design qualifications in India, necessitating the creation of a guiding framework that represents a common rationale/ philosophy for design curricula and its implementation. "The aim is to harmonise the different education**

**systems whilst taking into account their great diversity," an official statement said. RSN HRS**

**(Courtesy: Times of India)**



# Programme and Events

THE ANNUAL INTERNATIONAL BERKELEY UNDERGRADUATE PRIZE FOR ARCHITECTURAL DESIGN EXCELLENCE 2019

2019  
**berkeley  
prize**  
Architecture and  
Climate Resilience



ABOUT THE PRIZE  
ESSAY PRIZE COMPETITION  
TRAVEL FELLOWSHIP  
PREVIOUS FELLOWSHIPS

Click on photograph for details.

The Fifth International Conference on Universal Accessibility in the Internet of Things and Smart Environments  
**SMART ACCESSIBILITY 2020**  
March 22, 2020 to March 26, 2020 - Barcelona, Spain





## International conference on 'Designing for children' with focus on 'Play and Learn'

Saturday 7th to Sunday 8th of December 2019



### 2019 VIC PREMIER'S DESIGN AWARDS ENTRIES NOW ONLINE

The 2019 Victorian Premier's Design Awards Entries are now available to view online. With over 200 entries across 8 categories, the entries showcase the high-quality of design in Victoria.

Winners of the 2019 VIC Premier's Design Awards will be announced at the 2019 VIC Premier's Design Awards Ceremony on 21 November at the newly opened MPavillion in Melbourne.

Good Design Australia proudly manage the VIC Premier's Design Awards in conjunction with Creative Victoria.

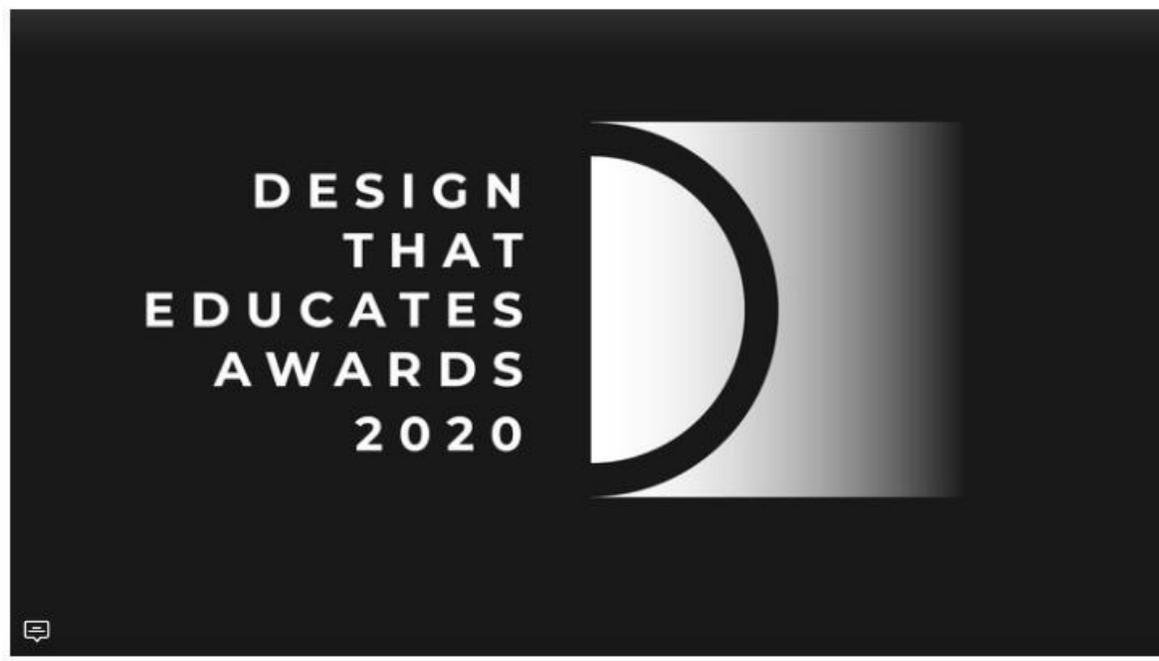
## **NEW FOR 2019 - THE WOMEN IN DESIGN AWARD!**

Good Design Australia is extremely proud to announce the new **Women in Design Award**, that will be presented as part of the 61st annual Good Design Awards.

The inaugural Women in Design Award seeks to recognise and celebrate women who have made significant contributions to the industry and hopes to encourage a more diverse and equal representation within the industry and leadership roles in particular within the design and creative industries.

