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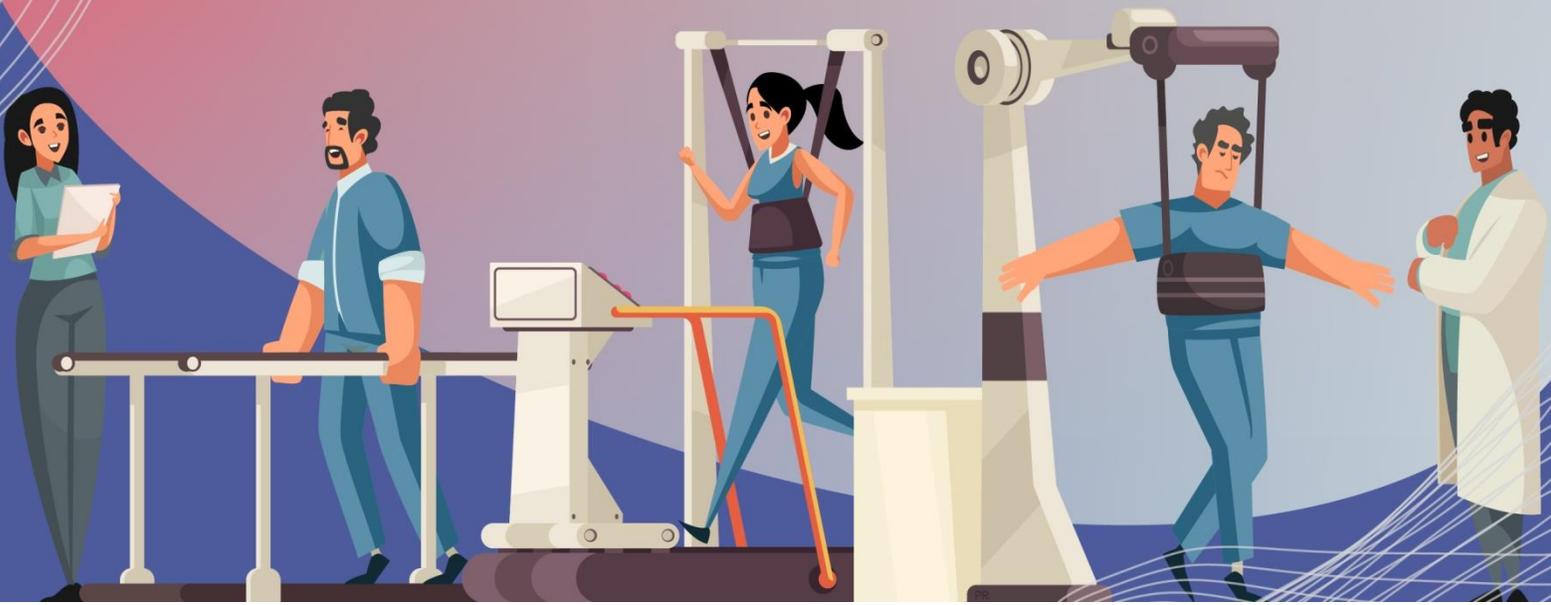
Design for All

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June 2021

ReDesigning Spinal Cord Injury Rehabilitation - Future Speak

Guest Editor: Dr. Ketna L. Mehta, PhD
Founder Trustee & Editor, Nina Foundation



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GUEST EDITORIAL :

**ReDesigning Spinal cord injury rehabilitation -
FutureSpeak**

Dr (Ms.) Ketna L. Mehta, PhD

Founder Trustee & Editor 'One World', Nina Foundation

We all love watching movies - they are a great way to communicate about a healthcare condition in an entertaining form. Here are some of the popular movies on paraplegics and quadriplegics (spinal cord injury) emotively bringing out the tremendous life challenges.

** The highest grosser movie of all times AVATAR from Hollywood had Jake Sully a paraplegic marine as the main protagonist.*

** Guzaarish from India ,Bollywood heartthrob Hrithik Roshan amazingly performed as Ethan Mascarenhas a quadriplegic.*

** The InTouchables French movie had the loveable Philippe as a quadriplegic.*

**A very popular Indian regional filmstar Dalquer Salmaan played a photographer with spinal cord injury in KULLANTE BHARYA in Malayalam.*

** Of course our SUPERMAN Christopher Reeves who played a cop with spinal cord injury in Above Suspicion same year as his horse riding accident in 1995.*

From movies and reel life let me draw your attention to our Heroes in real life. All LIVING LEGENDS.

Over the years the highest civilian awards from India both the Padma Bhushan, Padma Shri have been conferred upon

Maj HPS Ahluwalia, chairman of ISIC (Indian Spinal Injury Centre Delhi, who has quadriplegia. A million salutes!

Mr S Ramakrishna founder of AMAR SEWA SANGAM, Ayikuddy in South India has quadriplegia and Javed Ahmed Tak from Jammu and Kashmir with paraplegia both honoured with Padma Shri in 2020!

On Indian Television, in the last season of Kaun Banega karodpati -KBC (very popular show hosted by Mr Amitabh Bachchan a global actor had 2 Karma Yogis Navin Gulia (ex army) and Deepa Malik (the first indian woman to win a medal in the Paralympics 2016) and there are so many variously decorated heroes like late Mr Rajinder Johar (FOD) Nazeema didi Hurzuk, Mr K K Abdullah et al. Salute to them all for fighting against all odds and shining as exemplary role models.

There are 1.5 million Indians currently living with sci and millions globally. Our Nina Foundation's grassroots rehabilitation work for 21 years surprises us each time when we counsel the new rural and urban poor friends with spinal cord injury and discover the variety of ways in which sci happens.

Madhu rolled from her terrace while which was barely 2 yrs old, Dinkle at 6 years was in Bhuj earthquake, Mr N D Dharap had the house roof fall on his head, he is 93 yrs old now, Javerben Chheda was in a religious procession when a tree branch fell on her, Our Young friend Kisan fell into a open manhole, Chirag in a train blast, Waiting at the bus stop and a vehicle hits, bullet injuries, Electric shock,Lightening strikes, air pockets in an aircraft and hit

head on the roof of the aeroplane, leaning or cleaning the balcony and losing balance n fall, Fall from tree, ladder, construction site, electric pole. While walking in a village and a bull runs into you from rear.

Road accidents - buses, cars, tempos, trucks, bikes, rickshaws.

Swimming, diving, ganpati visarjan, dahi handi, stampede at large gatherings, sports, adventure, fall from camel or horse.

Traumatic causes are 90% and diseases of the spine like cancer or TB is also significantly growing (Sanika, Suraj, Prashant, Tanya and so many more children battled both cancer and now life long spinal cord injury.)

Spinal cord injury can happen to anyone, Anytime, Anywhere, Any age, Any place. Its not from birth, Its incurable- there is no CURE. Billions of dollars worldwide is being poured into research for a cure, in fact Elon Musk with his Neuralink has also making news in recent times.

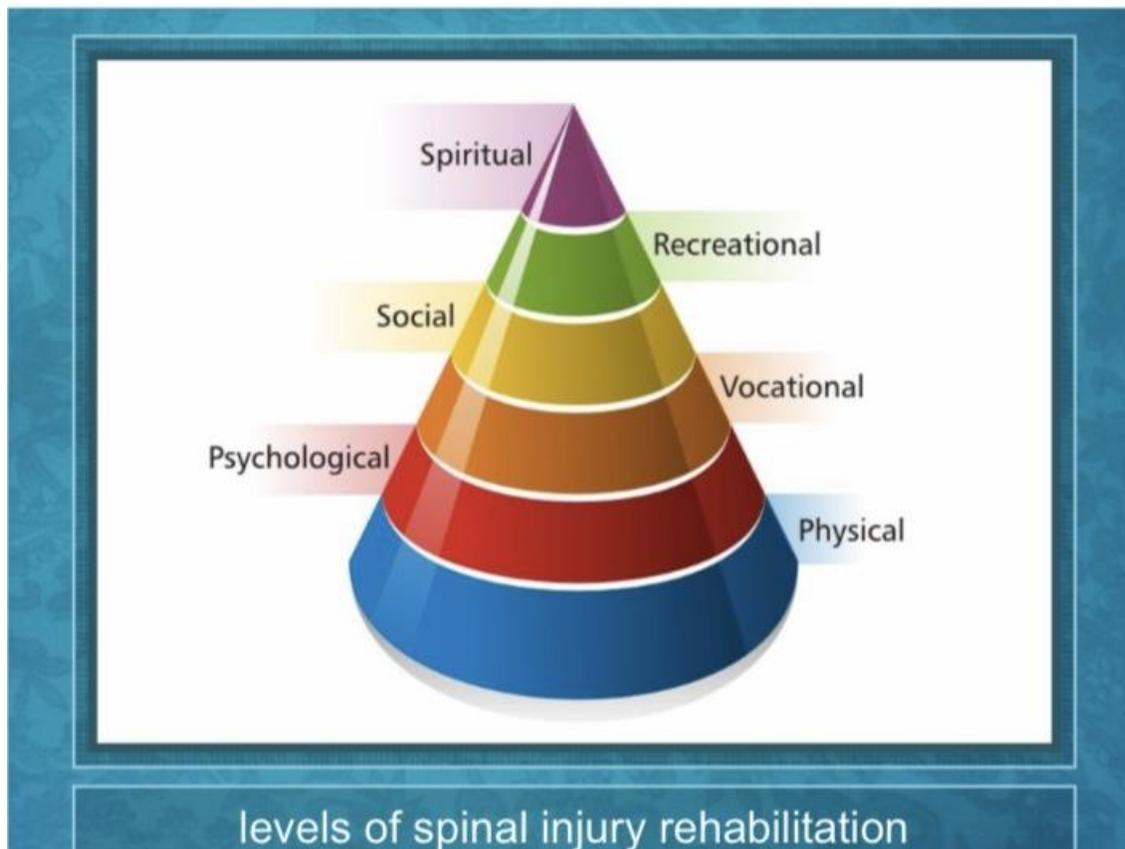
WHAT IS THE SOLUTION?

A small 14 letter word. But with a HUGE IMPACT. REHABILITATION for a reasonably good quality of life with as much as independent living skills as possible.

AND WHAT IS SCI REHAB?

Rehabilitation is at 7 levels which is an outcome of my phd are the only means to have a reasonably good quality of life.

PHOTO-1



So why make a big deal about sci rehabilitation?

WHAT HAPPENS post a traumatic or a non traumatic spinal cord injury?

1. Human Anatomy impact:

Imagine someone who had experienced only fever or a headache or a bruise is now paralysed without sensation from the level of fracture in the spinal-cord it could be cervical to dorsal or lumbar.

We cannot get up on our own from our chair or stand up, or even move our toes. The life of the entire family and the one affected turns 360° upside down. Spinal-cord injury is much

more devastating than any other disability (so says WHO Research)

Well, when the spinal cord is damaged the communication between the brain and the body is disrupted, resulting in loss of movement and sensation from below the level of injury. Spinal cord injury is more than not being able to walk: it affects basic bodily functions such as loss of sensation, and can cause breathing difficulties and inability to control body temperature amongst many other things.

For Bladder voiding of urine a catheter has to be inserted each time. For regular Bowel movement- we have to have measured quantities at fixed schedules - fibrous food, no indulgence as there are bowel accidents. In the initial phase not to have control over your MOST BASIC routine activity comes as a shock. A grown up person 'shitting in their pants' literally. The family too has to adjust to this new reality and urine leakages and bowel accidents creates a strain in family relations too especially when homes are small.

Also most Indian rural and poor homes have community washrooms far away and predominantly Indian style. As persons with spinal cord injury don't have trunk balance very rarely can paraplegics squat with crutches. It is relearning a 'different method' and adjusting to this new reality. For everyone in the household.

On top of that there is no sensation of mosquito bite, hot-cold water, pressure, we cannot move our ankles, toes... as both the motor nerves and sensory nerves are in trauma whether complete or incomplete.

2. Psychological impact: To come to terms with the new reality and accept this life altering change ...the parents during counselling always ask 'when will my child walk'?The entire life ahead for whether a child, youth, women or elderly turns topsy turvy. To accept and to come to terms with this is compounded due to the fact there is no psychological counselling offered post spine surgery. Youngsters are embarrassed to be seen on a wheelchair or with scoliosis and thin legs,. So much so that homes, buildings, outside built environment even hospitals are not wheelchair friendly and becomes a frustrating period, compounding lives.

3. Educational Impact: The initial vigorous rehabilitation is for two years and due to lack of enough awareness about rehabilitation centres it takes a long period to learn to manage their bladder, bowel, schedules etc. Of course most schools, colleges, coaching classes, hospitals or homes in India are wheelchair accessible. Schools do not allow mothers to visit to help the young child with catheterisation in the initial phase and so also socially distanced from their regular activities.

4. Employment impact: Nina Foundation counsels and supports rural and urban poor friends who were doing physical labour like in construction sites, road building, farmers, most are not literate, there are electricity issues in villages and they are stumped as to how to continue to take care of their families financially. Its interesting that the disability pension in India (which strangely varies state to

state) average is Rs.1200/ per month which is dollars 13 dollars a month only.

5.Social impact: Temples, parks, shops, religious functions, weddings, each and every aspect of life becomes out of bounds. Socially cut off from the mainstream of human connect.

6.Recreational impact: Cricket grounds, play areas, badminton and tennis courts, swimming pools, changing areas, clubs, gymkhanas are not equipped and so we are cut off from all outdoor sports.

7.Spiritual impact: The Indian society mores mention KARMA that you must have done something very bad for this state of affairs in this present life. Shakes the faith and belief and takes some time to re-design thinking and move ahead.

8. Secondary complications impact: In the lifetime of a person with spinal cord injury either all or some of these issues are faced...these are the secondary complications of living with sci, sometimes turning fatal.

- *pressure or bed sores*
- *Urinary Tract Infections*
- *Spasms*
- *Conjectures*
- *Swelling and edema*
- *Autonomic dysreflexia*

- ***Surge in Blood Pressure***
 - ***Kidney stones***
 - ***Kidney failure and need for dialysis***
 - ***Burnt skin due to electric blanket or hot water or keeping a hot beverage or plate with hot food on the thighs or sitting on a hot surface like a car parked in the sun.***
 - ***Osteoporosis***
 - ***Anxiety attacks, depression, stress***
 - ***Fractures***
 - ***Spondylosis***
 - ***Frozen shoulder***
 - ***Falls during transfers***
 - ***Fatigue of the muscles due to overuse, tennis elbow***
 - ***Diaper rash***
 - ***Catheter injury***
 - ***Constipation, piles, Fissures***
 - ***Need for surgeries like penile implant in males for fertility and removal of uterus in females due to heavy bleeding and dependance on a caregiver.***
-all this due to a fracture in the spine!***
And there is more -
The apathy and indifference by the civil society to bring about a radical change in the built environment, healthcare

systems and their attitudes. Each one of us have our circle of influence and lots can be done for both prevention and spinal cord injury rehabilitation. Design for All's Dec 2019 part 1 issue which Dr Sunil Bhatia invited me as Guest Editor is also worth a re visit titled 'Quality of life of living with spinal cord injury-Rehabilitation Design Challenges and Solutions'

Medical texts, research papers talk about what we lose post a sci whereas NINA FOUNDATION ethos is what we do continue to have

- ***A fully functional brain to think, a heart full of dreams and a desire to live life to the fullest,***
- ***with a never- say- die spirit and***
- ***willpower to make all the impossibles possible, to scale every mountain, practically and metaphorically.***

Quality of Life thus is overall wellbeing as well as neurological and functional changes over time. Overall wellbeing conveys how satisfied are we with our lives and Life Satisfaction Parameters.

Life Satisfaction Parameters are:

1. Self Care (managing independently bladder, bowel, bathing, skin, pain management, fitness, exercise, cooking, ADL (Activities of Daily Living), manage home etc)

PHOTO -2





Jan. 2019

NINA FOUNDATION SPINAL CORD INJURY REHABILITATION COMMANDMENTS & PROTOCOL POST SPINAL CORD INJURY



REHABILITATE.
RELIEVE. REJOICE.

Nina Foundation is focused on helping friends with spinal cord injuries and their families acting as a resource centre guiding them, mentoring them and providing support.

- 1) Take adequate sunlight everyday.
- 2) Positive reading, viewing, sharing and communicating - books recommended:
 - You can heal your life - Louis Hay
 - The power of the subconscious mind - Joseph Murphy
 - Positive attitude for positive results (several authors)
 - Must watch video - The Miracle Man (real story)
- 3) Regular daily practice of Pranayama and Yoga. To calm the mind and also make us more resilient mentally.
- 4) The central key to recovery is intensive, relentless physiotherapy for 6 hours a day for 2 years post spinal cord injury is a must. Become an active participant and focus on the particular muscle group mindfully. Exercise with a WISH and strong DESIRE to get better. Don't expect anything in 3-4 months. This fitness routine must be continued life long with at least one hour each day for physiotherapy.
- 5) Have complete, absolute faith and trust in the therapy team, become an active member of that team and be proactive.
- 6) Initially set daily goals and then weekly and monthly goals. Become a fitness enthusiast and work on making the upper body extremely strong (depending upon the level of injury).
- 7) Get involved in sports, games, social outings with family and friends, start facing the world and people with a smile and be happy! Enjoy every moment & live in the now.
- 8) Work therapy is very important too. Involve yourself in any work or activity, even home related, family related, help children with their studies, projects but must not supersede daily therapy routine. Doing meaningful and constructive work even learning a new language or helping family, neighbors and friends with your skill sets is helpful in recovery.
- 9) Visually and mindfully be aware about your body/anatomy and do not develop any secondary complications like urinary tract infections, bedsores, pressure sores, bone health degeneration or muscle tone wasting.
- 10) Homeopathy medicines through a qualified doctor recommended for overall well-being immediately post spinal cord injury and for headaches, fever, pain, etc.

- 11) ACCEPTANCE of this temporary new reality and living in the moment helps us a lot to take each day as it comes.
- 12) Every friend with spinal cord injury is different and everyone has the potential and has to believe they can improve either to walk or re-write medical textbooks and surprise their doctors. YOU can be the next miracle.
- 13) The mind is the most powerful important part of the body and it is very essential to keep believing that you will achieve everything that you ever wanted to in your life and to stay positive at all times. No ups and downs. Only positivity.
- 14) Hydrotherapy (exercises in water) have shown great results and if available can be done regularly.
- 15) Visualisation is the formation of a mental image of something, imagining and making it possible. There are several techniques which has to be regularly followed.
- 16) Affirmations is the practice of positive thinking and self-empowerment having a belief that a positive mental attitude supported by affirmations will achieve success in anything.
- 17) Stem cell treatment is experimental, unproven and our Nina Foundation eminent doctors team does not recommend spending money on it.
- 18) The family has to be supportive, caring, fully motivated and positive. Appreciate the hard work and fight to recover and be communicative, involving them as before in all decisions.
- 19) Laughter therapy by being in the company of people who will make us laugh. Small and young children to play and interact, sharing stories also help a lot, watch comedy shows, stand up comedians or reading jokes which makes us roll with laughter.
- 20) 2.5 to 3 litres of water and fluids per day is mandatory for good bladder health. One glass of plain lime water each day acts as a natural antidote safeguarding against urinary tract infections.
- 21) Good amount of fiber in daily diet helps with bowel management so carrots, leafy vegetables, salads, curds and fruits are a must. Fixed timings and measured quantities help in timing regular bowel movement.

30

2. Vocational- work

3. Financial- I requested one of our Mumbai based old friend with spinal cord injury Chirag Chauhan to research and

specifically create an article around this topic with the high average cost of living with paraplegia and quadriplegia in India. It is so very important because as an NGO Nina Foundation receives requests from so many for basic needs-monthly medical needs, their first active wheelchair for moving out of bed after years of being confined etc.

4. Leisure and recreation, what Human Rights and CRPWD ratification are we talking about. Unheard of!

5. Sexual Life

6. Family Relationship (Re integration to normal living index)

7. Partner Relationship

8. Social Contacts-Relatives, Friends, Colleagues.

9. State of Mind.

Nina Foundation's primary focus is the community of friends with spinal cord injury especially those who are affected physically, financially, relationship wise, emotionally & psychologically. The ecosystem in which we live comprises of all kinds of human beings. Indifferent behaviour, non-compassionate bad attitude, discriminating non-cooperative no proactiveness no idea of kindness. We get frantic calls divorces, family members usurps farming property, stop taking care, dumps them (leave them in hospitals and don't come to take them back), women are not made part of the homes, family farms and don't have a voice in the management of their own house, deprive of food choices, marriages and are not empowered to take decisions of their own lives, even in urban settings- basic decisions to drive a modified vehicle or travel with family like before etc

becomes a sore point and strained relationships, with no communication even within the house on a daily basis.

