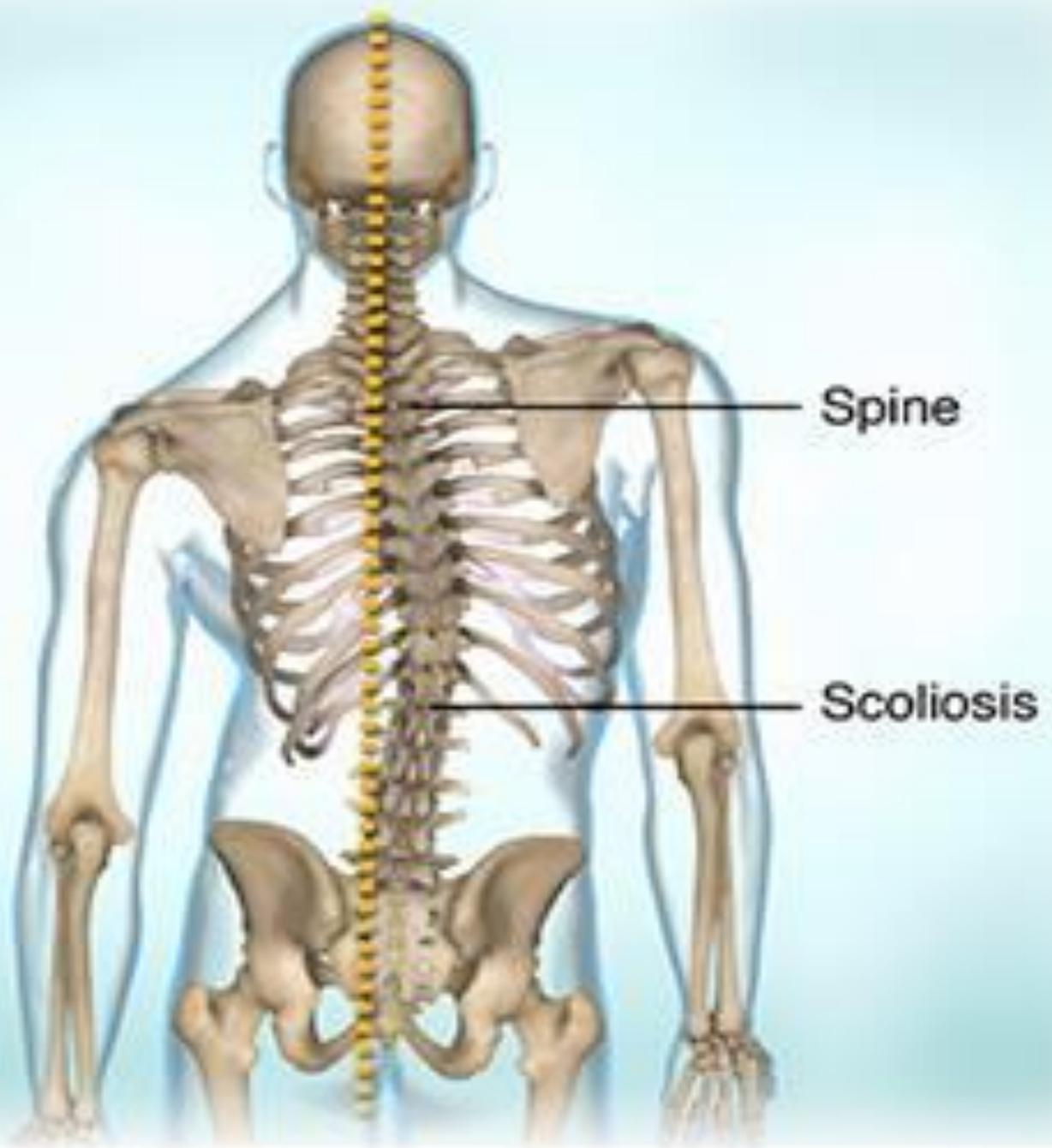


Design for All



Guest Editor: Dr. Peter Gibilisco

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GUEST EDITOR:



Friedreich's Ataxia does not affect my intelligence, but many working in the disability field act as if do not believe this. But the reality can be highlighted by my academic qualifications, which are a double degree from Monash University, Master of Arts from Monash University and a Doctor of Philosophy from University of Melbourne. My PhD was achieved late into the progression of my disease, when I was 43 years old. Many say to me that this was a huge achievement, and I am aware of some taken-for-granted misunderstandings about Friedreich's Ataxia. At the time of my diagnosis when I was 14, medical specialists told my parents that 'I would not live much beyond the age of thirty'. One can only imagine their response if they were then told I would obtain a PhD! These days, I still perform research and Melbourne University gives me honorary fellow status. I have written and published over 100 articles and currently now authored three books.