The Selection Committee for this Award will comprise of Australian and international leaders in the design and creative industries. Confirmed Selection Committee Members include:

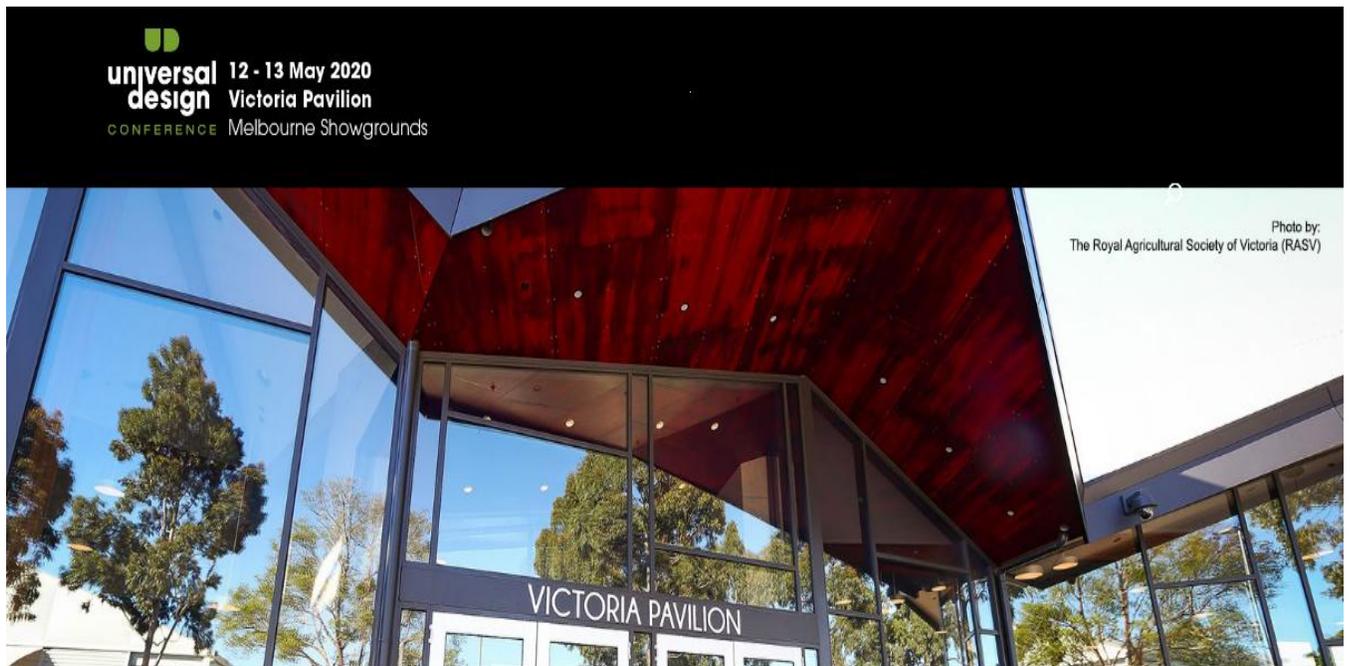
- Liza Chong, CEO INDEX:Design to Improve Life (Denmark)
- Margaret Petty, Executive Director of Innovation and Entrepreneurship UTS (NSW, Aus)
- Sarah Weir, CEO Design Council (UK)
- Claire Beale, Executive Director of Design Tasmania (TAS, Aus)
- Eunjo Maing, Director / Head of D-TEC at Korean Institute of Design Promotion (Korea)
- Trish Hansen, Founding Principal Urban Mind (SA, Aus)
- More to come...





FIFTH INTERNATIONAL CONFERENCE ON UNIVERSAL  
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June 15 - 17 2020 at Dipoli, Aalto University, Espoo



**Deadline extended! Good Practices 2019**



You can submit your project, product or service as Design for All Good Practice until Friday February 21 2020 opting to the International Awards Design for All Foundation 2020

**IAUD Award 2019: Call for entries**





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Pedagogy and Contextual Aesthetics

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## Global Challenges in Assistive Technology Research, Policy & Practice

August 27-30 2019 Bologna Italy

[www.aaate2019.eu](http://www.aaate2019.eu)

### Call for Papers

Basic research & Applied research  
Special thematic sessions

Deadline for submission:  
28 February 2019

### Call for other contributions

Educational sessions  
Policy sessions  
Product and Prototype presentations  
*See website for deadlines*



### Conference topics

- ↓ Assistive technology (AT) for cognitive, sensory and motor disabilities
- ↓ AT service delivery systems, practices, quality and outcomes
- ↓ AT education, training and professional development
- ↓ AT in low- and middle-income countries
- ↓ Emerging and innovative AT
- ↓ Alternative and Augmentative Communication
- ↓ AT and social assistive robotics
- ↓ AAL, smart environments and IoT
- ↓ eAccessibility
- ↓ Universal Design
- ↓ Mobility and seating solutions
- ↓ Ageing and technology
- ↓ AT for rehabilitation
- ↓ AT, virtual and augmented reality
- ↓ AT, digital health and innovation in care
- ↓ AT in education
- ↓ Policy and social aspects related to AT

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#AAATE2019

[aaate2019@aiasbo.it](mailto:aaate2019@aiasbo.it)

Spring Edition 2019 – Dateline New York



### 2019 Spark Design Awards Are All Underway

The Spark Awards are welcoming entries now. They include 10 general categories, with 2 student competitions and our brand new award for CleanTech Design. All of these awards have many sub-categories, so be sure to check them out at Spark:



### 2019 Awards

- Student Design (Spring & Winter)
- Product Design
- Graphic Design
- Health, Medical & Universal Design
- Spaces & Architecture Design
- Digital Design (includes UI, UX, IXO & HCII)
- Mobility & Transport Design
- Experience & Service Design
- CleanTech Design

### Note To Students & Educators

The 2019 Spring Student Awards are open and already receiving some cool designs. Standard deadline is coming up May 20th and the Late and Final Deadline is June 12. Join Us and tell your pals!