PHOTO-3



**NINA
FOUNDATION**

Nina Foundation empowers fellow sci to learn to MANAGE their lives. Management is the way forward. Because the innumerable obstacles and speed bumps faced are so many, most uncontrollable variables that we tell them 'move on' we can't wait for things to be as per our needs, but with ULTRA CONFIDENCE using your mind and talent.

Thro

Through our superior counselling and solutions oriented approach we are an extended family and see even if one person believes in you, smiles and supports you when it matters the most, we can win and achieve all that we want to. ignore the rest that's the mantra in a real-life situation depicted in the movie the miracle man what work was his approach to keep a board bored with the acronym SNIOP (Susceptible to Negative Influence of Other People) and proved it on discharge when he actually got up from his

wheelchair and stepped out of the hospital, walking taking baby steps. Wow.

Pain points, issues are a many. Here are three most important solutions we look forward to through our media campaign.

PHOTO 4,5, 6

#OurLawToo

1.5 MILLION SPINAL CORD INJURED IN INDIA

WE URGE SPINAL CORD INJURY TO BE INCLUDED IN RPWD ACT

Nina
FOUNDATION

REHABILITATE.
RELIVE. REJOICE.

JOIN OUR
12th
SPINAL CORD INJURY
AWARENESS DAY
25th JUNE, 2020

**NINA
FOUNDATION
CAMPAIGN**
#ISupportNinaFoundation

SHOW YOUR
SUPPORT BY
**SHARING THIS
CAMPAIGN**
IN YOUR SOCIAL
MEDIA HANDLES
AND ADD
#OurLawToo

www.ninafoundation.org



#22ndDisabilityInRPWAct

1.5 MILLION SPINAL CORD INJURED IN INDIA

WE URGE SPINAL CORD INJURY TO BE INCLUDED IN RPWD ACT



REHABILITATE. RELIEVE. REJOICE.

JOIN OUR 12th NINA FOUNDATION CAMPAIGN
#1SupportNinaFoundation
SPINAL CORD INJURY AWARENESS DAY
25th JUNE, 2020

SHOW YOUR SUPPORT BY SHARING THIS CAMPAIGN IN YOUR SOCIAL MEDIA HANDLES AND ADD #22ndDisabilityInRPWAct

www.ninafoundation.org



#AddSpinalCordInjury

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SPINAL CORD INJURY AWARENESS DAY
25th JUNE, 2020

SHOW YOUR SUPPORT BY SHARING THIS CAMPAIGN IN YOUR SOCIAL MEDIA HANDLES AND ADD #AddSpinalCordInjury

www.ninafoundation.org

Affordable Rehabilitation Services, accessible homes and Assistive Technology is required. Our authors for this issue is known to be since a long time and its curated by self covers every aspect of these pain points. I am grateful to all of them for lovingly and promptly agreeing and submitting their articles as per our deadline.

Assistive technology, physio equipment -even in rural areas hospital beds, air beds, good quality calipers, crutches, cushions, should be available on hire, rent- of course duly sanitised now.

If the mind is capable then its even possible to prove the medical books wrong- so said..... Dr Nina Doshi's mantra (my elder sister and the raison de etre for Nina Foundation's existence:

'Take stock of your Talents,

Believe in our Dreams,

Be ready to work twice- as -hard because our mind is magical, we can ACHIEVE all that we wish, our body cannot limit us!"

The Design community and Public at large can play a humungous role in 'ReDesigning the way we approach a spinal cord injured.'We all can participate in a proactive manner to provide all friends with spinal cord injury a *PATH STREWN WITH ROSE PETALS.*

PHOTO 7



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REHABILITATE.
RELIVE. REJOICE.



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Designation:

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- **Immediate Past President, Association of Spine Surgeons of India (ASSI)**
- **Chief of Spine Service & Medical Director, Indian Spinal Injuries Centre**
- **Executive Member, Asian Spinal Cord Network (ASCoN) and International Group for Advancement in Spinal Science (IGASS).**
- **Member Advisory Committee, Stem cell expert group of Indian Council of Medical Research (ICMR), Central Drugs Standard Control Organization (CDSCO),**
- **Section Editor, Journal of Clinical Orthopaedics and Trauma**
- **Publications: 123 peer reviewed Journal publications and 22 Chapters**
- **Awards: XIII National Excellency Award by TP Jhunjhunwala Foundation, ISCoS Society Medal Award for 2013, India News National Health Award in 2018 for excellence in spine and orthopaedics, ASCoN Star award by Asian Spinal Cord**

Network in 2018, ASSI Research Awards for 7 consecutive years from 2013 to 2019, best Spinal Surgeon award by MTI Indian Medical Tourism Summit 2020

- **Editor-in-Chief: ISCoS Textbook, elearnsci.org – a web resource of ISCoS**

New trends and practices to overcome challenges in providing affordable Spinal Cord Injury Rehabilitation

Dr Harvinder Singh Chhabra

Abstract

Spinal cord injury (SCI) and the resultant paralysis has devastating physical, mental, social, sexual and vocational consequences for the injured. SCI results in major financial burden to individuals and society as a whole. Comprehensive rehabilitation management is important for improving quality of life of a person with SCI and helps their integration into community. A developing country like India has meager resources, and is demographically large. Along with standardized quality of care, rehabilitation processes/management also needs to cater to individualized needs of patients with SCI. It is therefore important to identify an affordable and sustainable model which would expand the coverage of rehabilitation services for persons with SCI. This will require proper and judicious use of resources and a multi-sectoral approach. Such practices will involve improving access through increasing the infrastructure for SCI and creating a network, increasing awareness about SCI and its management, appropriate human resource development, networking amongst stakeholders, telemedicine & promoting research.

Keywords

Spinal Cord Injury, Rehabilitation management, developing countries, affordable, sustainable

Introduction

Spinal Cord Injury (SCI) is the most devastating ailment that could affect the mankind.^{1,2} Every year SCI affects a large number of young to middle aged population, which are the most productive years of their life.^{3,4} Every year 250000-500000 people suffer from SCI globally.⁵ The average annual incidence of SCI in India is 15,000 with a prevalence rate of 0.15 million.⁶ According to the World Health Organization (WHO).The incidence of SCI in developing countries like India is increasing because of rapid development and increase in number of vehicles.The injury results in physical, psychological, emotional and financial burden not only on the individual but also on the family and the societyand therefore poses a major public health challenge.^{7,8} Management of SCI was revolutionized during and after the II World War.^{9,10} The management of SCI is not limited to the injury alone, but necessary inputs from medical, social and legislative fields are required lifelong. The economic impact due to SCI in developing countries is expected to increase in similar proportion to that of the developed nations.¹¹ As per the statistics from USA, depending on the severity, SCI can cost an injured individual \$334,000 to 1 million the first year after injury. Costs in each subsequent year range from \$41,000 to 178,000.¹² Although similar data is lacking amongst other countries like India, the enormity of the expenses involved can be imagined.¹³ The major goal of SCI rehabilitation is to make the individual as independent as possible in his/her activities of daily living and to get him/her back to a near normal life style. It is therefore imperative that sustainable and affordable rehabilitation services are expanded in developing countries like India.

Improving access: increasing the infrastructure for SCI and creating network

The rehabilitation services are integral component of comprehensive management of patients with SCI and continuous advancements in technology has improved the outcomes and quality of life in these individuals. However, there are factors in developing countries like India, which create an immense challenge to comprehensive management and community inclusion of patients with SCI.¹⁴ The incidence of SCI is comparatively low in comparison to other ailments. Also the management of SCI is much more expensive and for the same cost, a bigger population can be covered for management of other ailments with more noticeable results.¹³ It has been mainly in the past 2-3 decades that the countries like India have focused on setting up SCI management services and dedicated centers. However the numbers of such exclusive centers are frequently insufficient to meet the needs of the population.¹⁵ Lack or mismanagement of patient with SCI in countries like India begins at the site of injury. Most of the patients with suspected SCI are transported by vehicles which are not meant or equipped for proper positioning and transfer of injured patients.¹⁶ Also, patients with SCI should ideally reach definite SCI centre within 2 hours of injury,¹⁷ whereas, in an Indian study, 22% of patients with SCI reached the definitive SCI centre after 1 month of injury.¹⁵ The services available in current health care services in countries like India lack proper medical and rehabilitative facilities, with minimal availability of specialized assistive technology and no opportunity for vocational, recreational rehabilitation processes, hence impeding quality of life and community inclusion.^{15,18} Management of patients with SCI in India face many challenges, and this affect all aspects of

comprehensive rehabilitation management. Community inclusion and Quality of life for patients with SCI can only be improved if a multipronged action is initiated. Improving access and increasing the infrastructure for SCI management would involve sensitizing government officials & health care providers as well as medical/paramedical professionals about the impact of SCI prevention and management on the quality of life following SCI and the need for setting up SCI management centres. There is a need for all the stakeholders to collaborate pool resources. Another strategy to improve access is to ensure proper grading of services for judicious use of resources. At present there are different type of SCI units including Acute + Rehabilitation care under one facility, only acute care, only rehabilitation care, inpatient Rehabilitation facility, outpatient Rehabilitation facility, SCI Units under General hospitals and home based Follow-up care.

In the past few years/decades great advances have been made in the rehabilitation management of patients with serious traumatic as well as non traumatic spinal injury. Special spinal centres cum research have played an important part in these advances. An important component of such specialized management SCI centres would be the standardization of medical care protocols and procedures which are now an established practice that helps create a safer and more affordable patient culture. Proper grading of such SCI centres would help in judicious utilization of resources, which are always meager in countries like India. Standardization of management of SCI would help improve quality of care, safety and efficiency of medical centres.

Despite the revolutionisation of SCI management, there is no global consensus on a standardized definition of a spinal cord injury (SCI)

unit. Specialized care SCI units have shown to reduce the length of stay, complications and better neurological recovery in patients with SCI.¹ Studies have also shown decreased neurological deficit in Level 1 and 2 Trauma Centres, especially where surgical volumes are high.² Hence it is important to identify the requirements both in terms of facilities and manpower available in defining the level/grading of a spinal cord injury unit. International Spinal Cord Society (ISCoS) - Spinal Trauma Study Group (STSG) is doing this exercise to define a SCI unit and develop a grading system which would hold relevance both in developed and emerging countries. This would help in standardization of management of SCI and help improve quality of care, safety and efficiency of medical establishments working in this field. ISCoS-STSG has proposed a grading system of a SCI Unit based on the resources and the elements of spinal cord injury care available. It has broadly classified management of SCI as 'Acute Care' and 'Comprehensive Rehabilitation', supported by ancillary functions/departments and divided SCI Units into Level 1 (provides highest tertiary level of acute and rehabilitation care for a patient with SCI) to Level 5 (provides basic rehabilitation, community outreach and home care services to persons with spinal cord injury). The level wise manpower requirements and the other resource requirements as defined by the STSG have also been defined as have been measures (matrices) to assess the quality of service being provided by the SCI unit. 'Peer counselor' and other support staff from within SCI community to be accommodated at all levels of functioning of a SCI Unit.

The grading system thus proposed foresees levels which could perform as a network such that all patients with SCI would be able

to re-integrate within community. Every Level 3 - 5 SCI Unit should be attached to a Level 1 or 2 SCI Unit for easy transfer of patients as and when necessary. There should be a build up a culture of meetings to talk about the individual course of patients between the SCI Units and they should conduct regular scientific meetings amongst the SCI professionals.

However, this will need to go through a validation process before implementation. Furthermore, like any such system, it is expected to gradually evolve as practical issues get obvious with implementation.

Increasing awareness about SCI and its management

Another strategy for sustainable, affordable practices for expanding the coverage of SCI rehabilitation would be to increase awareness amongst all stakeholders including policy makers, health Care providers, professionals, consumers and society. It would involve creating awareness Programs for Prevention & Management of Spinal Ailments, emphasizing the need for Collaborating with WHO, NGO's and Consumer groups for policy /guidelines development and demonstration of their effectiveness, sensitizing policy makers for enforcement of region specific regulations and guidelines, promoting community awareness about SCI acute management, long term management and community inclusion and promotion of SCI awareness programs by various means including social media and telehealth. The goal of rehabilitation management of patient with SCI is to lead an inclusive life. Because of the permanence of disability in complete SCI injuries, prevention assumes special significance. The common saying is, 'Prevention is better than cure'. But in fact, where a SCI is concerned, 'Prevention is Cure'. Awareness Programs amongst general public for Prevention & Management of

SCI would facilitate an inclusive life for persons with disability and ensure success of prevention programs. In the endeavor to increase awareness, IScoS and its affiliated societies have been observing 5th September as SCI day since 2016. They are working towards promoting SCI Day via various means like social media, consumer groups, increasing awareness amongst all related Societies and lobbying to get recognition for SCI day.

Appropriate Human Resource Development

Another important strategy for expanding SCI management would be development of trained human resources. It is important to liaise with concerned local authorities for inclusion of SCI management within the curriculum of health professional degree programs at all levels.

Networking

There is a dire need for promoting sustainable, affordable practices for expanding the coverage of SCI rehabilitation but the challenge is equally big. Thus there is a need for promoting networking of various NGOs/Societies /organizations working in this field. There is a need for them to pool resources and collaborate in order to overcome this challenge. There is a need for Collaborating with WHO, NGO's and Consumer groups for policy /guidelines development and demonstration of the effectiveness of such awareness programs. There is a need to sensitise policy makers for enforcement of region specific regulations and guidelines for prevention of SCI.

Telemedicine

'Telehealth' is the next step in the continuity of health care, allowing patients and caregivers to receive the quality of follow-up care at their homes using common technologies audio or video based. This assumes all the more importance in people with

impairments/disabilities since they face multiple challenges accessing healthcare and the complexity of patients needs changes in post discharge care. Telemedicine provides an alternative service delivery model.

Advantages of telehealth include, improved quality of care, continuity of follow-up care, customized Client Centered Care, better access to specialist care and reduced travel time and costs for the patient.

Promoting research

The bigger the challenge, the more the need to come and with innovative techniques. Hence Research assures importance to promote sustabnable and affordable practices for expanding coverage of SCI rehabilitation. It is thus important to coordinate with SCI Centres/Units to contribute data to a centralized database, promote newer techniques for management of spinal cord injury and promote researchers to highlight newer techniques

Conclusion

There are numerous challenges in India for provision of affordable access for SCI management. As we move forward in 21st Century, we need to have a patient centric approach while providing quality of care. This is achievable by a sustained multi-strategic, multi-pronged approach with involvement of all stake holders including patients, medical professionals, media, NGOs, healthcare industry and government bodies. Sustainable and affordable practices for expanding the coverage of SCI rehabilitation in India would involve improving access through increasing the infrastructure for SCI and creating a network, increasing awareness about SCI and its management,appropriate human resource development, networking amongst stakeholders,telemedicine & promoting research.

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Redesigning Spinal cord injury rehabilitation: State of the art , affordable & compassionate.

Dr Amit Ramesh Dhumale

Before I elaborate on SCI rehab at Jupiter , I would like to talk about how Rehab department came into existence at Jupiter hospital Thane.

This was made possible by Dr Ajay Thakker Chairman & Dr Ankit Thakker CEO , Jupiter hospitals. When I met Dr Ajay 4 years back (this was before setting up the service) I had expressed my concern to him that, in the present day state of the art neuro-rehabilitation services are limited , expensive& donot have easy access. There was a need of making Neuro-rehabilitation services accessible to the all sections of the society and not just the super rich.

For any healthcare service to be sustainable it has to affordable. With a visionary & perfectionist approach we have made this vision a reality by setting up a successful neuro-rehabilitation facility , state of the art and yet affordable.

We will be talking about components that make a comprehensive SCI Rehab center but, before that the most important ingredient that a Rehab physician and his team should have are Empathy & Compassion.

In my opinion below are three best practices that can be implemented to help establish a more empathetic approach to patients with paralysis.

1.Giving a Personal touch

This can be controversial and many Rehab physicians may not agree with this but relationships matter. Take the time to get to know a

few personal details about each patient, their hobbies / interests. Not only does it matter when considering treatment options, but it is also crucial for expressing compassion and empathy. This makes the patient & their family feel that Rehab team cares. This goes a long way.

2. Positive Gestures

Expressing empathy and compassion include the use of nonverbal cues and positive gestures such as open body language, listening, making eye contact, taking notes, or repeating what a patient says to confirm understanding. Positive gestures demonstrate empathy and reaffirm that the patient is being listened too. Listening to what the patient has to say is extremely important instead of predominantly keeping them at the receiving end of a conversation.

3. Ask for Patients Feedback / Reviews

Providing patients with the opportunity to share their thoughts is an important part of effective communication. Open-ended questions such as “What do you think?” or “How do you feel about that?” are effective ways to engage patients in an open discussion while demonstrating compassionate care.

Empathy and compassionate care is not only the responsibility of the Rehab physician , but is also the responsibility of every member of the rehab team. Patients spend a significant portion of their time interacting with the therapist ,nurses, medical assistants, and receptionists. These interactions can provide many opportunities for demonstrating compassion and empathy toward patients. Therefore, training, encouraging, and ensuring support staff engage in compassionate, empathetic patient care will significantly influence a **patient’s overall experience.**

SPINAL CORD INJURY

An injury to the spinal cord is a nightmare and the Spinal cord injury treatment process is even scarier and difficult to comprehend for a lay person. Paralysis is a lethal blow not just to the patient but the whole family particularly if an earning member is involved. It is a huge burden on the family & the healthcare system. Post the surgery, spinal cord injury rehabilitation process needs to be supported in the best possible way, with an active support from an expert team, during the recovery period. Rehabilitation after paralysis plays an important role in nursing the individual back to good health. We have some of the best neuro-rehab services for treating complications of spinal injury.

There are various types of spinal cord injury - Traumatic spinal cord injury, Ischemic spinal cord injury, Tumors of the spinal cord, Vascular malformations such as Arteriovenous malformation, aneurysm, Spinal cord infections, Auto-immune conditions such as multiple sclerosis, transverse myelitis, Spondylitic myelopathy (degeneration of the vertebral column), etc.

SYMPTOMS

The commonly seen spinal injury symptoms in the individuals affected by these conditions are

- *Weakness of the arms and/or legs***
- *Decrease or loss of sensation***
- *Bladder and bowel dysfunction***
- *Swallow dysfunction***
- *Breathing difficulty***

MEDICAL COMPLICATIONS

There are medical complications of spinal injury, that can be noted after a few weeks or months after the injury. Some common ones include

- *Infections such as Pneumonia and Urinary tract infection*
- *Venous thromboembolism such as Deep vein thrombosis (blood clot in the veins of your arms and/or legs) or Pulmonary embolus (blood clot in your lungs)*
- *Pressure ulcers*
- *Heterotopic ossification – a condition which causes stiffness of your joints*
- *Nerve pain, as well as muscle, tendon and joint pain*
- *Spasticity – muscle tightness*
- *Autonomic dysreflexia – a condition which causes headache, increased flushing and sweating, changes in your blood pressure and heart rate*
- *Orthostatic hypotension – a condition which causes a decrease in blood pressure with change in position*
- *Sexual dysfunction*
- *Fracture*
- *Osteoporosis – a condition which causes thinning of bones*
- *Changes in the mood such as depression and anxiety*

HOW JUPITER HOSPITAL REHABILITATION CAN HELP

Jupiter Hospitals SCI Rehab program is in the true sense interdisciplinary. Rehabilitation is an integral part of the hospital services in line with evidenced based medicine & best practice guidelines. The coordinated, structured & integrated team approach

makes it truly interdisciplinary with weekly case conferences by the rehab team keeping the patients needs at the centre.

Convenient one stop access to all multiple therapy services , all under one roof that caters to all the rehabilitation needs of the patient .The SCI Rehab program provides customized & tailor made programs suited to the needs of the individual. Regular interdisciplinary case conferences to monitor the progress of the program towards achieving measurable functional goals & endpoints.

Rehabilitation is an integral part of the hospital services at Jupiter hospital, thane - 2000 squarefeet advanced rehab lab with dedicated rooms for inpatient SCI rehab program & advanced rehab technology (Robotic rehab, sensor based rehab, computer assisted rehab & virtual reality), all in the same vicinity for easy / safe patient transfer & maximise sessions as per need of the patient.

Spectrum of care: SCI rehabilitation__: Integrating rehabilitation services to the main stream healthcare is the need of the hour. At Jupiter hospital the rehab starts from the intensive care units followed through the impatient ward journey till they are discharged & continue their rehab as needed on outpatient basis.