However, there are many degrading effects to be battled with, such as blindness, very poor speech, hearing impairment, poor heart and limited mobility and coordination. But in all spheres of

life, I've always tried my best; the jury is out, but there is still some chance that my writings may create change.

Editorial:

Dr Peter Gibilisco

My academic knowledge is completely connected with the many problems that have arisen for me from my biomedical conditions. I feel I have to state this because it is something I have had to say again and again during my academic career. But, that being said, I find it to be a fantastic motivation to me to be invited to act as guest editor for the Design for All Institute of India. To put it simply, it was so very hard to achieve my academic qualifications but I did what needed to be done and now, today, my disability has deteriorated so profoundly that such an invitation allows me at this point to express my appreciation for this wonderful and heightened form of respect.

'It is such a joy for me to be asked to be the guest editor for Design for All, and I have invited a handful of incredible people to share their perspectives. First, my good friend Steffan Irugalbandara brings to the fore his beliefs concerning failure and the positive steps that may become issues from it.

Currently, I have many close friends who have migrated from Sri Lanka. This brings me to an article that I coauthored where we talk about my friendships, Sri Lanka's devastating effects upon that country from the civil war and the tsunami which still has a profound effect upon the friends who have encouraged me in this article. That being said by way of introduction, we then look more broadly at Sri Lanka and people with severe disabilities.

Next is a book review from a dear and close friend of mine, Bruce Wearne. Bruce was there throughout every stage of this book and whenever I was in a situation where I was in need of help he was always there, a great friend. Bruce also follows with a brief writing on the social aspects of Friedreich's Ataxia.

Next my good friends from the Friedreich Ataxia Clinic share their expertise in their respective fields pertaining to the care of Friedreich's Ataxia. Professor Adam Vogel writes on the complexities of Friedreich's Ataxia and speech therapy. Associate Professor Louise Corben highlights the strains on mobility that Friedreich's Ataxia patients endure, and how they can be overcome with suitable, individualised disability equipment. Finally Professor Martin Delatycki gives background on Friedreich's Ataxia for anyone who wishes to learn about the disability.

And finally, is my book's abstract which basically runs along the lines of the dangers of organized care becoming careless.

Dr Peter Gibilisco



Steffan Irugalbandara

Bachelor of Management | Master of Marketing

2015 Graduate of the Year, Deakin University

2016 and 2017 Student Excellence, Monash University

Originally from Colombo, Sri Lanka I attended the oldest Catholic high school in the country; St Benedict's College. This was my home for both my primary and secondary education where I excelled in many extracurricular activities including theatre, basketball and prefectship (student leaders). In my final year in school in 2011, I was appointed Head Prefect (school captain) of St Benedict's College, alongside being President of the Drama Club and Vice-Captain of the senior basketball team. Once graduating from high school in 2012, I took the biggest step in my life in migrating to Melbourne, Australia with my family.

Once in Melbourne, I pursued my higher education first at Deakin University, Burwood where I completed a Bachelor of Management majoring Marketing and Commercial Law. My time at Deakin was a time I cherished due to my academic performance,

which resulted in winning multiple awards. The internship I undertook was awarded the best internship in 2014, I was inducted into the 2015 Dean's Merit List and was named the 2015 Bowater Graduate of the Year.

Following my undergraduate studies, I received a scholarship to study a Master of Advanced Marketing from Monash University, Caulfield. This was a challenging stage in my life as I had just commenced working fulltime as a Marketing Officer at Deakin College. Despite balancing both fulltime work with fulltime studies, I was able to continue my academic performance and excel in my postgraduate education. Here too, I was able to win numerous awards including being part of the 2017 Dean's Merit List as well as the award for Academic Excellence for two consecutive years (2016 and 2017).

I currently work as a Senior Marketing and Communications Officer at the Faculty of Business and Law at Deakin University. Here I oversee various digital marketing campaigns, social media and content marketing activities. My long-term goal is to work in marketing consulting and be a most sought-after marketing executive.

Overcoming the fear of failure

Steffan Irugalbandara

Bachelor of Management | Master of Marketing

2015 Graduate of the Year, Deakin University

2016 and 2017 Student Excellence, Monash University

Leadership is neither a position nor a title, it is who you are. Working in marketing and communications, I believe that everyone one of us has a unique leadership brand. This brand carries certain attributes and qualities that define who we are as a leader.