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UIA Prizes 2020

## Friendly and Inclusive Spaces Awards Entries closing: 30<sup>th</sup> November 2019



**FRIENDLY  
AND INCLUSIVE  
SPACES AWARDS**

Organised by the UIA's Work Programme Architecture for All, the Friendly and Inclusive Spaces Awards were established to encourage and acknowledge architects who have created exemplary friendly, inclusive and accessible buildings and public spaces. Entries must demonstrate that they have met the highest standards of universal and inclusive design, where the completed buildings and places contribute to the quality of life of all those who may use them.

A special award will also be given for evidence based design research that makes a significant contribution to improved quality of life through facilitating a better understanding of human centred design and its application to the design of the built environment.

### **Award Categories**

1. New Buildings
2. Refurbished Existing Buildings, including Historic Buildings
3. Public Realm
4. Research

### **Eligibility**

Built works designed by architect member(s) of a UIA Member Section that have been completed since 30 November 2016.

Research by an architect or architects completed since 30 November 2016 which advances the theory and practice of friendly and inclusive design.

### **Awards**

A medal and up to three (3) Honourable Mentions will be presented in each of the Categories 1, 2 & 3.

The winner of Category 4 and up to two Honourable Mentions will receive UIA Certificates.

The Jury reserves the right not to make any award if, in its opinion, no entry reaches the required standards.

### **Judging Criteria**

Entries in Categories 1, 2, and 3 will be judged on the overall quality of design and how the project has addressed accessibility and inclusive design. In particular, the Jury will consider whether the quality of the architecture:

- Enhances user experience through use of friendly scale, form, colour, material and light
- Takes account of human diversity and needs
- Facilitates orientation, navigation, wayfinding and ease of understanding

## The 2020 Global Search for Excellence in Design and Innovation



### 2020 GOOD DESIGN AWARDS OPEN FOR ENTRY

Good Design Australia is calling for Australian and international entries to the 2020 Good Design Awards. Through the annual Good Design Awards program, we recognise and celebrate excellence in cutting edge design and breakthrough innovation.

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& AIAP

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MASTER  
IN VISUAL  
DESIGN



AIAP



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IN VISUAL DESIGN  
2019 // RAFFLES MILANO



# Job Openings

## 1. Job Opening

**Tenure Track Assistant Professor in Industrial Design, School of Design, San Francisco State University (SFSU)**

**Dear Design Educators, Colleagues and Associates,**

**The School of Design at San Francisco State University is seeking qualified candidates for a new faculty position in Industrial Design. This position is a tenure track, Assistant Professor appointment. (See Attached .PDF)**

**The mission of San Francisco State University is to create and maintain an environment for learning that promotes respect for and appreciation of scholarship, freedom, human diversity, and the cultural mosaic of the City of San Francisco and the Bay Area**

**To fulfill its mission, the University is committed to attracting, recruiting, and retaining a diverse faculty body whose teaching demonstrates an active engagement with their individual fields of study and whose creative and scholarly work is an extension of the classroom, laboratory or studio.**

**We are seeking to hire faculty who support industrial design curricula, research and contemporary applied learning experiences that reflect all dimensions of human diversity, and that encourage innovation, critical thinking and a commitment to social justice.**

**Responsibilities: The candidate will teach undergraduate and graduate courses in industrial design, mentor and advise undergraduate and graduate students, develop an active program of scholarship or creative work in their area of specialty, participate in ongoing committee membership and service assignments, and aid in supervising lab and shop spaces, and build bridges with industry and community partners.**

**The full job description and application procedure is available at: <https://design.sfsu.edu/jobs-design>**

**Questions about the role may be directed to the SFSU, School of Design, Search Committee Chair, Ricardo Gomes, at [ricgomes@sfsu.edu](mailto:ricgomes@sfsu.edu).**

**Thank you for your attention, possible assistance, and collegial support,**

**Ricardo Gomes, IDSA**

**Professor/ID Search Committee Chair**

**415-338-2229**

**<https://faculty.sfsu.edu/~ricgomes/>**



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## **Administrative Assistant for this special issue**



**Dr. Khushboo Gadda has done her Bachelor's in Physiotherapy from Nair hospital and currently pursuing Masters of Physiotherapy in Neurosciences from Seth GS Medical college and KEM hospital.**

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