- ***ICU based Early mobilization protocol***
- ***Comprehensive Inpatient Inter-diciplinary rehabilitation program***
- ***Out-patient rehabilitation program***
- ***Daycare rehabilitation program***
- ***Rehab OPD Clinic***

Interdisciplinary Core team – SCI Rehab

REHAB PHYSICIAN (PHYSIATRIST)

Patients are evaluated by the Rehab physician first to determine the nature and severity of the medical condition and then come up with a treatment plan that best suits them. Depending on the patient's symptoms and medical complications, the treatment plan will include recommending therapy services, prescribing medications and performing injections as needed. Medications are commonly prescribed for medical complications as well as to reduce symptoms directly related to spinal cord injury such as pain, tightness of muscles of arms and legs and bowel and bladder dysfunction. The physician performs injections such as tendon injections, joint injections for joint or muscle pain as well as Botulinum toxin (commonly referred as Botox injections) and nerve block injections to help relieve muscle and tendon tightness.

PHYSIOTHERAPIST

Physiotherapist will focus on various physical exercises to improve weakness in legs, improve their bedmobility, static / dynamic sitting balance, walking and reduce muscle tightness. They can also use physical modalities to reduce pain and inflammation, muscle and tendon tightness, and prevent muscle atrophy.

OCCUPATIONAL THERAPIST

The Occupational Therapist will focus on various physical activities required for daily living for patients with severe physical and/or cognitive impairment and also teach cognitive exercises thereby compensating the cognitive deficits in any. Occupational therapists also focus on various physical exercises to improve weakness in the upper limbs & transfer training. The final phase of

treatment involves patient training for successful community integration (education, employment etc).

ORTHOTIST

They can fit you with an orthosis to reduce muscle tightness as well as improve your walking and arm function.

NEUROPSYCHOLOGIST

A Neuropsychologist evaluates patients with depression and anxiety, that is commonly seen after any major life-changing illness or injury and guides them through the process of rehabilitation thereby improving their quality of life through motivation and counselling.

NUTRITIONIST

Malnutrition or undernourishment is a common problem in this population. For optimal recovery, a Nutritionist recommends an appropriate intake of nutrition.

REHABILITATION NURSE

Our inpatient rehab program is strengthened by dedicated Rehabilitation Nurses. They train patients with central nervous system injury to manage their bowel and bladder with guidelines laid down by Rehab physician as part of bowel & bladder training. Performing and training wound care management for patients with pressure ulcers are also handled by a Rehabilitation Nurse.

Goals of SCI Rehab program should be Specific, measurable, achievable, relevant & time bound.

Aims of SCI Rehab program should be ,to promote maximal restoration of function , to facilitate early / smooth reintegration of the patient into the community .

EXPECTATIONS OF RECOVERY

Depending on the severity and chronicity (time duration since injury/illness) of the injury/illness, recovery duration may differ.

Complete neurological recovery is often possible if the injury is mild and incomplete. In the case of a moderate to severe incomplete injury or a complete injury, full neurological recovery may not be possible; therefore SCI Rehab will help you to optimize your independence and integrate you into the community despite your physical limitation. If the injury is too severe, then the goal would be to improve your quality of life by helping you be as independent as possible with your day to day living, decrease pain and prevent complications. Rehab counselling plays a huge role. Indeed at times it is a tight rope walk as we donot want to push a patient with complete SCI into depression but at the same time at all costs avoid making promises we cannot keep. This is why making realistic goals is so important. At times , this can also be very stress-full for the Rehab team as along with the patient we too have to face the harsh realities of life at times.

Specialized SCI Rehab services provided –

- ***Robotic Rehabilitation***
- ***Motor Re-learning program***
- ***Balance & coordination training***
- ***Gait training***
- ***Hand Rehabilitation***
- ***Facial Rehabilitation***
- ***Sensory integration therapy***
- ***Constraint induced motion therapy (CIMT)***
- ***Proprioceptive neuromuscular facilitation (PNF)***
- ***Neuro-developmental therapy for adult & children (NDT)***
- ***Geriatric Rehabilitation***
- ***Spasticity management***
- ***Bladder & Bowel retraining***

- **Activity of daily living Training**
- **Splinting / Orthotic management**
- **Assistive devices (Assessment & training)**
- **Wheel chair training**
- **Transfer training (Surface to surface transfer)**
- **Sexual Rehabilitation**
- **Job evaluation& modifications**
- **Home modification for architectural barriers**
- **Fall prevention**
- **Patient & family counselling& education**

Advanced Rehab technologies

- **Robotic & computer assisted rehabilitation for Wrist , hand & fingers**
- **Robotic & computer assisted rehabilitation for arm & shoulder for task oriented training**
- **Interactive therapy surface for motor training**
- **Sensor based rehabilitation device for static & dynamic balance assessment & training with seating & standing features**
- **Computerized work station for continuous record of all patients**
- **Myofeedback using surface & cavity electrodes which gives visual biofeedback on a LCD screen.**
- **EMG biofeedback & Functional electrical stimulation**
- **Virtual Reality treadmill with unweighing system**
- **Antigravity treadmill**
- **Dynamic stair trainer**
- **Lokostation (USA) – Advanced Robotic Gait rehabilitation tool which comfortably redistributes the patients weight with offloading system to reduce the risk of falls**

- **Mechanised devices for early mobilisation (Sit to stand) - Sara Plus & Sara steady**
- **Over-head rail system connecting patient room to any part of the Rehab lab for gait training & patient transport.**

The SCI rehab program at Jupiter hospital, thane is state of the art yet affordable with a personal touch of empathy & compassion.





Chirag Chauhan is a practicing Chartered Accountant for now close to 10 years.

Post his graduation he was required do his internship and undertake training for his Chartered Accountancy course. In July 2006 due to a terrorist attack Chirag was left paraplegic. He was a victim of the July 2006 bomb blasts in Mumbai. He had lost his father just few years before this accident. Now this accident left him with a permanent disability.

Chirag was shattered and had lost his will to live at one point. Immense support from family and friends did wonders to his life. Extensive physical therapy, well wishes from all near and dear ones is the result of what Chirag is today.

Post injury Chirag burned the mid night oil to pass his CA exams. During his exams his hands did not even have the strength to write a 3 hour long exam. He practiced and did extensive therapy so as to support his hand and sit and write. He passed CA finals with flying colours.

Once he was a CA, there were very few organisations who could afford to offer him a job, due to his disability. He still did not loose heart and kept searching. He got into Big4 Accounting Firm which has wheelchair friendly offices. After that he switched to another job to with MNC Bank for better prospects.

He soon realised that being in employment did not suit him. Being an entrepreneur was his calling. He soon quit a steady, excellent paying job to start on his own.

Today, nearly after 13 years of his clearing CA,he is doing supremely well. He is generating employment and is mentor to few start-ups . Is his own BOSS and living life to his fullest. His ambition is to generate more employment by expanding his profession. Helping the needy by various ways and means and also is Trustee of Arvind Foundation

Spinal Cord Injury – A lifelong Expensive Affair in India !!!

Chirag Chauhan

The backbone of a human body is the Spinal Cord. It supports the entire functioning both physical and neurological. You all must have done some massive research on Google about the same. Thus let's jump into the financial injury caused due to Spinal Cord Injury.

Spinal Cord Injury

Spinal cord injury (SCI) is damage caused to the spinal cord of a human that results in a loss of function, could be mobility and/or sensation. Records state that frequent causes of a spinal cord injuries are heavy trauma. Causes could range from vehicle car accidents, gunshots, accidents like fall from stairs,skiing, skating, severe exercising or could be because of various diseases like polio, spina bifida, Friedreich's ataxia, etc. There are no definitive treatments yet for spinal cord injury. At present various research are on to test new therapies and it is progressing rapidly.

In India it is estimated that every year approx. 25 thousand people suffer from SCI and there are approx. 1 million people with SCI in the year 2021.

SCI results into paralysis which results into devastating physical, mental, social, sexual and vocational consequences for the injured. In addition, the injury increases the economic burden on the person who sustains an SCI and potentially on his or her entire support network; especially family, extended family and friends.

SCI could be of two types, quadriplegia that results in the partial or total loss of use of all four limbs & torso and paraplegia is similar to the above, but, does not affect the arms. The loss is usually of

sensory and motor area, which means that both sensation and controls are lost.

We took some interviews and research of both quadriplegia and paraplegia injured people in India which gave us following outcomes:

1) One time rehabilitation and yearly expenses

Major financial expense of a person who suffers from SCI are as follows:

One-time expenses

| At the Time of Injury | Quadriplegia | Paraplegia |
|-----------------------|-----------------|-----------------|
| Operation | 2,00,000 | 1,00,000 |
| Hospitalisation | 3,00,000 | 2,00,000 |
| Rehabilitation | 2,00,000 | 1,00,000 |
| Wheelchair | 50,000 | 20,000 |
| Total | 7,50,000 | 4,20,000 |

Monthly expenses post SCI

| Per Month Expenses | Quadriplegia | Paraplegia |
|---|--------------|------------|
| Caretaker / Attendant | 15,000 | 10,000 |
| Treatment of infections, bedsores, etc and Medicines including diapers, etc | 10,000 | 7,000 |
| Transportation for education or job | 10,000 | 5,000 |
| Frequent urine infections | 10,000 | 5000 |

| | | |
|--|----------|----------|
| treatment, jelly, urine bags, diagnostic costs | | |
| Miscellaneous | 5,000 | 2,000 |
| Total | 55,000 | 29,000 |
| Total Yearly | 6,60,000 | 3,48,000 |

The expenses in four metro's are 30% higher than and other than metro and villages. Further, the above are just indicative and estimates.

2) Institutional REHAB vis –a- vis Home REHAB

At present, all developed countries have Institutional Rehabilitation centres. Europe, USA, Japan all have good centres. Once a patient is admitted the entire responsibility lies with centre. Daily food, hygiene, activities and other things are taken care of with other fellow SCI patients. A lot of these centres are funded by the government. Centres are built completely to accommodate wheelchairs, ramp based access and lifts.

Basically, the whole centre is PRO support of SCI affected persons.

In India, given the size of our population and the sheer number of SCI people, such institutions are extremely rare. Where these centres do exist, its soo expensive that hardly a handful of people can afford it. Thus in India largely the rehab is done mostly at home.

This causes numerous problems to SCI people like:

- *Tremendous burden on family to be prime care givers*
- *Movement of patient on everyday basis for intense therapies like physiotherapy, diagnostics centres etc*
- *Unavailability of public transport resulting on reliance to be made on private and expensive transports*

- ***Inaccessible lifts, ramps or washrooms at all the above mentioned places***
- ***Loss of jobs of both SCI and the prime care giver. This leads to serious financial stress***
- ***Physical and mental distress of the prime care giver***

3) Incomesources in Indiafor SCI person

80% of the person who has spinal cord injury are men. Further majority who suffer these are in the age bracket of 18 to 40 years. In mostcases ,the source of earnings before injury and after injury is not the same. It is usually due to lack of infrastructure and wheelchair accessible workplaces.

Past history reveals that an SCI person who lives in cities are able to work, and earn livelihood, in small cities. However, in villages majority do not have any means to earn and are dependent on savings or/and their family members. Basic expenses of treatment for bed sore, nutritious food, basic cushions are unaffordable by vast majority of SCI patients.

Blessing in Disguise

The digital and technology boom, current COVID scenario and the vast majority which is now working from home has opened up many opportunities for people suffering from SCI. The educated and persons with skills can get many jobs sitting from the comfort of their homes.

Research states 60% of people with SCI are non-earning in cities in India and the ratio is as high as 90% in villages and smaller towns.

4) Investments and savings

Investment pattern of SCI affected are in line with others as there are no customised products available in the Indian market. Majority of SCI and family members have fixed deposits in banks and some

investment in Mutual Funds. 90% of them do not take professional advice on investments and tax planning, resulting into some falling trap of ponzi schemes and losing even their capital. Others spend their savings to get quick recovery, like trying stem cells treatment etc, which later do not give them the desired result and result in loss of saving and capital

5) Tax concession to SCI patients by Government

Majority of medicines and supply of essentials like wheelchair, cushions, excersing machines etc are liable for Goods and Service Tax, which makes them costly and expensive for SCI people.

An Income Tax deduction upto Rs 1.25 Lakh can be availed from income, which is general for all category of disabilities in India. At present there are no specific tax deduction or concession for SCI

6) Pension by Government

Different state provide pension to person with disabilities. Pension ranges from Rs 1000/- to Rs 2500/- per month which is too low to even cover monthly medical cost of an SCI person, forget about other basic survival requirements for SCI

7) Mediclaim and Insurance

There are no rules or guidelines by IRDA (Insurance Regulator in India) for insurance or mediclaim requirement for SCI. There are process defined for person with disability, however it vague. 95% of the people do not get life insurance and mediclaim benefit after SCI even if they are willing too or afford the premium amount.

8) Loans for Education and Business

Government via various schemes provides loan in range of Rs 50k to 5 Lakhs at concessional rate for person with disabilities in India. However the process is very cumbersome and completely offline, which makes it difficult to avail the benefits.

9) Education level

75% of SCI finds difficult to communicate in English language and majority are comfortable in their first language or native language. If a person gets SCI at a young age or at school there are 50% chances of his or her completing graduation and if the said person is in small town or village the changes are less than 20%.

Majority of colleges have reservation and provide scholarship and fee concessions for SCI students. However, majority of these schools/colleges are not accessible and do not have wheelchair friendly toilets which makes it difficult for student to continue.

Solutions to make SCI Financially Independent

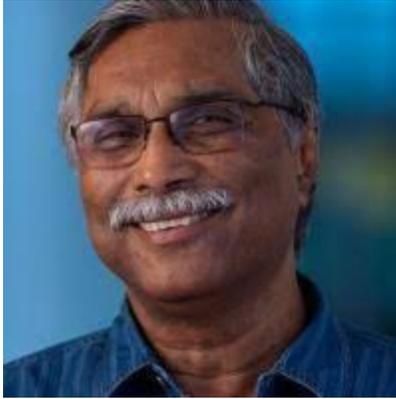
- *Let SCI family form a private trust with income up to Rs 6 Lakhs exempt from Income Tax***
- *Provide cash back of GST paid on wheelchair, disability aids and Medicine***
- *Give alternative investment option in lines of senior citizen saving scheme which offers higher rate of interest especially to SCI***
- *Separate guidelines needs to be drafted for Medical and life insurance for SCI***
- *Online Loan approval and disbursal for SCI form all public banks with standard SOP***
- *Link all scheme and benefits with disability card issued by central government to easy and quick access both online and offline.***
- *Dedicated help desk for mental health issues like depressions etc***
- *Customised curriculum by university for SCI***
- *Provide wheelchair accessbilerestrooms and toilets in schools and colleges and other commercial premises.***



Dr. Priyanka Rawal is a researcher and designer who has completed her Ph.D. in Design from IDC School of Design, Indian Institute of Technology Bombay. Her Ph.D. research was "Frameworks to Design and Deliver Educational Aids for Patients in Spinal Cord Injury Rehabilitation". She was awarded first prize in the category "Innovation in Spinal Cord Injury Care" at the International Spine and Spine Injuries Conference (ISSICON'20).

She has done her M.Des in Design from the Indian Institute of Information Technology, Design and Manufacturing, Jabalpur. She is currently working as a Lead Designer in Tata Elxsi, Bangalore.

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Dr. Gaur Gopal Ray joined the Industrial Design Centre (Now IDC School of Design), Indian Institute of Technology Bombay in the year 1979 (retired 2020). He was also the Head of the Department from June 2010 till September 2013. He was also attached as Honorary Professor to the Department of Biotechnology and Biomedical Engineering of the same institute and looked after the ergonomics programs for both. Prof. Ray did his M.Sc. in Physiology (1973), with specialisation in Ergonomics from the University of Calcutta and Ph.D. in Physiology in the area of Ergonomics, (1981) from the same University. In 1981 Prof. Ray received the UNDP Fellowship for working at different institutions abroad for a period of about 12 months. Prof. Ray was appointed as a visiting faculty of Tufts University, USA, and University of Lulea, Sweden. Prof. Ray is also visiting Faculty at several Universities in India.

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Understanding Indian Spinal Cord Injury Rehabilitation Ecosystem

Priyanka Rawal, Ph.D.; Prof. Gaur G. Ray, Ph.D.

Abstract:

This work, describes the study carried out with 82 SCI (Spinal Cord Injury) individuals throwing light on the flow of these individuals from accident location to their settlement in their final living setting. Further, it divides this flow into three settings, Initial Care, Rehabilitation and Post-Rehabilitation Settings. Finally, observations about the interactions of the SCI individuals with these settings are noted to uncover various pain points that can be utilised in redesigning SCI rehabilitation in India.

Keyword:

Spinal Cord Injury Rehabilitation, Spinal Cord Injury Ecosystem, Post-rehabilitation.

Article:

Experts around the world put much emphasis on rehabilitation to prevent complications associated with SCI (Spinal Cord Injury) and support an individual in having a fulfilling and productive life. WHO defines rehabilitation as a "set of measures that assist individuals in achieving and obtaining optimal functioning in interaction with their environments" (WHO, 2011). Byrnes and colleagues state that the goal of a rehabilitation program is to promote optimal recovery and to prepare patients for self-care management after discharge from the program (Byrnes, et al., 2012) (Williams, 2008).

In short, rehabilitation means preparing SCI individuals for their environments. This makes it essential to understand the environments and the interactions of SCI individuals with it. One significant aspect of doing so is to understand the flow of SCI individuals in the SCI ecosystem, i.e., the movement of individuals from the time of injury to entering back into the society. Understanding this flow is basically mapping the user journey, a user research process in design used to provide meaningful insights into a user's life in and around the rehabilitation phase, to find their pain points, needs, and motivators.

Given the importance of the rehabilitation process, presenting a comprehensive picture of the flow of Indian SCI individuals becomes significant in identifying their needs. Such needs and insights will provide valuable inputs for better patient-centred care.

This article covers the insights from a part of my doctoral research study that discusses the flow of SCI individuals. In addition, some significant insights developed from the study are also discussed.

To grasp the ground realities of the SCI ecosystem and gain insights into its basic layout in the Indian context, a study was conducted with post-rehabilitation community homes and at private residences of SCI individuals in the cities of Pune and Mumbai, India. Eighty-two SCI individuals agreed to face-to-face interviews. The participant cohort consisted of civilians and veterans with SCI and their caregivers wherever available.

Based on the responses from these participants, it was concluded that they followed one of the possible paths to their final living setting, as depicted in figure 1.

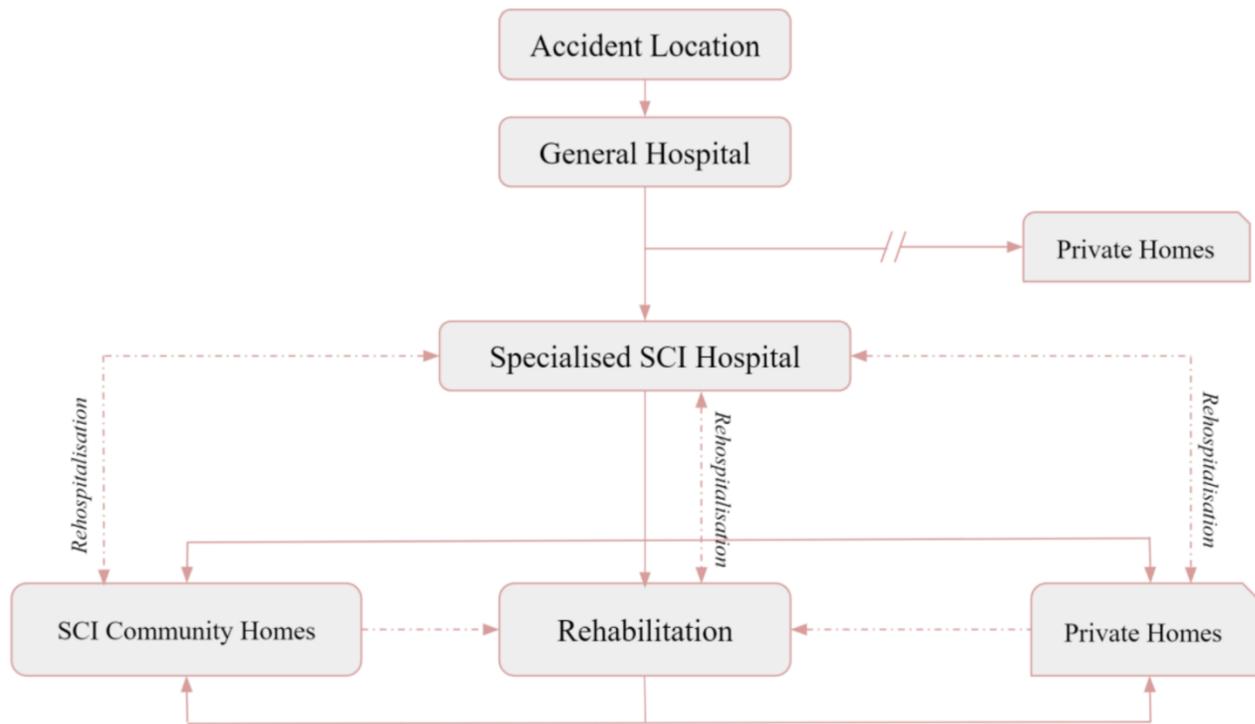


Figure 1: Format of the flow of SCI individuals within the SCI ecosystem

The post-SCI journey can be divided into three kinds of settings the SCI individuals interact with, based on the SCI individual flow diagram (figure 1). The earliest stage is the *initial care setting*, next is the *rehabilitation centre setting*, and the latest is the *post-rehabilitation community homes/private residence setting*. Subsequent subsections provide an insight into the status quo and functioning of the three settings.

I. Initial Care Setting

Initial Care setting is the time right after an individual suffers an SCI till the time they are in the care of the first medical facility (general or specialised hospital) they reach. Our research revealed that the initial contact point for most of the participants is a general hospital for this setting. Most of these hospitals were reported not to have

SCI specialists. Here, the SCI individuals are operated for their injury. In some cases (15%), SCI individuals were sent back to their homes right after, instead of a rehabilitation centre. 9% of the patients and families preferred to go home rather than joining a rehabilitation centre due to a lack of information or understanding of the significance of rehabilitation. Most of the rest were simply directed to the rehabilitation centres without informing them of the concept and the need for rehabilitation. This mostly led to the patients and caregivers believing that rehabilitation was meant for completely regaining their pre-injury body functionality.

Also, an Indian study reported that 63% of patients reached an SCI specialised institute only after 2-3 transfers to non-specialised facilities (Chhabra, Sharma, & Arora, 2018), leading to loss of crucial rehabilitation time. Further, no data is informing how many patients never reach an SCI specialised facility.

In our study, rehabilitation was completely absent in 12% of the participants. These participants were contacted at their private residences. These participants reported that they were not informed about the significance of rehabilitation or did not join rehabilitation due to financial constraints. Out of the participants who did reach a specialised SCI hospital, they were usually recommended to go to rehabilitation centres for further rehabilitation and adaptation to their altered lives after the injury. However, the participants reported that they were not informed about the concept and significance of rehabilitation.

In a nutshell, a lot of friction and information gaps were observed in the SCI individuals reaching the SCI rehabilitation centres. These

information gaps were seen to either completely prohibit SCI individuals from availing rehabilitation, or for the many who reached, precious early rehabilitation time was lost. Secondly, the individuals who were recommended to seek rehabilitation centres, were ill-informed about the concept of rehabilitation, raising false impressions and hopes.

Here, the significance of connecting general hospitals with specialised SCI hospitals and rehabilitation centres was realised. Further, the importance of dissemination of information to the patients about the concept and significance of rehabilitation at the early stages of their injury became apparent.

II. Rehabilitation Centres

This setting is the time spent by SCI individuals in the rehabilitation centre after initial care and before entering the final living setting.

Chhabra and colleagues say that rehabilitation care centres should include services like physiotherapy, occupational therapy, psychological management, sexuality and fertility management, assistive technology, wheelchair clinic, peer counselling, educational classes, vocational placements, pre-discharge home visit, and follow-up home care services (Chhabra, Sharma, & Arora, 2018).

Such comprehensive services were found missing in most rehabilitation centres during this study, also reported by another study (Chhabra & Arora, 2013). It was observed that the service structure, quality and expenses of the services at various rehabilitation centres vary due to many factors like its type, i.e., defence or civilian, duration of stay, range of services, equipment and specialisation of the rehabilitation team. Further, no

standardised rehabilitation structure or informational ecosystem was observed in these centres. Lastly, understaffing at the rehabilitation centres was also noted as a significant issue causing incomplete rehabilitation. All these factors were seen to affect SCI individuals' readiness for their lives post-rehabilitation in the final living setting.

III. Post-Rehabilitation Community

This setting comprises the Community Homes and Private Residences of the SCI individuals. Considering the needs of SCI individuals post-rehabilitation, Indian Central Government has developed community homes for defence veterans, including essential medical care, infrastructure support, assistance for daily activities, and vocational training, to provide quality life to these veterans. They have a choice to go to their private residences or remain at community homes established by the government. In addition, married veterans have a choice to live with their families in the family quarters inside the community campus. In our study, veterans from weaker financial backgrounds were observed to prefer remaining in community homes.

On the other hand, civilians go back to their private residences or civilian community homes after completing the rehabilitation program. However, most of the families of the SCI individuals from underprivileged backgrounds often cannot modify their private residences or cannot support the needs of the people with SCI. Hence, such SCI individuals end up transferring to the civilian SCI community homes wherever possible, which are mostly free of cost and are entirely run on funding through charitable donations, which could be quite erratic.

The civilian community homes that participated in this study were found quite lacking in the quality of their services and infrastructure and only supported male individuals. They were observed to have minimal staff. The only staff member with medical training was the Nurse; however, the Ward boys with no medical education were also seen to be responsible for medically demanding tasks. Since such community homes depend entirely on charity, many times, they can not provide even essential support.

Although after rehabilitation, the SCI individuals transfer to community homes or private residences, they visit rehabilitation centres or specialised SCI hospitals to get medical support if needed, such as for a secondary complication like Pressure Injury and Urinary Tract Infection.

Civilians were observed to have a tougher time adjusting to life post-rehabilitation due to the lack of infrastructural, financial, familial and emotional support. Hence, post-rehabilitation settings for civilians emerges as a potential action space for researchers and designers.

Concluding Thoughts:

Many pain points were uncovered in the three settings that SCI individuals interact within their post-SCI journeys.

In the conversation around redesigning rehabilitation in India, it is essential to recognise the need to develop a robust informational ecosystem that not only informs the SCI individuals and caregivers about rehabilitation tasks and processes but also about the intentions, expected outcomes and significance of these tasks. This contextualisation and dissemination of information should happen not only within the rehabilitation setting, but should begin in the

initial care setting and continue into the post-rehabilitation community setting.

Secondly, the general and specialised hospitals within the initial care settings must be connected to one another to enable quick transfer of patients as and when required.

Thirdly, it must be realised that not all SCI individuals return to their private residences post-rehabilitation, primarily due to the weak financial backgrounds and the feeling of being a burden on the family. Reimagined rehabilitation should cater for the needs of such SCI individuals and prepare them for a tougher life at sub-par civilian community homes.

Fourthly, a need is identified to reimagine the post-rehabilitation community homes, especially for civilian SCI individuals from financially challenged communities, to improve their current post-rehabilitation experience.

Lastly, the patient flow diagram is intended to give a holistic picture of the interaction of SCI individuals with the SCI ecosystem. It can be utilised as a map to identify the gaps in Indian SCI rehabilitation at various levels.

The researchers hope that this user research sheds light on some of the human issues within the current SCI ecosystem in the country and proves helpful for further investigations.

Acknowledgement:

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Dr Shivani Gupta founded AccessAbility, a cross-disability consultancy working for the inclusion of persons with disability. AccessAbility started as the first professional and the premier accessibility consultancy service in India with its motto "Access = Ability" that metamorphosed into a consultancy working toward inclusion and participation of persons with disabilities rather than only accessibility. Shivani founded AccessAbility after completing her M.Sc. in 'Inclusive Environments – Design and Management' from the University of Reading, UK. She is presently pursuing her PhD at the Maastricht University, Netherlands. Her thesis titled 'Invisible lives – Lives of persons with severe disabilities in rural India' highlights the lack of support services and accessibility in these areas. Shivani has worked on international projects with the Office of the United Nations High Commissioner for Human Rights, Centre for Inclusive Policy, International Disability Alliance (IDA), and CBM International and undertaken accessibility work in several countries, including Egypt, Jordan, Pakistan and Fiji. She has also co-authored publications about improving accessibility in physical environments,

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Low-income home in rural India: Challenges for persons with disabilities, especially persons with spinal cord injuries

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Introduction

According to the WHO, each year, there are up to five lac new persons with spinal cord injuries (SCI) globally¹. According to an international conference on spinal injury, there are fifteen thousand new cases of spinal injury added each year in India². There are multiple functional limitations associated with SCI, including mobility loss, loss in sensation, incontinence, renal problems, pressure sore, blood pressure, chronic pain, depression, to name a few¹. The mortality rate amongst persons with SCI is 2 to 5 times higher than those without SCI. Yet, SCI is clubbed under the locomotor disabilities category of the 21 types of disability under the Rights of Persons with Disabilities Act, 2016³ legislation. Thus the system doesn't fully recognise the additional functional limitations they encounter.

Rehabilitation, however, is the key for the better life outcomes of persons with SCI. As a part of rehabilitation, ensuring they return

¹ *Spinal cord injury: Key facts, WHO, 2013. <https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury>*

² *Chhabra, H.S & Mittal, R. (n.d.), Spinal cord injuries, Rehabilitation council of India. <http://www.rehabcouncil.nic.in/writereaddata/spinal.pdf>*

³ *The Rights of Persons with Disabilities Act, 2016, Department of Disability Affairs. <http://disabilityaffairs.gov.in/content/page/acts.php>*

to an accessible home is a precondition to enable some persons with spinal cord injuries (SCI) to live independently, requiring a lesser amount of support to undertake activities of daily living. The lack of home accessibility has often resulted in their inability to get out of home and amplifies the amount of support they require from their families. This impacts their autonomy and can result in a lowered self-esteem of the person with SCI due to over-dependence⁴. Yet home accessibility is not an aspect that has been much debated or demanded by the disability movement in India.

Home accessibility is essential not just for persons with disabilities but also for older persons, and both these groups benefit from inclusively designed infrastructure. Still, the focus of the disability sector has remained on the public environment accessibility with the prevalent debate around inclusion in their communities and not at home. However, the older persons movement is more focused on home accessibility, which has created a demand for assisted living centres that have mushroomed around the country.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) addresses home accessibility in article 19 on living independently and being included in the community. According to the convention, home accessibility is vital to enable persons with disabilities to live in a living arrangement of their choice.⁵ India has ratified the CRPD and has taken steps to harmonise its disability legislation, the Rights of Persons with Disabilities Act 2016. The act

⁴*Dimensions of invisibility: insights into the daily realities of persons with disabilities living in rural communities in India, Disability & Society, 2020 DOI: 10.1080/09687599.2020.1788509*

⁵*General Comment General comment No. 5 (2017) on living independently and being included in the community. Committee on the rights of persons with disabilities*

address homes from the perspective of the shared or public areas constructed with the house but does not explicitly address individual dwellings.

Homes, however, are spaces where we spend the maximum amount of time throughout our lives. Therefore, their accessibility has a significant role to play in the quality of life they live. The impact of inaccessible homes is most challenging for persons with disabilities living in low-income housing, whether in the urban slums or rural areas, mainly because houses here are very small congested spaces, with difficult access to sanitation facilities and water.

In this article, first, I provide more details on what accessible homes imply and the situation of these in India for persons with disabilities. Second I share a case study from the Anantapur District of Andhra Pradesh of rural homes and the challenges persons with disabilities, especially those with SCI, face due to the inaccessibility of these homes, finally provide recommendations for the way forward.

Home accessibility in India

Home accessibility implies structural alignment of the home infrastructure to include accessibility features such as a step-free entrance, wide doors, lowered height of electrical points, adequate manoeuvring space, a wide enough bathroom to accommodate a wheelchair user, and so on. However, since families may not have a person with disabilities requiring accessibility, the demand for accessibility features may not be included from the beginning of the project. As a result, if accessibility is retrofitted in these homes later in life, as residents grow older, or anyone suffers a temporary

disability, experience pregnancy and have small children, it can be extremely expensive or even impossible to do at times.⁶

In India, personal spaces are not a part of the building bylaws, and individual homes are exempt from complying with accessibility in these bylaws⁷. Therefore, the government has no mechanism to influence the accessibility of personal homes. The government, however, does affect the design of houses built in urban areas or funded by them in rural areas. However, concerning persons with disabilities, their attention is more on the reservation of housing for persons with disabilities⁸. Therefore, there are inadequate efforts to include accessibility in the design of such projects.

Furthermore, the accessibility standards for physical infrastructure in India focuses on public spaces in urban areas and do not address the accessibility of personal spaces such as homes. As a result, there is no appropriate guidance to make homes accessible, particularly in rural areas. On the other hand, some countries have standards and guidelines for making the house more adaptable. Such design considerations make the cost of retrofitting accessibility features later in life is possible without much investment. For instance, in the UK, some councils have adopted the 'lifetime home' guidelines.⁹ that provide a few basic infrastructure guidelines for inclusion in the house design from the very beginning. The concept of lifetime homes considers that homes should be adaptable without much extra costs to meet their requirements

⁶ See *high cost of retrofitting*, page 10 *Inclusion imperative: towards disability-inclusive and accessible urban development*, CBM & World Enabled.

⁷ *Model Building By-Laws, 2016*, Town and country planning organisation, Ministry of urban planning. <http://mohua.gov.in/upload/uploadfiles/files/MBBL.pdf>

⁸ See details of Delhi Development Authority Housing scheme brochure, 2021 (page 4)

https://eservices.dda.org.in/public/uploads/brochure/YaxFa_1609401011.pdf

⁹*Lifetime Home Standards: 16 point criteria checklist*, (2010) Habinteg

through the lifecycle of the resident as young people, middle-aged people, have children, become old with geriatric disabilities etc.

While accessible Housing is an issue for all persons with disabilities, it is notably more challenging for persons with disabilities in rural India. Housing in rural India is generally low-income housing funded and constructed by local development organisations or more likely built under the Pradhan Mantri Gramin Awas Yojana (Prime Minister's Rural Housing Scheme) (PMAY-G). These houses may have different design in different. The PMAY-G scheme guidelines focus on providing a 5% reservation for persons with disabilities.¹⁰ There isn't adequate attention to accessibility aspects of homes.

The design of houses built under the scheme varies from region to region in different parts of the country depending upon weather, geographical location, local construction material, etc. The government offers the basic design, and accessibility is not a part of it. Moreover, according to the scheme, the minimum size of the house must be not less than 25 square feet area with a clean cooking area.¹¹ That is difficult to make accessible, especially for persons with mobility impairments.

In the next section of this article, we describe the design of the typical low-income home in the Anantapur district of Andhra Pradesh.

Case study: Typical house in Anantapur District and its impact on persons with SCI

¹⁰Amendments in the framework for implementation of PMAY-G, 2018, Ministry of Rural Development. http://rdd.bih.nic.in/Acts/IAY_G_07_03_18.pdf

¹¹Pradhan Mantri Awas Yojana – Gramin (PMAY-G), Union Ministry of Rural Development.

Houses in Anantapur are primarily funded by the government PMAY-G scheme; however, in addition, a non-governmental developmental organisation working in the area¹²also supports the villagers to build housing. Houses built here have a basic design with one room, kitchen, a veranda in front of the house and a toilet that has a separate entrance.

All houses here have a plinth with a step or two at the entrance. Some persons with disabilities have managed to get a ramp made with the support of the NGO's working in the community. However, those who do not have a ramp (constituting most people) remain confined to their homes, rarely going out. Such persons with disabilities often do not see the benefit of having a wheelchair used only outdoors.



Picture1 All houses are built on a plinth a foot or two high.

Living area

The living area for rural people includes the veranda outside the house and the one-room inside the house.

¹² See Rural Development Trust; [Habitat](#)

The veranda is the common area where residents spend their day whenever they are at home, often with visitors. For persons with disabilities, this constitutes a considerable amount of time. They rarely go out of the house, often because of a lack of mobility device or someone to support them to go out or inaccessibility of the public environment.



Picture2 A veranda at the entrance common sitting place



Picture3All doors, especially the entrance door, have a threshold.

Anantapur is a dry area and home for snakes, lizards and scorpions and other insects and small creatures that can enter the house. Therefore, all doors in the house have thresholds. Thresholds are also a culturally important feature of the house here and are attached to religious beliefs. Often there are religious markings on the threshold. While thresholds seem essential to have, especially at the entrance, these restrict persons with disabilities.

There is usually one room used as the living room by all. The living room typically has slab shelves on one side to store various things. Additionally, depending on their requirements, people may keep wardrobes, bed, chairs, trunks, and all other odds and ends in this room. Therefore, how crowded or full the living room is, depends a bit on the size of the family. The living room may be packed with no space to manoeuvre if families are large or have limited things and adequate space to move around if there is only one resident.

The small living area is a challenge specifically due to this. First, most persons with spinal cord injury may not crawl like many other persons with locomotor disabilities and can only bottom shuffling or need to be carried. Bottom shuffling may be hazardous for them since they are already at risk of getting pressure sores. Second, having only one small room can compromise the privacy they require to address their bladder and bowel management requirements. Women with SCI are disproportionately impacted due to lack of privacy to manage their incontinence and menstrual needs.



Picture 4 living room of a family of three members



5 Living room of a single resident

In rural areas, it is common practice to undertake all activities like eating, cooking, sleeping on the floor. However, some persons with disabilities use a folding cot to sleep. Since the floor level is the level for activities, disabled persons are usually required to sit on the floor.



Picture 6 Transferring from floor level to the cot is difficult for some and impossible for others.

There are critical challenges this puts forth specifically for persons with SCI. First, single persons with SCI are prone to pressure sores, and rehabilitation experts prescribe a cushion to be used on a wheelchair by them. However, in rural areas, such requirements are ignored, and they sit on a concrete or stone floor for long hours, putting them at a higher risk of getting pressure sores. Second, only a handful of persons with SCI may transfer onto a cot or a wheelchair without receiving a significant amount of support. Thus it becomes difficult in the long term for the family as they begin to experience back pain and other health issues. Third, even for the person with disabilities, it is dangerous and makes them not get into the wheelchair as often they may like to not wanting to trouble their family members.



Picture 7 Being physically lifted from floor level to the wheelchair increases health risks for both the person with disabilities and their family.

Kitchen and bathroom

I club these two aspects in this case study as both of these require access to water. Unfortunately, rural areas most often lack access to a plumbing water supply. Therefore, water is gathered from the common water supply areas such as a hand pump, well, a water tank etc., in the village and stored in the bathroom and the kitchen for use, making it challenging for persons with disabilities on many

fronts. First, reaching the common water point can be difficult due to untarred pathways; second, the water point may not be accessible. Finally, carrying water back home from the water point may not be possible without some assistive device. Therefore, due to not having access to piped water, persons with disabilities become more dependent on their family members.

For persons with SCI, lack of access to adequate water results in added challenges for them and their families because of the incontinence they experience. For example, in addition to accessing water for toileting and bathing, there may be added water requirement to wash clothes and self more regularly. Moreover, clean intermittent catheterisation that they may be practising for bladder management requires access to clean water to perform.

In addition to access to water, there are other barriers they face, especially while using the bathroom. Toilet in the houses are located away from the main home and has a separate entrance. The toilet entrance is not too wide and has a threshold. The bathroom area is small without much manoeuvring space. The toilet is most likely Indian style that requires squatting on the ground.



Picture 8 Toilets are usually Indian style and relatively small in size. This family has, however, put a water tank with piped water connection.

However, persons with disabilities and their families recognise the importance of an accessible toilet. As a result, some people have changed to western-style commode to improve accessibility, often from their funds.



Picture 9 Some persons with disabilities have retrofitted western water closets. A water storage tank is constructed behind the water closet.

Many families continue with open defecation that again puts the persons with disabilities at a disadvantage and increases the support they require. For persons with SCI, open defecation poses several challenges. First, the route to getting to the fields on the wheelchair is inaccessible. Second, their inability to squat on the floor may make it difficult for them and add the support they require from their family members.

Cooking is an activity undertaken only by women. Therefore, the accessibility of the kitchen is essential for women with disabilities. Kitchens are usually constructed for cooking by a standing person. In such instances, the reach of the person with disabilities may be difficult. Some women with disabilities can manage to work in the kitchen sitting on a chair.



Picture 10 Some women with disabilities sit on a regular plastic chair and work in the kitchen

Cooking at ground level is also a common practice in rural areas. Women with disabilities who can crawl find such an arrangement suitable. However, alternate solutions, including floor level mobility devices, may be required for women with SCI.



Picture 11 Cooking at ground level is common for women with disabilities who can crawl.

To summarise, low-income homes in rural India are not suitable for persons with disabilities especially, those with SCI who face additional challenges due to the home design. The built-up area of such a home is 25 square feet according to the PMAY-G scheme, which is too tiny for designing an accessible home. Moreover, it denies them the right to privacy for persons with SCI, making it extremely difficult for them to function and remain healthy.

The geographical location and the regional customs of people play an essential role in how homes are designed. However, altering design based on such perceptions may be difficult. For instance, all activities in rural areas are generally undertaken at the floor level, making it difficult for the families and for persons with disabilities who bottom shuffle or need to be lifted to move. In the case of persons with SCI, it increases the risk of their getting pressure sores. Moreover, transferring to a wheelchair or a cot from floor level is also more challenging for them, requiring additional support from their families.

The lack of piped water in rural homes significantly increases the amount of support that persons with disabilities require from their family. Thus, discriminately impacts persons with SCI for whom access to water is critical for managing their incontinence. Furthermore, lack of access to water also reduces the chances of persons with disabilities contributing to family activities such as washing clothes or utensils. However, few families with a disabled family member have made adaptations, especially in the toilet, attaching a pipe to their water tank or building a water storage space in the bathroom.

Finally, open defecation is still prevalent in rural areas. While it is difficult for all persons with disabilities, it is notably more difficult

for persons with SCI who may find it difficult to reach the fields and squat.

Way Forward

About seventy per cent of persons with disabilities in India live in rural parts of the country. Living in rural India is marked by a shortage of basic services and facilities and a lack of livelihood opportunities in general for all. Persons with disabilities are disproportionately impacted by this, mainly because not only do they encounter the general scarcity of options, but additionally, they are entirely dependent on their families due to lack of accessibility and other support services. Therefore, the challenges for persons with SCI are multiplied, as discussed in the case study.

Lack of accessible homes for persons with SCI infringes on several human rights. First, it denies them to right to have an accessible home as is mandated by the CRPD. Second, their right to privacy is compromised since they do not have privacy to manage their bladder and bowel without disturbing the family. Third, their right to mobility within their homes is denied that forces them to sit long hours on the hard floor, bottom shuffle for mobility, putting them at a higher risk of getting pressure sores, thus impacting their right to life and good health itself.

Moreover, all persons with disabilities in rural areas depend on their families to support them because of the inaccessibility of homes, making it difficult to do activities themselves. However, for persons with SCI, the inaccessible homes make them more dependent on their families, which increases the stress of their family caregiving.

Therefore, it is crucial and urgent to relook at the low-income housing system of our country. Furthermore, as the rural areas in

the country proceed towards prosperity, there is a need to address disability-specific issues such as the accessibility of homes simultaneously.

The minimum house size of 25 square feet under the PMAY-G is indeed too small to design a house that is accessible. Therefore, not taking into consideration the requirements of persons with disabilities. Therefore, there is a need to address this first point of inaccessibility and increase the minimum space allocation per house to allow in-home accessibility for all persons with disabilities, specifically considering the needs of persons with SCI.

Simultaneously, however, it is vital to consider functioning from the floor level, which is a common socio-cultural practice in rural areas. Thus, making a wheelchair an unsuitable device for use within the home. Therefore, the suitability of a wheelchair as a mobility device for indoor mobility of persons with disabilities, especially for persons with SCI in rural areas, maybe reevaluated. Gupta, Meershoek and Witte, (2019)¹³ identifying this issue suggest a need for further research in suitable indoor mobility devices for low-income homes in rural areas.

Furthermore, home accessibility as a topic needs further deliberations within the disability movement to create an actual demand. The government is obliged to draft legislative policies around it.

Some crucial aspects that need to be addressed are:

¹³*Barriers to using mobility devices in rural homes in low resource settings: development of a practical assessment tool for local fieldworkers. Edited by Layton, N. & Borg, J. [Global Perspectives on Assistive Technology](#) – Proceedings of the GReAT consultation 2019. WHO Headquarters: Geneva, Switzerland. 23-24 August 2019, (Pg. 270-284)*

- ***Providing accessibility of individual homes as a criterion to be included in all policies and schemes related to housing to be adopted.***
- ***Research and development of standards for accessible homes for low-income and middle and upper-income housing are universally applicable across the country. Such criteria may like Lifetime Homes, make housing more adaptable to become accessible when required during the lifecycle.***
- ***Awareness-raising of persons with disabilities, their families, and the community at large about the benefits and needs of universally designed homes that can account for the life cycle changes residents experience. Simple leaflets with ideas and other information may be developed and disseminated.***
- ***Capacity building of professional such as architects, interior designers, occupational therapists etc., in designing accessible homes.***
- ***Research and development for assistive devices for independent living specifically from the point of view of persons with SCI.***
- ***Creation of a government scheme that provides financial support and technical advice to persons with disabilities, making it possible for them to modify their homes to meet their requirements.***



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THE MIND AND BODY CONNECTION IN SPINAL CORD INJURY

Dr. Khushboo Gadda

Abstract: The mind and body connection is a connection between what we think and what appears physically in our body. This mind and body connection can influence our physical health to a great extent and help in the recovery process. In this article I have touched upon the neuroscientific theory behind this terminology and given practical pointers at the end for individuals with Spinal Cord Injury who can use the mind- body connection to optimize their physical recovery.

"Do you remember the first day of your job? Do you remember your accident when you had the spinal cord injury or the hospitalization after that? The first thing you will remember is how you FELT when you experienced it. It's all about EMOTIONS."

Morris E. Goodman (born November 9, 1945) is an American motivational speaker and author. Morris was never a motivational speaker from the first. He in fact had his own insurance company. In the year 1981, he got his pilot license and purchased his own airplane and in march 1981, while attempting to land he met with a crash which fractured his C1 and C2 vertebrae and made him totally paralyzed. In fact, he was not even able to breathe let alone move a single muscle in the entire body.

When he was in the hospital, the doctors had confirmed the news, that without a ventilator and a breathing support machine, he will

never be able to breathe on his own. He was there throughout this news and heard every single word. If it was someone else, they would have given up on it and left it to fate. But he was determined to not be that person. He knew that even though his BODY is not with him for now, he still has his MIND and that was enough for him. He strongly visualized himself walking out of that hospital and in a matter of 6 months with intensive treatment, physical, speech and occupational therapy, he was able to WALK out of there. He is called "THE MIRACLE MAN" because even though it was predicted for him that he would not be able to even breathe, let alone walk, he did what someone else in his place would have just given up.

I came across Morris Goodman's story when I was reading *The Secret* by Rhonda Byrne. I was really touched by this story and decided to get into the depth of the Mind- Body connection. So I picked up the next book on this topic which was *Becoming Supernatural* by Dr. Joe Dispenza. So much of his work on the mind-body connection comes from the fact that he himself, Dr. Joe, had met with an accident which had given him a spinal cord injury with 6 vertebrae fractured. He was told by the doctors that he will be required to place a steel rod in his spine to align his vertebrae and he might be paralyzed for the rest of his life. But since he is a neuroscientist himself, he decided not to let this decide the prognosis. He started mentally imagining and healing his vertebrae through his mind. And voila! In a matter of a few months he was able to walk out of there with his recovery done.

Now, earlier, I might have scoffed at such stories and would have thought that this is just a piece of luck and maybe some good western medicine, but after a few years of seeing neurologically

impaired patients and seeing the results of how a strong mind can do wonders on the physical body, it led me to change my mind. Since I am a science student, I can only understand things in the way of scientific research and actual evidence. So, after a year of reading and learning about the mind-body connection “scientifically” and biologically, here I am presenting my knowledge on this subject.

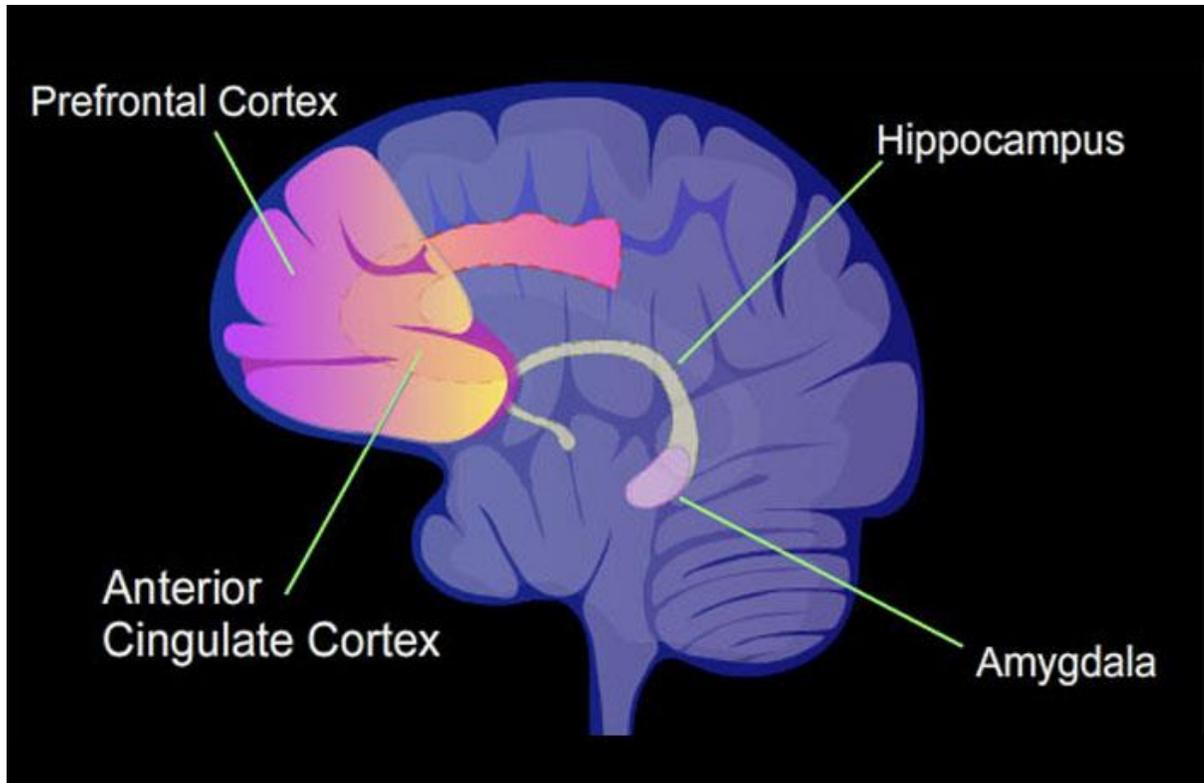
A. Where do thoughts come from?



When homo sapiens (humans) evolved from apes millions of years ago, we had an unusually large brain size. This was because our prefrontal cortex (the part of our brain behind the forehead) had evolved so well from our predecessors. The prefrontal cortex is mainly responsible for our thinking process, decision making power and storage of memories. Whenever we are facing a situation, our prefrontal cortex is able to immediately recollect something similar which must have happened in the past and is able to help us decide what we should do in a particular situation. The ability of the prefrontal cortex to think is so good that even when we are doing nothing, it is able to still generate thousands of thoughts. I am using my prefrontal cortex currently to write this article and am able to

generate words. Now this PFC is both a boon to us AND a curse. Let me explain how.

B. Emotions and memories

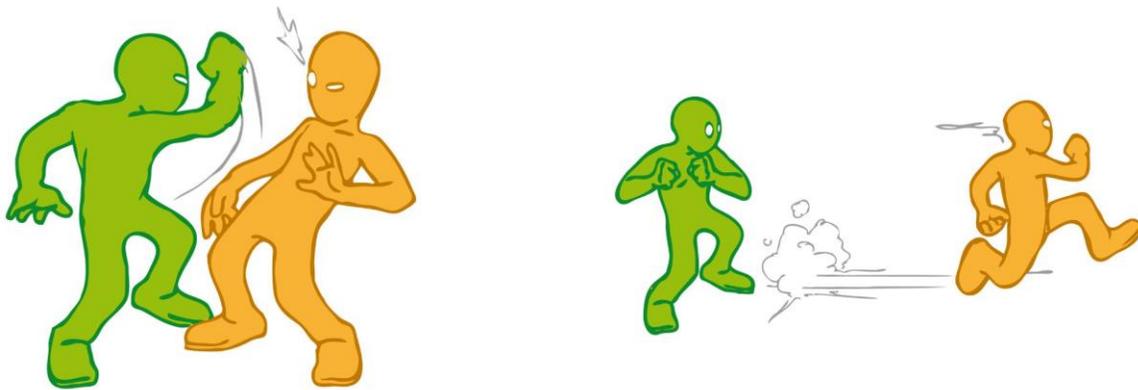


The emotion centre of our brain lies in the hippocampus and amygdala- both are deep inside the brain. This centre is also found in animals. This is mainly responsible for generating emotions like happy, sad, angry, jealousy etc. Now, the link between the prefrontal cortex and the amygdala is very strong. Whenever we are facing a situation, the first thing is that our sensory system- eyes, ears, nose, smell, taste and touch is recording and capturing that information. The information is then sent to our prefrontal cortex which stores it as a memory, but not before it associates it with a strong emotion through the emotional centre of our brain. Think of a random memory, you will find that the only way you have remembered that

memory is because you have associated it so strongly with an emotion.

Do you remember the first day of your job? Do you remember your accident when you had the spinal cord injury or the hospitalization after that? The first thing you will remember is how you FELT when you experienced it. It's all about EMOTIONS.

C. Fight or Flight Response



When our ancestors used to stay in the forest, they were sometimes faced with dangers- by the attack of a wild animal. Now their body would help them to react to it by the fight or flight response. What does this response do?

Huge amounts of adrenaline and cortisol would gush from their brain to their entire body and this would help them to generate enough power and force to either FIGHT that animal or RUN from the animal. This would help them to survive in the forest. Once the danger was gone, the adrenaline and cortisol levels in the body would go down and immediately their body and mind would be calm.

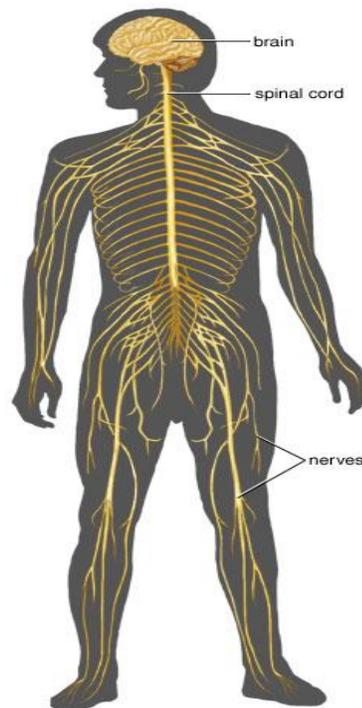
Now, in the modern world, due to so many stresses from our environment- stress about our job, about our family, about our body,

about what will our future hold and the recovery process of our injury, about the stress itself, this has led to the adrenaline and cortisol hormones being released in our body in large amounts ALL THE TIME.

Is this good for us?

We are constantly living in a survival mode. Our prefrontal cortex keeps having negative thoughts and emotions and very few positive thoughts. This is why we are always tired, low on energy, drained out and fall sick easily.

D. Neural Networks



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Imagine that our body is like a building and the electricity supply of our body are the neurons going from our brain to our spinal cord and to the rest of the body parts and back to our brain. This is why, whatever thoughts we have are all translated into physical parts of our body. There is a hormone called serotonin which gets released in our brain whenever we do physical activity or exercise. After moving

our body and physically releasing the serotonin hormone, our mood becomes better, our mind becomes sharper and we are able to concentrate better.

E. The immune system

In the past year or so the immune system of our body has received a lot of attention due to the covid infection. They say that if you are mentally strong, your immune system will work well and it will be able to fight the infection. How does that work?

The IgA antibodies are particular ones which are released from our immune system when there is an infection. We need a large supply of IgA antibodies to fight the virus. Our brain has tremendous control over the production of IgAs. When we are thinking positive or negative thoughts, it gets circulated in our entire body through neural connections and blood supply. This controls each and every cell in our body. The chemistry of cells in our body can be altered by our mental strength alone and there have been multiple scientific studies done to back this statement. This also influences the production of the antibodies.

This is the reason why, recovery process, be it from an infection or from an accident or spinal cord injury, can be influenced tremendously by our mind and thoughts alone.

F. What can we change to influence and optimize our mind- body connection?

I am about to give a few practical tips on how individuals with spinal cord injury or anyone for that matter can learn to work on their mind-body connection to facilitate their recovery, enhance their connection with their body and how they can feel good about their own body. Keep in mind that this can require intensive work and

regular habitual practice to really become better at it but the results can be extraordinary. More than anything, the reason why I love this process is because through my own experience of treating neurologically impaired patients, I have been able to achieve a lot of goals which I set for them. Let's go through the pointers.

1. Share energy and thoughts with someone who is at the same level as you are.

Atoms that vibrate at the same energy and frequency eventually go on to form a molecule which is chemically bonded very strongly. In a similar way, try to bond with people who are at the same level of energy and frequency as you are. This can be by going online and finding support groups that are formed by people with spinal cord injury, Nina Foundation is doing an excellent job at that, by peer interaction and support. Try to avoid people who are pulling your energy down.

2. Protect your energy and space

When we wake up in the morning, we are recharged and have a fixed energy level. When we interact with people throughout the day or work on projects that require our mental and physical effort, we are utilizing energy from our supply. If you are particularly feeling drained out in the middle of the day, try to protect your energy and speak to a smaller number of people if it is not necessary. Make things easy for you. This again helps a lot in the recovery process. Even if you do feel that it is unavoidable, come to my 3rd pointer.

3. Have a morning and a night routine

As I said, we have a fixed supply of energy when we wake up in the morning. Technology has done a fabulous job of draining us and taking away that energy. So everyday in the morning make it a point not to check your phone for at least 1 hour after waking up. Try to

practice gratitude, mindfulness and meditation for that 1 hour. Similarly, before sleeping, since we are constantly loaded with distractions throughout the day, our mind is in a constant state of activation. So before you sleep, practice a night routine, which can include reading or listening to spiritual things so that it can help your mind to relax.

4. Practice essentialism

How often does it happen that we schedule too many things in a day? Practice NOT doing that. Schedule only one thing throughout the day which is the most important and work on it the most. This again helps in having your mind concentrate on just one task.

5. Be mindful

Whenever you are exercising or undergoing your physical therapy session, out of that 1 hour of therapy, for how long do you stay in the moment? Answers would be hardly 15 minutes in total. Our mind is constantly thinking thoughts and getting diverted all the time. Practice staying in the moment and use all your 5 senses- eyes, ears, nose, taste and touch. Be mindful of what you are doing in your physical therapy sessions and your recovery process will be that much faster.

6. Practice mental imagery and mental rehearsal

Even when you are not actually doing the movement or exercise, when you are sitting or lying down, try to mentally picture yourself doing it and rehearsing the exact movement. Concentrate on it completely. If your goal is to achieve walking, imagine yourself walking and actually doing it. Mental imagery is a very powerful process and it can manifest in your physical body eventually.

7. Meditation

Remove one hour from the day and just sit by closing your eyes and meditating. Observe your breath and the different sensations running through your body. Concentrate on your heart centre and the energy inside your body.

8. Sleep well

This is the most powerful and underrated weapon that a person can use to make their physical health better. Sleep for 8- 10 hours on any given day is known to enable tissue healing and help in the recovery process. Even if you are not able to achieve a deep sleep, try to close your eyes and just lie down completely relaxed.

Above are the pointers which I suggest to every patient and this has helped their recovery.

In conclusion I would like to say that even though the cards have been dealt differently to certain individuals, what they can make of it and how they play their game depends a lot upon them. You can practice and learn how to use your mind-body connection to help you in your process of recovery.



Letter from the Chairman's Desk By Sunil Bhatia PhD

My maternal grandfather visited our place and was facing a medical issue with teeth and the dentist advised for extraction of the tooth. His tooth was extracted and the pain was so great he was unable to eat his meal. My mother offered crushed hot cooked bread in the bowl after adding clarified butter along with sugar and without much difficulty, he swallowed his food. The next day my mother prepared liquid food and he drank without experiencing pain. I was watching my mother who was very caring and concern for others and I believe these two ingredients are basic for creativity. The way she was caring for her father, realized there is no substitute for human assistance, do not know at what stage of life it is needed, the best assistive device is human and all other assistive devices are no match. Designers are designing the assistive device in absence of human around the suffering person. We should learn from the mother how she is assisting everyone and wish to keep everyone in the family and happy surrounding and will not allow to slightest such things that may turn anyone temporarily differently-abled person by losing normal expected behaviour. Whenever she realized her cooked food is not up to her set standard in mind or expectation of others she covers up by adding extra clarified butter over food that smell enhances the mood and does not behave in other ways

and remain not normal but delighted . That adding a clarified butter for mood enhancer was nothing but assistive technology. Disturbance in physical and mental health makes a person differently-abled person and need the support of assistive technology for getting back to normal. Mother are the best designer of assistive technology and how beautifully turned the crying child to normal either by distraction or emotional support or does what he likes or help in getting what he wishes. The idea of living in social structure real foundation has come to the existence because of by-product of assistive technology.

My parents are no more but their impression will wipe out from my mind with my death. One day I noticed whenever my mother flattens the bread with a rolling pin uses a spread of dry flour and as she satisfied with rolled bread she holds that in her hand and throw it in the air from one hand to another. Out of curiosity, I asked her why do you do this exercise not with every flattened bread but with some exception. She gave the answer that was beyond my imagination by striking with hand in holding bread in the air for removal of extra dry flour from both side of the surface of flattening bread otherwise it will not cook evenly and wherever dry flour that area will be cooked fast and rest will not get proper time for cooking. Another reason is extra dry flour will stick with fingers while breaking the bread. I am alone after the death of my parents and prefer to cook myself and feel I do not need any assistance . One day I found cooking oil is over and thought to make the vegetable with gravy. I was shocked with the prepared vegetables without cooking oil and found my spices are not evenly spread and taste is not what with cooking medium oil. That very moment I realized the wisdom of our ancestors who took assistive technology to that level where the

modern person cannot think and use of fat of any kind help the proper even cooking and flavour of spices evenly coated over vegetables. Watering is needed as food for the plant but using an artificial device with a shower for making the experience as a monsoon that delight, is unimaginable assistive technology for proper growth.

Why does someone need assistive technology? If someone is temporary or permanently injured and wish to be independent and does not wish to trouble other humans around with seeking less support for getting back to normal life. It is the degree of dependency for making independent of suffering person helps in designing the need of assistive tools. In primitive times, someone might have encountered such a situation and fellow human offered his shoulder for allowing hold by hand around his neck for the injured person for reaching his the destination was the first assistive device and later wish of person for independence thought of holding the strong stick for the walk was first artificial the external assistive device that has replaced human role and designed on ability for overcoming his disability. When injuries were deep and his able parts were not giving proper support to overcome for movement and should be transported for his safety then the idea of assistive technology of ambulance surfaced and first might be carrying on shoulder or back or hold as small child carry by mother on side of the hip bone later thought of carrying by tying with strong stick and carry on the shoulder by two or more and the latest version was sedan chair and the idea of the automobile changed the face of ambulance and it is now not only transport but provide assistance for life saving technology for patients.

Human five organs are assisting in running our body smooth and safe and any deficiency creates imbalance and life turns tough. Weak eyesight forced for designing assistive tool of specs, hard hearing for hearing aid and when correction for getting back to normal life is the reason of the birth of medical science. Initially cure was possible with natural product later with organic elements and ultimately surgery came into existence. Smile and cry is another assistive tool that helps in the progress of humans. The idea of walking, swimming is the first step when primitive people learnt the art of using different body parts for overcoming the crisis. They used strong stick when injured user wish to be independent of human assistance for walking. It might be possible it was used as killing animals by beating and the same help in walking the injured person.

Helping for loved ones or fellow human is not limited to human but I noticed in dog or cat hold their puppy in their mouth for transportation in a safe place and they are not using artificial means but what their body parts can do they are offering for assistance. After the birth of baby elephant or horse, mother kick the child that helps in standing on their own feet. Even some bird makes the nest for hatching the eggs and beyond the reach for enemies not to be prey at the safest place at the height of the cliff jumps from a very high cliff and chickens follow the mother of jumping and in this process, they learn the art of saving life by flying.

Primitive people realized that after defecating and washing the private parts chances of getting infected with the other body parts through hands was very high. There was one way for using hands by holding some material to get rid of stick material from orifice but cleaning with water replaced all other method and later hand was

washed with water and as knowledge improved by adding something that can disinfect properly. How long people should not touch other parts for minimizing infection was a great issue and they devised psychological design by assistive technology of using soil or mud or leaf for dry or wet washing of hands that allows for move on next work . It is the washing of hand that psychological assisted in move to the next job. It is still visible in many cultures. A handful of water for cleaning the mouth after coming out of the toilet is another habit that is primitive and it is our psychological design made feel clean .

Primitive people have used live animals as assistive device and used leeches for curing for sucking and taking out pus from the cyst and other side used poisonous animal as assistive tools for killing others. They used a long rope for tightly tying near the snake bite for controlling the blood not to allow for the spread of poison in the body and cut the area with a sharp knife for oozing out poisonous blood of that area for saving a life. When fire management was unknown it was not assisting in the progress of humans but gradually primitive people learnt the art and used it for safety, light and cooking medium and this management has changed the human face and establish it as superior among all living beings. Even in agriculture, a farmer fixes the stick with a tender plant for exposing proper sunlight and as it stands its own in a few days then removes that tied stick. Domestic animals and the design of various assistive tools have allowed people to grow beyond the physical capacity of man.

There are various form of assistive technology surfaced for human progress and the idea of designing clothes was the result that not only protected from vagaries of weather but protected private parts

that has sex hormones from attraction of others , later armour for the soldier and fire-resistant dress for fire personal is ultimate assistive technology tools, curtains are another example that allows the choice of light in the house.

Modern society feels money power and will get all the assistance but forget the emotional element that is real power in assistive technology. Institutionalization of social structure will not serve the purpose unless and until the emotional quotient is missing. Our society has evolved because of emotional elements and assisting others for progress was the reason for the birth of social life. Modern people are moving away from emotion and turning to technology for support but there is no substitute for the replacement of human. Covering up the low content of emotional factor modern designing institutes for taking care of differently-able people are emphasizing more on devices dependent systems . Earlier it was the responsibility of the family to look after differently-abled person and enjoys the same respect in the hierarchy of the family. This arrangement was due to our social structure and values inbuilt in it where emotion factor was high and survive with local design devices. If anyone can afford the assistive devices and not willing specialized institutes for taking care but consultation proper guidance is no issue is the best arrangement over available options. The family arrangement is based on love and dedication where institutes can have dedicated staff but that level of emotion is missing what a family provide for support.

There are various ways when our ancestors have designed assistive tools. One how to complete the job in hand with ease and another is to meet the challenges in completing. Sailor uses pedal as assistive technology for reaching the desired destination. Even use the

stars and moon position of the sky as a navigation tool for a long journey. The kitchen needs cutting tools and utensils. I consider the first manmade design of cutting tools of the axe as the greatest revolutionary first step for the progress of humanity. Agriculture also witnesses various assistive tools. The stem would have stem if a man would have not designed arrow as assistive tools for killing prey for the foods as well for safety not to be prey for the enemy.

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With Regards

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July 2021 Vol-16 No-7



Raja Schaar

Raja Schaar, IDSA is Program Director and Assistant Professor of Product Design at Drexel University's Antoinette Westphal College of Media Arts and Design. She also co-chairs IDSA's Diversity, Equity, and Inclusion Council. She is an industrial designer with an extensive background in museum exhibit design who is passionate about ways design can make positive impact

intersections with health, the environment, and education.

Raja's interdisciplinary research focuses on addressing inequities in maternal health; methods for engaging black girls and underrepresented minorities in STEM/STEAM through design and

technology; innovation and entrepreneurship education; and biologically-inspired design and sustainability.

Raja currently co-leads two collaborative research projects. She works with faculty from Drexel's College of Nursing and Design and Merchandising Programs the development of low-cost wearables for maternal health. She is co-PI on an interdisciplinary research project funded by the US Department of Education Promise Neighborhood Grant entitled "Black Girls STEAMing through Dance," where she works with students and faculty from Drexel's departments of Computing and Informatics, Dance, and the School of Education to uncover STEAM identities, literacies, and self-concept in African American girls through the development of wearable technology. Raja is also PI on a Venture Well Faculty Grant that connects Product Design, Biomedical Engineering, and Entrepreneurship to examine the role of clinical immersion on product innovation on campus.

As an educator, Raja works to infuse Drexel's Product Design Curriculum with society-centered design principles that address impactful, real-world problems. She teaches a number of traditional and research-based studios across the curriculum, but her favorite courses to teach are Interdisciplinary Product Design, Bio-Inspired Design and Sustainability, Design and Waste, and Wearables for Health.

Before joining Drexel's Product Design faculty, Raja taught at Georgia Tech School of Industrial Design and the Wallace H. Coulter Department of Biomedical Engineering at GA Tech and Emory University. Raja received her BSID from Georgia Tech in 2001 and completed her graduate work at the School of the Art Institute of Chicago in 2003.

December 2021 Vol-16 No-12



Ricardo Gomes, IDSA

Professor Ricardo Gomes has been a faculty member in the School of Design at San Francisco State University for over 29 years. He was the Chair of the DAI Department from 2002-2012.

Prof. Gomes coordinates the Design Center for Global Needs and the Shapira Design Archive Project in the School of Design (DES).

This non-profit international research and development center is dedicated to promoting responsive design thinking methods and solutions to local, regional and global issues such as: inclusive/universal design, health care, the aging, community development, social innovation and sustainability of the built environment.

Prof. Gomes was awarded the 2020 Faculty Award for Excellence in Service Learning, from the Institute for Civic and Community Engagement, SFSU; and the IDSA 2020 Education Award presented in recognition of significant, distinguished, and long-term contributions of faculty to the field of industrial design academia

Prof. Gomes is on the Board of Directors of the Institute for Human Centered Design in Boston. He is also a member of the Industrial Designers Society of America; and Trustee of the Beta Beta Chapter, Epsilon Pi Tau International Honor Society for Technology in the School of Design, SFSU. Prof. Gomes was a Fulbright Research Scholar

from 1984-1986 at the University of Nairobi, Kenya. He conducted post-graduate research and product development of a container system for mobile health care delivery in East Africa from 1982 – 1987. In 1986, he was Program Coordinator of Design Projects in Developing Countries, Les Ateliers, Ecole nationale supérieure de création industrielle (ENSCI) in Paris, France where he directed student liaison projects with European international development agencies.

For over 30 years, Prof. Gomes has conducted keynote speeches, presentations, symposiums and workshops at universities and international conferences throughout Africa, Asia, Europe, Latin America and the U.S. In addition, he has served on juries related to Inclusive Design; Universal Design; Design for Social Responsibility; Sustainability; and Equity for BIPOC in the Built Environment.

Prof. Gomes received his MFA in Industrial Design for Low-Income Economies from the University of California, Los Angeles (Design of a Container System for Mobile Health Care Delivery in East Africa). He received an M.A. in Architectural Building Technology from School of Architecture and Urban Planning at UCLA (Analysis of Alternative Building Materials and Construction Systems for Small-scale Industries in the Cape Verde Islands, West Africa); and a BFA in Industrial Design from Massachusetts College of Art (Design of an Adaptive Structural Environment for Severely Disabled and Developmentally Challenged Children).

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Sunil Bhatia

Design for All

Drivers of Design

Expression of gratitude to unknown, unsung, unacknowledged, unmentioned 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 our 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.

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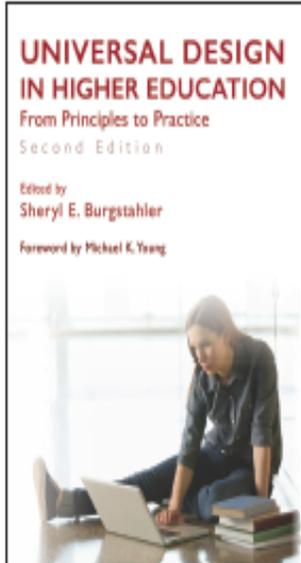
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SHERYL E. BURGSTAHLER is an affiliate professor in the College of Education at the University of Washington in Seattle, and founder and director of the university's Disabilities, Opportunities, Internetworking, and Technology (DO-IT) and Access Technology Centers.

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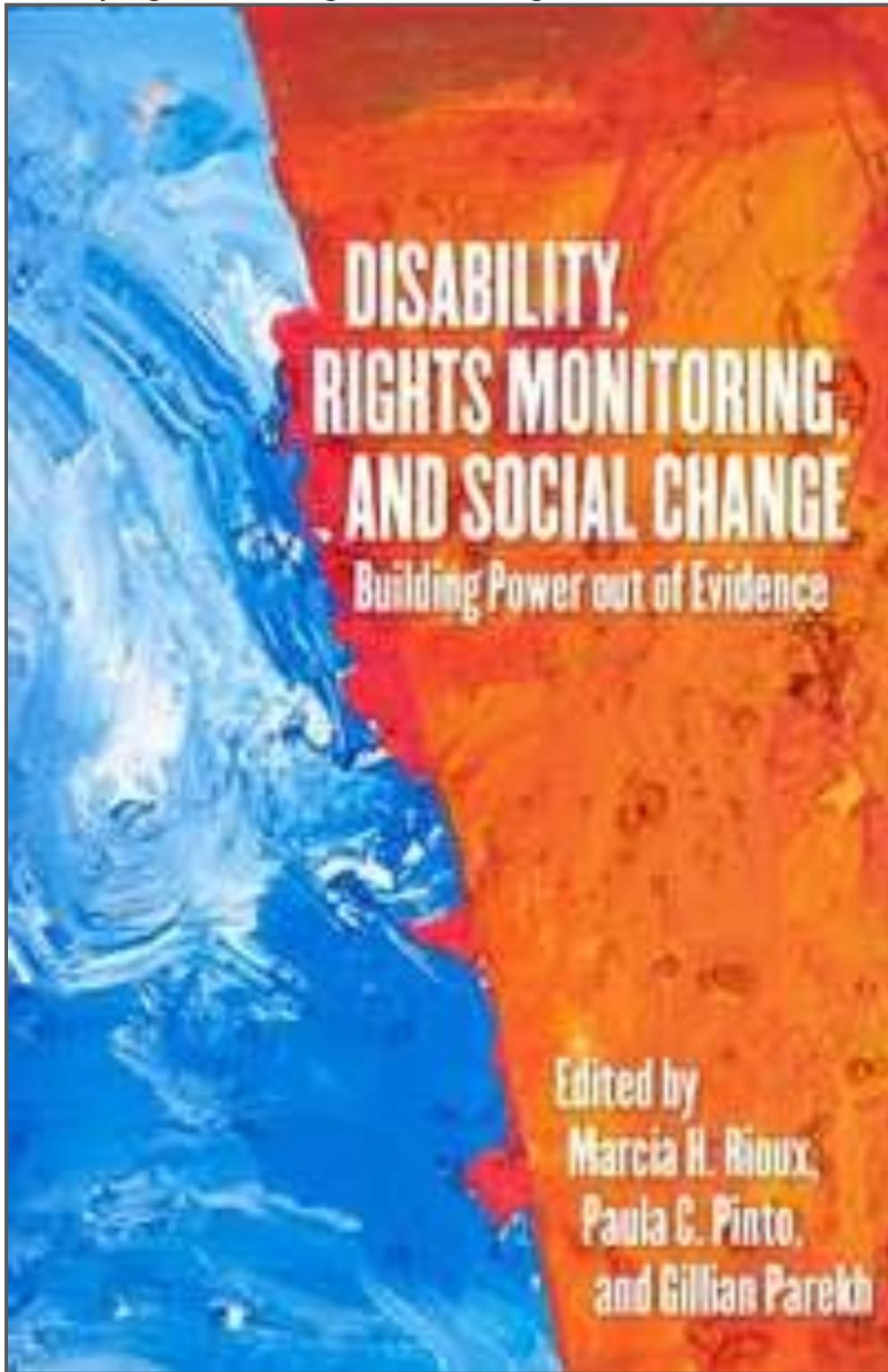
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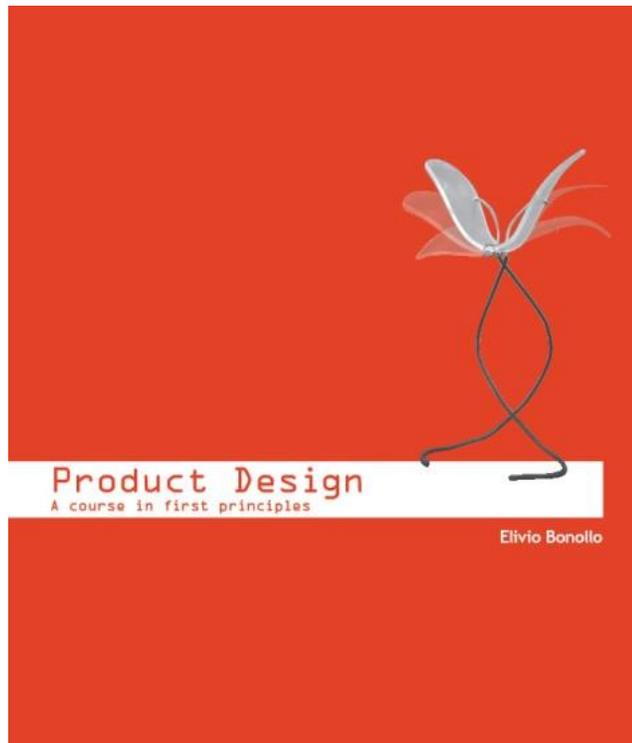
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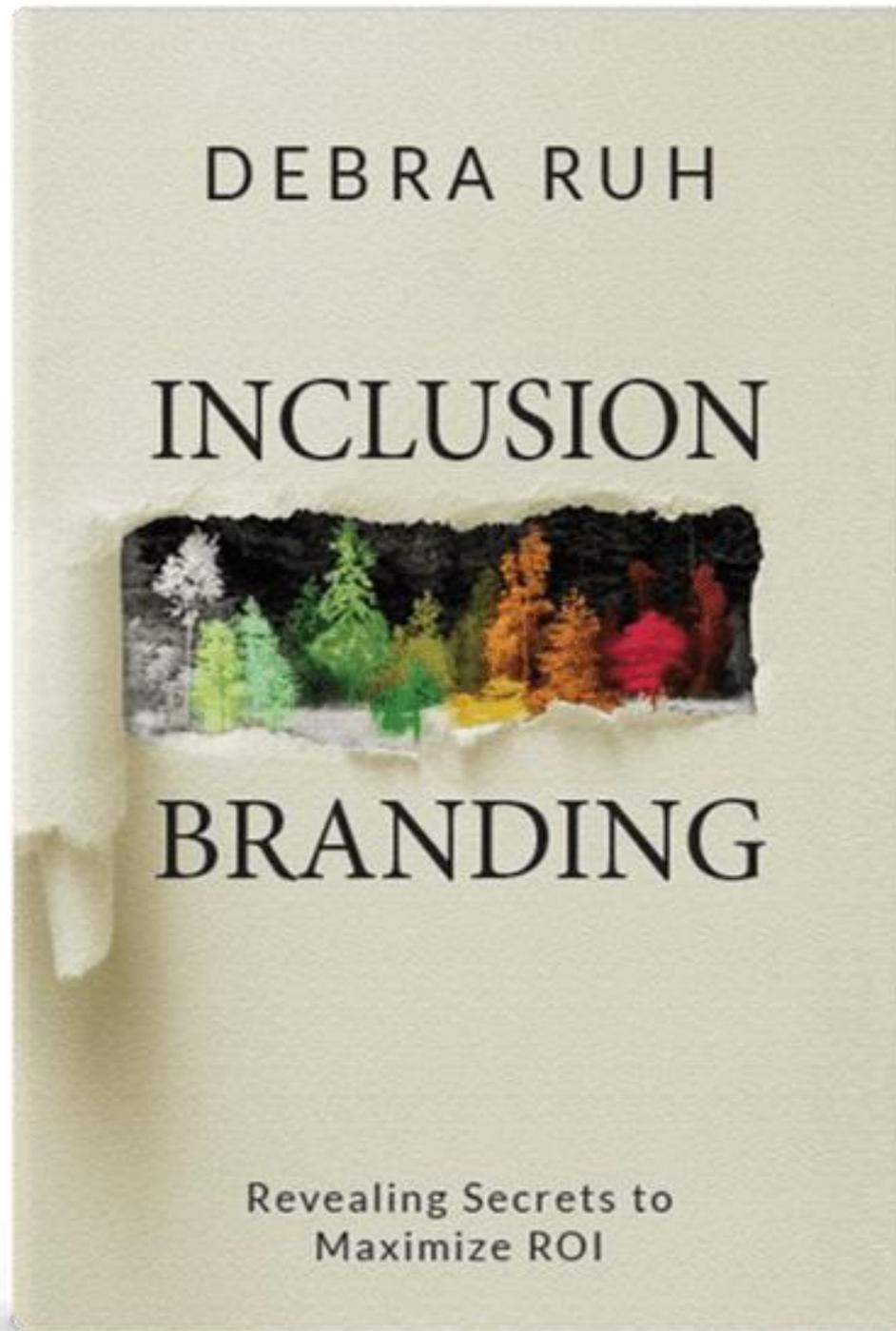
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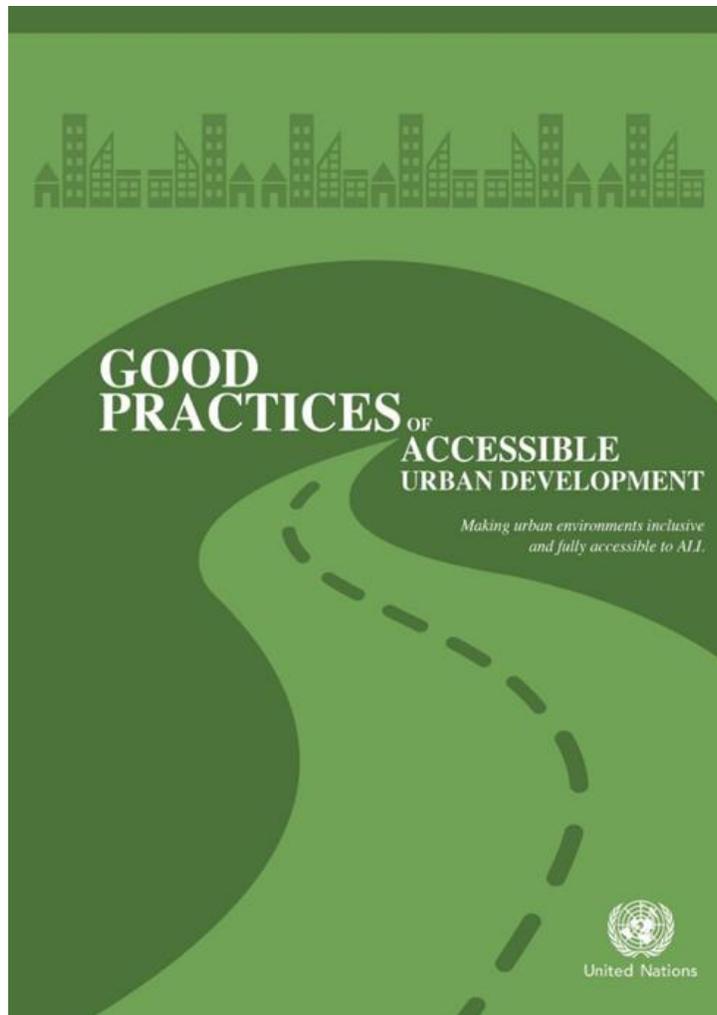
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READING HINTS: ePub files can be read with the iBook app on Apple MacBook/iPad devices; ePub files can also be read on Desktops PCs, Laptops and Surface devices using readers such as the Microsoft *freedaePub* reader. The Kindle (mobi file) reader 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.





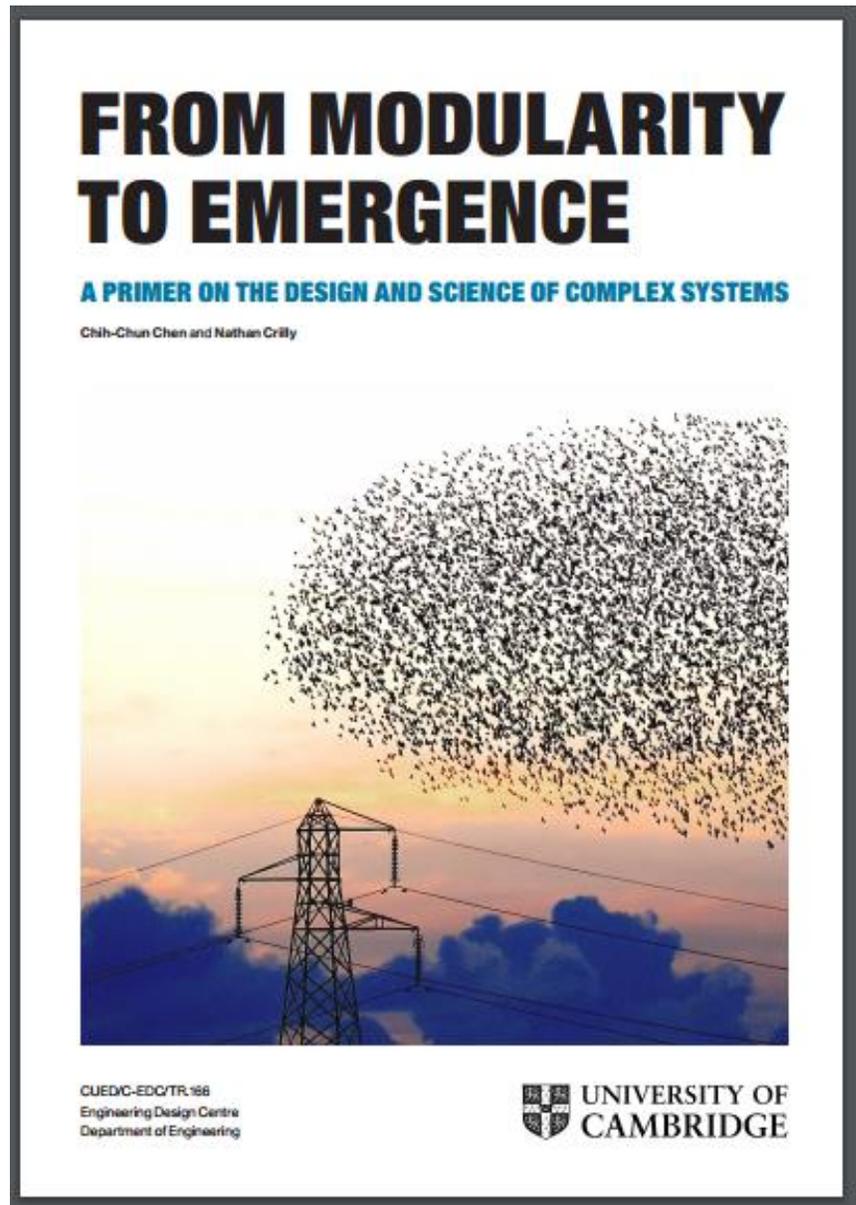
In light of the forthcoming United Nations Conference on Housing and Sustainable Urban Development (HABITAT III) and the imminent launch of the New Urban Agenda, DESA in collaboration with the Essl Foundation (Zero Project) and others have prepared a new publication entitled: "Good practices of accessible 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



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

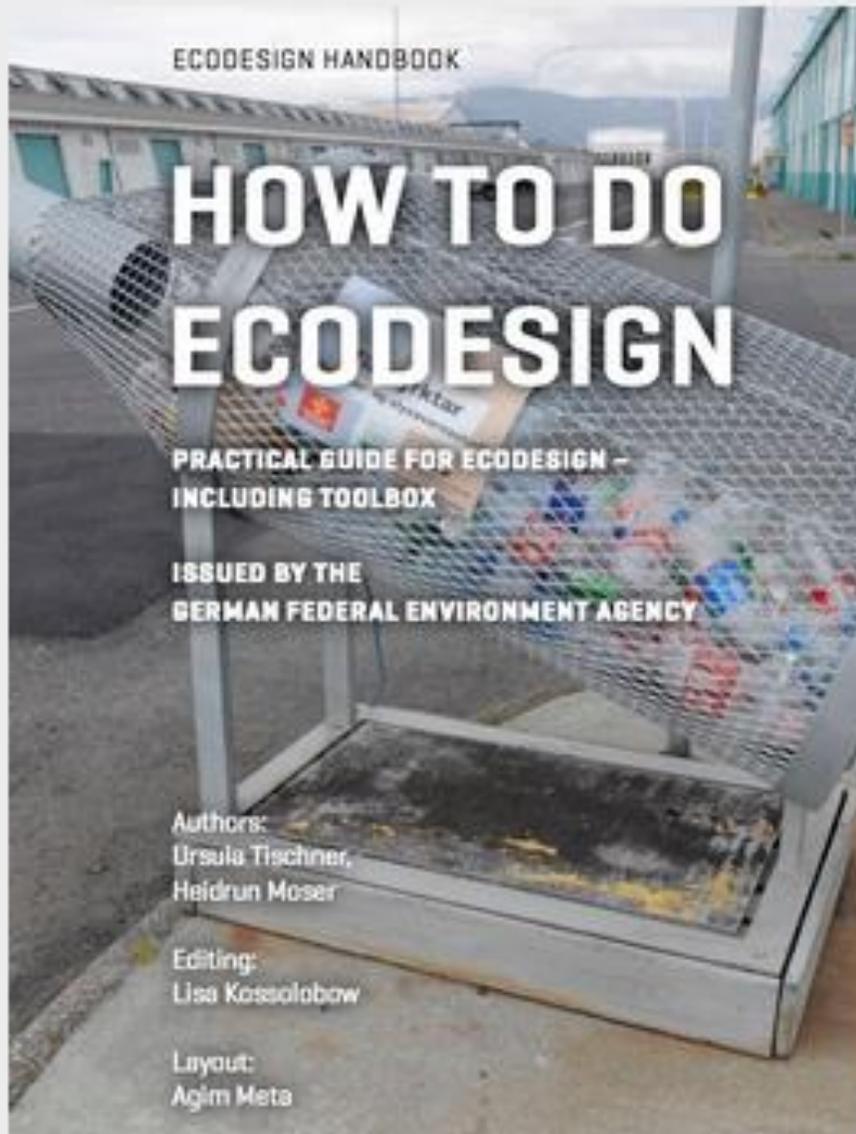
Editors:
Peter Stebbins
Ursula Tischner

CUMULUS THINK TANK
Publication No 1 of the Think
Tank Series from the Cumulus
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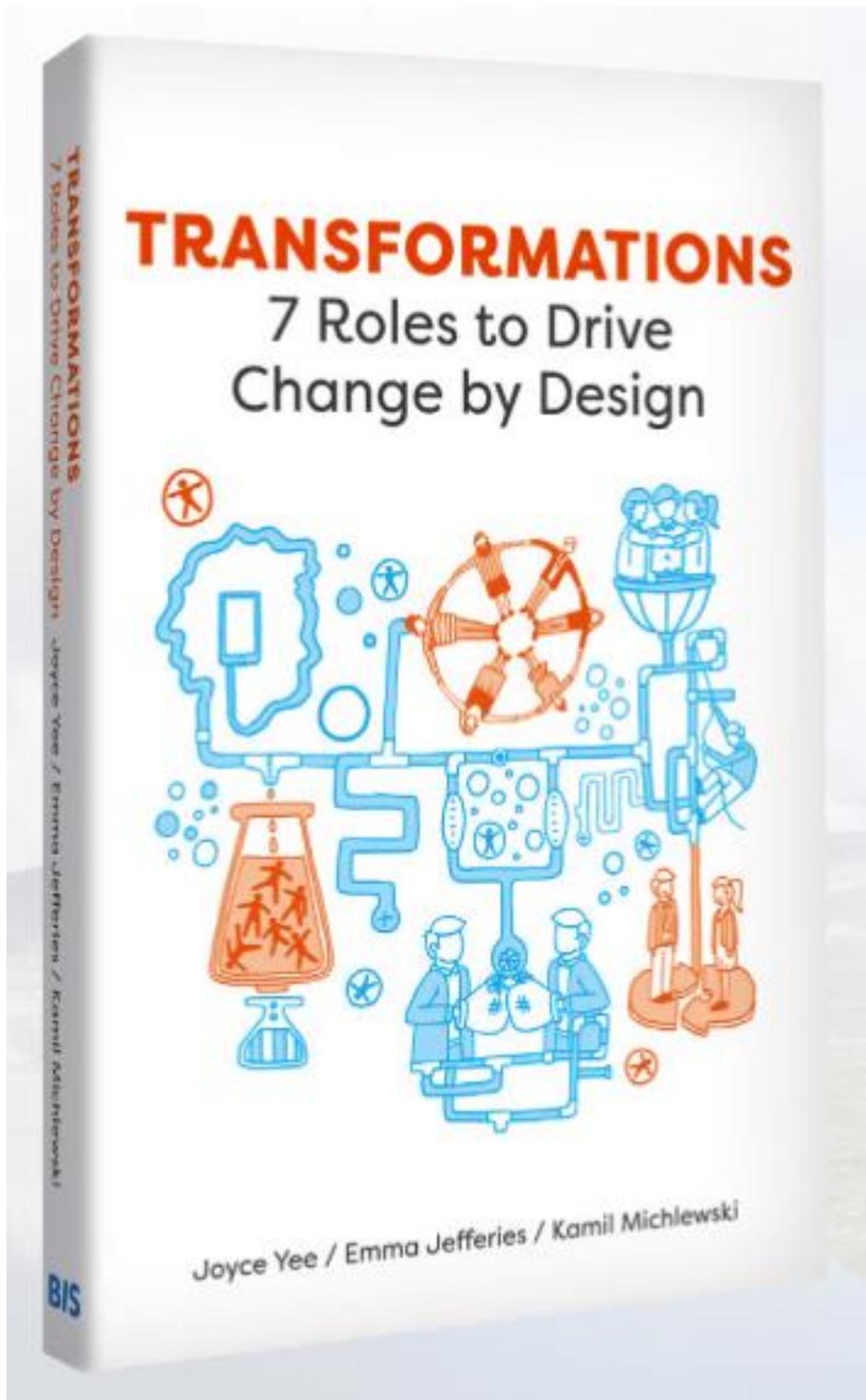
Cumulus
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Art, Design and Media



New iBook / ebook: HOW TO DO ECODESIGN



Practical Guide for Ecodesign – Including a
Toolbox
Author: Ursula Tischner



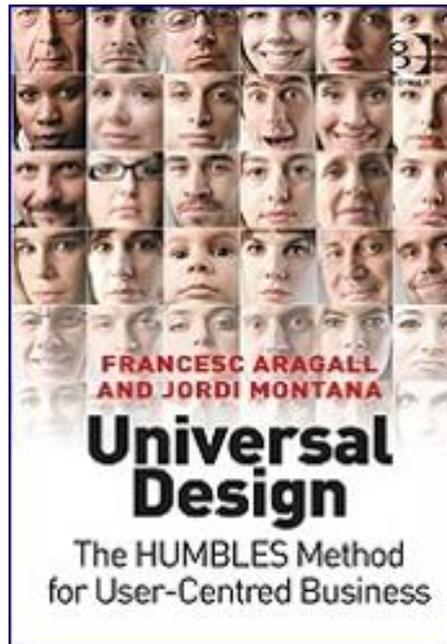
Amar Arnason and Sigurjón Baldur Hafsteinsson

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](#)

Appeal



Professor Ricardo Gomes offers a holistic vision of 2049 that relies on empathy and observation to build trust and embed healthcare services on an experiential level.

https://www.health2049.com/health2049/designing-world-class-healthcare?fbclid=IwAR0mko9EDgppEOME_Ph3R8vwAkVGNyqLe8C3jbN-68RCgCp_p1kdDZg8-g

Ricardo Gomes, IDSA

Professor/Coordinator

Design Center for Global Needs/Shapira Design Archive

School of Design

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<https://faculty.sfsu.edu/~ricgomes/>



News

1.

Using Inclusive Teaching Strategies to Promote Greater Success Among Minority Students

Phoebe S. Lin, PhD, and Lynne N. Kennette, PhD



Making learning accessible through an inclusive learning community is crucial for all students to feel seen, valued, and to maximize their potential by implementing a safe space (CAST, 2018). Ensuring that all students feel included is especially vital in remote learning, where they are likely to feel less connected to others to begin with. Universal Design for Learning (UDL), which maximizes student performance and success, argues that inclusion is a prerequisite for academic success (CAST, 2018). This manuscript offers recommendations

to combat prejudice and implement an inclusive learning environment by bringing equity to the forefront to better support minority students and improve their academic experiences and outcomes. Though this paper mainly focuses on supporting students of color, many of these teaching strategies can also benefit students of different marginalized identities, such as LGBTQA+ students or international students navigating North American culture.

Microaggressions

Microaggressions are indirect expressions of prejudice projected in speech (conveying a demeaning message), actions (refusing to sit next to a person of color), or culture (a predominantly white institution implies that people of color are not welcome), where repeated exposure results in decreased self-esteem and mental health outcomes (Pierce, 1995; Sue, 2010). Among college students, prejudice can decrease motivation in academics, career goals, and in extreme cases, lead to attrition (Fogliati & Bussey, 2013; Woodcock et al., 2012; Yosso et al., 2009). To avoid activating potential stereotypes that may lead to microaggressions or biased evaluation tied to a student's identity, instructors should grade student work anonymously. This feature has already been incorporated into many learning management systems (Blackboard, Canvas, Moodle, etc.), thus we recommend that instructors seek support (whether through the institutional office that maintains the learning management system, workshops/webinars, online videos, or teaching support groups) to familiarize themselves with teaching tools that would allow for anonymous grading. Additionally, instructors should offer as much positive feedback as possible (see Kennette & Chapman, 2021) to empower students from underrepresented groups and increase their self-esteem to help in combating negative stereotypes that they encounter.

The microaggression of racial spotlighting calls unwanted attention to a minority individual, such as asking them to speak as a representative for their racial group and/or stating that this individual's opinion can give "an outside perspective" (Carter, 2008). Racial spotlighting perpetuates prejudice by erroneously assuming that racial minority groups are homogenous and implies that the group is not part of the

dominant narrative. Rather than publicly singling out a member of a racial minority group, instructors can instead share the student's work anonymously. Doing so amplifies underrepresented voices so that these students can feel heard without placing unwelcome attention on them. Further, this gives students who are part of dominant groups the opportunity to engage in other perspectives to better understand those from different cultures with different identities and journeys. It is important to note that while sharing a minority student's work, the instructor should emphasize that there are many perspectives within racial groups and each student's thoughts are their own rather than a representation of all voices of their race.

Responding to microaggressions is often a lose-lose situation as the options are to risk further invalidation (such as being told the comment was just a joke) or to refrain from speaking out, leading to feelings of powerlessness. To educate students on examples of microaggressions and how they cause harm, instructors can share common microaggressions (e.g. "Did you get into college because of Affirmative Action?") to encourage a discussion on the hidden demeaning message and the harm caused. During remote learning, instructors can create an online system to give students a means to report racist/biased acts committed by others. Doing so gives the target a voice, can empower them, and ensures that action will be taken toward the offender, whether in the form of an educational conversation or punishment.

Stereotype threat

When reminded of a negative stereotype relevant to one's social group, we become preoccupied with not wanting to confirm the stereotyping, causing distraction, anxiety, and impaired performance—a process known as stereotype threat (Steele & Aronson, 1995). Long-term experience with stereotype threat can lead to lower motivation in academic achievement, which partly explains the difference between Caucasian students and students of color in academic performance despite similar levels of inherent ability (Aronson et al., 2002). To offset harms of stereotype threat, instructors should encourage students to adopt a malleable theory of

intelligence, which argues that cognitive skills can be further developed through effort (in contrast to a fixed theory, stating that skill level is stable). Research has shown that those who endorse a malleable versus fixed theory have greater intrinsic motivation to master academic material, leading to improved academic performance (Aronson et al., 2002). A direct method of encouraging the malleable theory of intelligence is for instructors to offer feedback that prioritizes work ethic and improvement above intrinsic ability.

An additional challenge faced by minority students is the lack of role models they can identify with (Fries-Britt & Turner, 2002; McDonald et al., 2004). Role models are more effective in inspiring success when their identity matches with the target (Marx et al., 2009; Marx & Roman, 2002). This shows them that someone with a similar background/journey has obtained success, making success more salient and tangible for the target (Lockwood, 2006). By highlighting similarities between target and role model, role models can also minimize or negate harms of stereotype threat through inspiration, showing that the social group can succeed despite barriers tied to systemic bias.

Additionally, instructors should emphasize the contributions of diverse scholars in their teaching for several purposes: to inspire success for students of underrepresented groups, counteract negative effects of stereotype threat, and highlight that the discipline has benefited from the works of individuals from a variety of identities and backgrounds. To do so, instructors could share a photo and/or provide biographical information of these role models in lectures or class discussions and select a textbook that embraces diversity and the contributions of various social groups to the field of study.

Using diverse perspectives and cooperation to enhance the learning experience

The jigsaw classroom utilizes direct interaction and cooperation between students of different identities to facilitate team-based learning and decrease prejudice (Aronson, 1978). By having students teach one another select portions of the course material and structuring the activity so that each member of the group makes a unique contribution,

students become better listeners, value the contributions of each group member, and learn to be more respectful of others, regardless of differences in identity (Aronson, 2002). Additional benefits of cooperative learning include greater perspective taking, lower levels of intergroup prejudice, and improved learning outcomes (Aronson & Bridgeman, 1979; Walker & Crogan, 1998). To implement this technique, instructors should assign groups and rotate group members across the semester to maximize students' experiences with diversity whether in identity (whether related to race/ethnicity, country of origin, sexual orientation, or gender identity) or perspective. Implementing a superordinate goal, which if accomplished through collaborative efforts benefits all group members, can also decrease hostility and improve intergroup relations (Sherif, 1954; Sherif et al, 1961). The Robbers Cave field study (Sherif et al., 1961) has demonstrated that after working collaboratively to achieve a superordinate goal, two previously competing groups discarded the "us versus them" mentality and instead became friends.

In remote learning, online tools can foster group work/discussion through shared pages, breakout rooms, or shared documents (for instance, through Google) such that students can communicate, edit one another's work, and see one another's feedback in real time. By encouraging group work even in remote learning, students may feel closer to one another via social bonding and collaborative efforts, motivating them toward higher achievement to benefit themselves and the social unit.

As higher education becomes more diverse with both local and international students, institutions need to integrate inclusion with their school's cultural values so that all students feel valued, capable, and are motivated to strive for success. This is arguably even more crucial now as institutions are moving away from traditional face-to-face teaching and towards embracing technological advancements that allow for hybrid or remote classes. As students spend less time physically on campus, it is necessary to emphasize that they are part of the community to help them avoid feelings of isolation.

Instructors must use their privileges and positions of power to advocate for their students, provide support by combating the prejudices they encounter, empower them by providing role models they can identify with, and facilitate greater empathy through cooperative learning. By promoting and maintaining an inclusive learning community (CAST, 2018), instructors can support improved academic performance and outcomes in all students (including the many minority groups that have not been the focus of this paper, such as LGBTQA+), thus better preparing them for the transition to a professional career and becoming well-informed citizens once they complete their learning goals.

Phoebe S. Lin, PhD, is an associate professor of psychology at Framingham State University, where she primarily teaches courses in the sociocultural domain. Her research interests are in the psychology of prejudice and inclusive teaching practices. She obtained her BA from the University of Michigan and her PhD from Wayne State University.

Lynne N. Kennette, PhD, is a professor of psychology at Durham College, in the School of Interdisciplinary Studies. She earned a PhD in cognitive psychology from Wayne State University in Detroit, MI. She is passionate about teaching and optimal student learning.

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(Courtesy: Faculty Focus)

2.

Winner announcement

Student design team 'Radar' (Delhi Technological University) wins Student Service Design Challenge

2021

Student teams from recognised design academies and universities from around the globe have invested 5 months in the design research, ideation and development of their service concepts. The Jury selected team 'Radar', a team of design bachelor students from Delhi Technological University, as the winner of this year's edition. Their 'Radar X' service offers a waste collection solution for healthcare facilities.

The Student Service Design Challenge aims to celebrate, encourage and inspire the next generation of designers. In this second edition, the challenge gathered students from all over the world: from India, Hong Kong, Mexico, Australia, Canada, the USA, and numerous European countries. More than 70 student teams representing 41 schools and universities answered the call to design sustainable close-loop service solutions that engage everyday users and facilitate the introduction of circular design into existing industrial processes.

The second prize winning team is team Comali (Universidad Nacional Autónoma de México) for their service to encourage the reuse of

school uniforms. This year the challenge has two third prize winning teams. Team Hula Hoops (Politecnico di Milano) for their service to extend the lifespan of toys, and team Bulky Bananas (Academy of Fine Arts and Design, University of Ljubljana) for their service to help fight hunger by reducing edible food waste.

With solutions focussing on a variety of issues around food, furniture, fashion, construction, toys, beauty, medical supplies, etc., it was difficult for the Jury to select the winning concept based on the challenge's comprehensive criteria: people centricity, society oriented, circular & sustainable, technology enabled, and business viable and experience based.

The Jury: "The desire and ambition of the student teams to redesign so many inconsistencies within our society and challenge the status quo have overwhelmingly inspired us.

Through their extensive research and focus on local issues, we learned about the problems of many different regions and countries and discovered how universal these issues could also be. Although this situation may seem pessimistic, it had quite the contrary effect on us; the solutions presented by the student teams are proof that these complex problems can be tackled and that with the right tools and mindset, it is possible to design better systems.

Furthermore, having their perspectives laid out in front of us allowed us to see what the next generation can and will do. This is a challenge of hope and optimism. As jury members, it is great to be part of this guiding process and offer a new generation of designers the confidence to follow their shared ambition to contribute actively (and even 'activistically') to a better world."

Winners

1.

GOLD winner:

**design-in-residence
+ EUR 3,000 for the University**

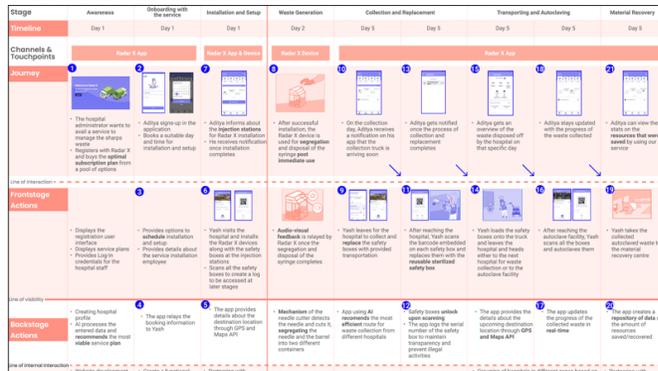
Radar X - a waste collection solution for healthcare facilities

The Jury selected 'Radar X' from team Radar (Delhi Technological University, India) as the winning service solution. Radar X is a

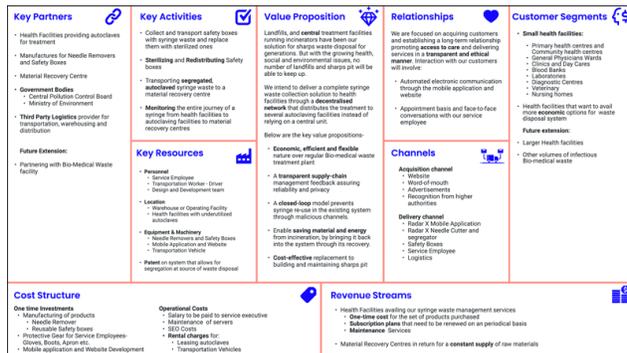
complete sharps waste collection solution for healthcare facilities. The service aims to make the process of medical waste disposal more efficient and economic by building a decentralised network that distributes the treatment to several autoclaving facilities instead of relying on one central collection unit.

Team Radar: "One of the biggest challenges the Indian bio-medical waste (BMW) management system faces is a lack of funds. To phase out chlorinated plastic bags, gloves, blood bags, etc. would be costly and overly lengthy. The problem is compounded by the presence of scavengers which sort out the healthcare waste precariously for recycling and illegal reuse of syringes. Our challenge was how can bio-medical waste be made safer to manage so that it is easily handled and efficiently disposed of. There is a great need for the rapid development of many more treatment facilities to fulfill the need for treatment and disposal of all the medical waste generated in India."

SERVICE DETAILS



Service blueprint



Business Model Canvas

JURY STATEMENT

"The medical industry produces an enormous amount of waste and the problem has clearly gotten worse due to the COVID pandemic. Radar X does a good job in addressing that. Although the team focused on their local context and provided a viable solution for that scenario, this is a problem that currently affects the entire world. We celebrate the courage to take on a complex and 'unattractive' problem that nonetheless requires immediate attention and action."

"The team tackles this very pressing topic through a well-described and comprehensive service concept. The team builds on an existing though untapped infrastructure while optimising it using a shared service model."

"It is a strong proposition, with a well mapped ecosystem, implementable and with an eye on ways to prevent waste."

"The team's evaluation, testing methods and application solution are excellent from a service design perspective."

ABOUT THE TEAM

Team Radar is a group of five undergraduate design students at Delhi Technological University, India. Their passion to challenge the current boundaries of experience design brought them together and drove them to participate in this challenge. Armed with varying interests and skills, each of the five members brings a different perspective to the table and complement each other's abilities.

"SSDC2021 has been an astounding experience overall. Being able to take part in the challenge and finally completing the solution is one of the most rewarding experiences we've ever had. It was a great opportunity to expand our horizons by looking at design from a holistic perspective. Thinking about an entire service is an enormous job but support from the challenge mentors has made this a very smooth process for us. And one important thing we take away is to tackle difficulties tactically rather than tackling them head-on."



Team members - Akshita Mishra (India), Akash Seth (India), Arnav Gupta (India), Raghav Byala (India), Ipshita Singh (India)

2 SILVER winner:

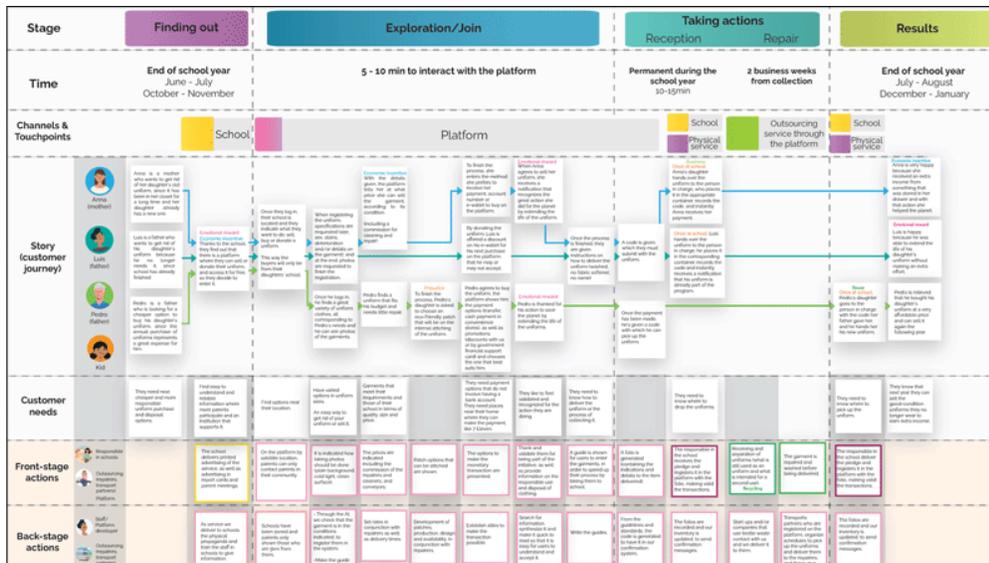
monetary prize of EUR 2,500 + EUR 2,000 for the University

UniforAll - a service that encourages the reuse of school uniforms

The jury awarded the Silver prize to team Comalli (Universidad Nacional Autónoma de México, Mexico) for: UniforAll. The service connects parents who want to donate, sell or buy school uniforms in good condition and at a low price through a digital platform. With purchase, collection, repair and redistribution of pre-owned uniforms, the platform aims to change the negative perception of reuse and prevent uniforms from ending up in landfills after just one wear.

Team Comalli: "It is estimated that in Mexico each year more than 1,700 tons of clothing are purchased for the new academic year, and more than 270 tons fall into disuse. After exploring the reasons behind this, we decided to look into ways of improving the experience of acquisition and disposal of school uniforms for parents who invest a lot of time, effort and money in the purchase of school uniforms each year. They struggle today because the cost of uniforms is high and their durability is short."

SERVICE DETAILS



Service blueprint



Business Model Canvas

JURY STATEMENT

“The concept addresses not only practical considerations but also takes into account emotional, social and economical dimensions. By engaging all stakeholders in the process, the team managed to come up with a realistic service that cleverly integrates existing

infrastructure and ecosystems, and that seems also fun and rewarding to use.”

“The team has identified a true pain point and has built a robust service ecosystem to solve it. The solution engages the community and schools to value used school uniforms and offers a well-defined service to make reuse possible.”

“We especially appreciate how the team tried to tackle and disrupt the secondhand-use stigma - by not trying to hide it but by subtly celebrating it through use of the patches that flirt with the rules of how school uniforms can be worn and represented. In combining practical application with a change in perspective and mindset, the service might also provide a pathway to leapfrog environmental awareness and design in a location where, currently, options are limited (no recycling infrastructure, etc.).”

ABOUT THE TEAM

Team Comalli is a team of five close friends studying Industrial Design at the Universidad Nacional Autónoma de México in México City. Coming from industrial design, they are interested in recognising and providing opportunities to build on and improve current processes around existing and future products, systems and services in order to offer user-centred solutions that contribute to sustainable development.

“It was important to externalise our ideas and develop them so that other languages and cultures could understand the solution we proposed.”



Team members - Aridayd Arellano (Mexico), Eva MédinaAlcántara (Mexico), Naomi Jardón (Mexico), AranzaMiroslava Cruz Michel (Mexico), Guillermo Mota (Mexico)

3

BRONZE winner (shared):

monetary prize of EUR 1,500

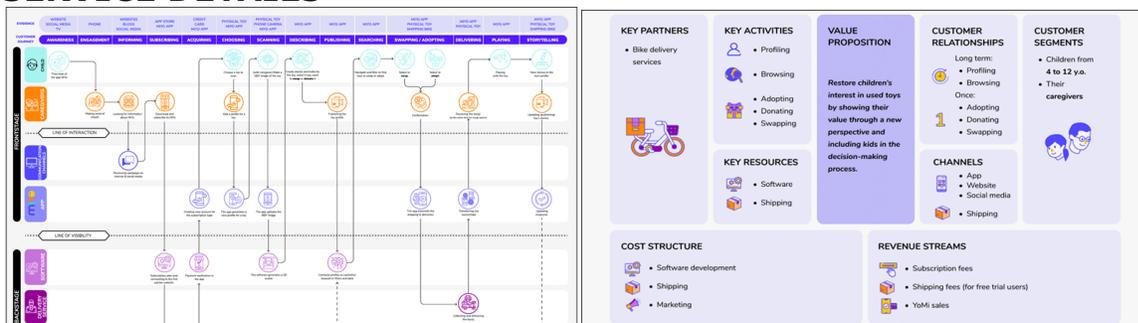
+ EUR 1,000 for the University

MiYo - Mine is Yours - a service that extends the lifespan of toys

The Jury awarded Bronze to team Hula Hoops (Politecnico di Milano, Italy) for: MiYo. MiYo is an online platform enabling children and their caregivers to act together towards a sustainable and extended lifecycle for toys by creating a local network of exchanges. It helps users understand the value of used toys through a new perspective while including children in the decision-making process.

Team Hula Hoops: "Toy waste is often overlooked yet plays a considerable factor in environmental pollution. As this industry grows along with consumerism, most toys end up in landfills. Toys are commonly discarded after a few months of usage, even if they are still in perfect condition. This happens because kids quickly lose their interest and toys lose their value over time. Our challenge was to help our users understand the value of used toys through a new perspective, while including children in the decision-making process, consequently increasing toys' lifespan and creating a loop in reusing them."

SERVICE DETAILS



Service blueprint

Business Model Canvas

JURY STATEMENT

"Team Hula Hoops presents a triggering service that can make us reflect on how we perceive previous ownership and re-use. Rather than using platform technology for selling and buying used toys, they chose a different path by giving discarded toys quite literally a

voice and making their history visible to let toys gain personality and become more attractive for reuse."

"The team has developed a really ambitious circular solution. One of the biggest obstacles to circular transition is retaining value for things people don't want anymore. This service solution addresses the problem head on by focussing on the child as the user. The idea proposes a change of mindset around value using technology to help children have an extended appreciation of toys. Of course, this should take place in a protected and secure environment for the children."

"Through engaging storytelling, children build valuable relationships with the things they already have by reimagining them, changing behaviours for the next generation."

ABOUT THE TEAM

Team Hula Hoops is an international team that brings together cultures from all corners of the world: Iran, China, Italy, Lebanon and Brazil. They are students of the Master in Product-Service System Design at Politecnico di Milano who share a common goal: to design services that enable more sustainable futures for humanity, putting themselves in the shoes of others and turning the world upside down to create new perspectives.

"Often the bigger impacts are achieved through simpler but strong ideas."



Team members - Emma Teli (Italy), Julia Rangel (Brazil), Mehrdad Atariani (Iran), Nardin Adel Shafik (Lebanon), Zhengang Lou (China)

(Source_ Philips Netherland)

Programme and Events



[Conferences](#) / [2021](#) / [August 2021 in London](#) / [Inclusive Design and Manufacturing](#)

ICIDM 2021: 15. International Conference on Inclusive Design and Manufacturing
August 19-20, 2021 in London, United Kingdom

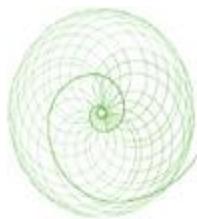


FIFTH INTERNATIONAL CONFERENCE ON UNIVERSAL DESIGN

June 9 - 11 2021 at Aalto University, Espoo

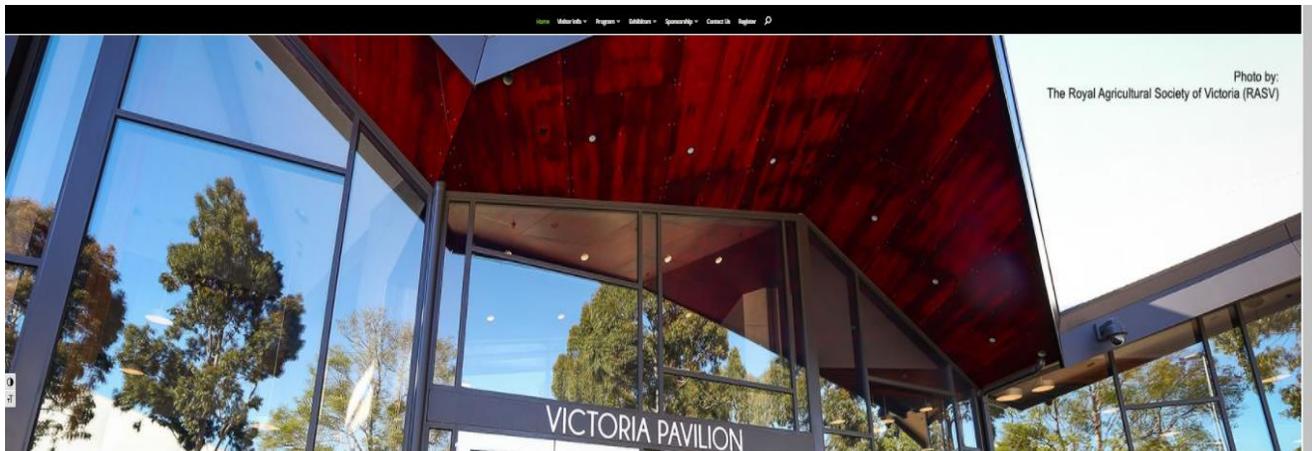
Universal Design Summit 7

Universal Design Summit is a preeminent conference in North America, drawing experts in universal design from across the globe. UD Summit has traditionally focused on universal housing and inclusive communities. Event organizers are pleased to announce the expansion of UD Summit to include inclusive design in digital spaces. Our current plan is to offer simultaneous)



Universal Design Summit 7 *Inclusion Fusion*

May 12-14, 2021



CONFERENCE

Mon 17 - Tue 18 May 2021
Victoria Pavilion
Melbourne Showgrounds



GET READY TO CELEBRATE GREAT DESIGN!

As restrictions start to ease across Australia we can't wait to celebrate the very best in design and innovation with our 2021 Good Design Award Winners. Booked for Fri 17 September at The Star in Sydney, this year's Good Design Awards Ceremony will be one you don't want to miss!

ENTER GOOD
DESIGN AWARDS

We think our design community deserves an extra special celebration this year, so save the date and get your entries in!



INTERIOR DESIGN
CONFEDERATION
SINGAPORE

IDCS Design Excellence Awards 2021

Mar 27, 2021 2:27 am EDT

The [Interior Design Confederation Singapore](#) (IDCS) is calling for entries for its 2021 Design Excellence Awards.

The leading awards program showcases the best interior design talent in Asia-Pacific.

The deadline for submissions is August 31, 2021.

TypoDay2021

6th & 7th August 2021

TypoDay 2021
6th & 7th August 2021

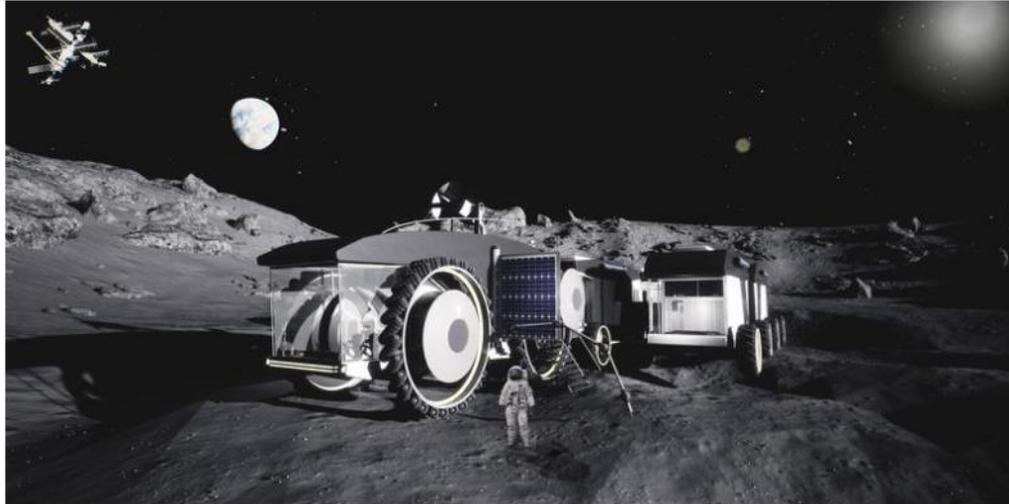
<http://typoday.in/>



**universal
design**

CONFERENCE

Mon 17 – Tue 18 May 2021
Victoria Pavilion
Melbourne Showgrounds



[Roving Hotel Concept](#), Simiao Wang, ArtCenter College

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The 2021 Spring Student Deadlines

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Late deadline period begins June 1. Late and final deadline: June 14



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