No buzz word is more widely desired and associated with leadership than the word success. People spend years in search of success, but the reality is not all achieve it, at least not all persist long enough to achieve it because of one fundamental element of success, the f word, failure. Failure is part of our lives and it's something we cannot escape.

JK Rowling, author of the Harry Potter books, said

“It is impossible to live without failing at something, unless you live so cautiously that you might as well not have lived at all—in which case, you fail by default.”

Failure is inevitable. With everything, there is failure, such as this article. If you don't remember at least one thing today, I have failed.

Michael Jordan, one of the greatest basketball player of all time once said,

“I have missed more than 9,000 shots, lost almost 300 games. 26 times I took the game winning shot and missed. I have failed over and over and over again. And that is why I succeed.”

We often associate failure with humiliation and shame. These feelings contribute to a psychological barrier known as the fear of failure. We are scared of failing because of the consequences, outcomes.

From my experience, I would like to write about three important steps that I’ve come across in my life which has helped me overcome this fear of failure.

- 1. Exit your comfort zone***
- 2. Reach out***
- 3. Don’t quit too easily***

1 EXIT YOUR COMFORT ZONE

The reason why a lot of people don’t become who they want is because they are too attached to who they’ve been. Comfort zones are beautiful places, but nothing ever grows there. Neale Walsch, a US author said,

“Life begins at the end of your comfort zone”

When I completed school in Colombo, Sri Lanka and moved to Melbourne, Australia in 2012, I was stepping into unknown territory with no friends nor familiarity. Being so used to my lifestyle in Sri Lanka and to be put in a totally different environment, I had to start my life from scratch. I was already out of my comfort zone. Upholding the values I’ve learnt, I adapted

myself to the new culture and entered life down under. Cultural and language barriers can be quite the challenge when you enter a new country, especially when the words mean different things in different countries.

I remember during the first months in Melbourne, I was heading to the beach with a few Aussie friends, a group of boys, and they go "Hey mate, don't forget your thongs". Thongs? You can imagine what I was picturing in my head. Because from where I come from thongs refer to a different attire. I soon realised that thongs in Australia mean slippers.

Cultural confrontation always puts you off. But it wasn't culture. With an overwhelming task of being the first in the family to enter university I made my steps outside my comfort zone. One step at a time, I took part in many activities building relationships with peers from around the world and ended up working in one of the leading universities in the country. My life began at the end of my comfort zone.

Tim Ferris in his *4-hour work week* book claimed that

"You can measure the number of successes in life by the number of uncomfortable situations you put yourself in."

So imagine the situations where you have to deliver a speech or speak publicly to a group, or imagine the interview you go through to get that dream job, knowing that rejection could be right in front of you. You need to put yourself in those situations to come out of your comfort zone.

But it's not easy. It is really hard and so often it's easy to read something like this and say 'okay, yeah I'll put myself in

uncomfortable situations', but actually it's so easy to think and talk about things, but to actually do them is another matter. So I urge you to be the one to put yourself in those uncomfortable situations, knowing that you are a step closer in overcoming your fears.

2 OUTREACH

The second step in overcoming your fears is outreach. Reaching out to take advantage of opportunities, enhances your ability to look beyond your fears.

The fear of failure originates within us typically derived from past experiences. The past does not equal the future! Your failures should not define who you are.

Well let me ask you this, have you ever been rejected by a girl or a boy? If you have not, you are either lying or you haven't started living yet! If you have, you would know it's hard to pick yourself up after a rejection of that nature. Am I too fat? Am I too tall? Is she not into men? The usual questions linger....

The tragedy of this experience is not the experience itself, it's the meaning that we usually take home with us. Because I was rejected then, I'll be rejected again. The past will equal the future. Perfect formula for misery. The past does not equal the future.

So you might wonder how you actually reach out? If I was to share a simple lesson that I've come across comes to one word, experimentation. By experimenting different ways of doing things you learn what's best for you, what works, what doesn't work. As Robert Kiyosaki nicely puts it,

“Sometimes we win, sometimes we learn”

I had a lecturer from Monash University (when I completed my Masters) who said and I hope my boss is not reading this. He said ‘go out there get a job, get paid to make mistakes, and then go do your own thing.’ So in his perspective failure is a vehicle, a friend, not an enemy. It’s a connecting point leading us to success, in other words the faster I fail the faster I learn, the faster I learn the faster I succeed. So maybe the lesson here is go and fail as fast as you can! Just don’t quote me on this.

3 DON’T QUIT TOO EASILY

So you’ve exited your comfort zone, reached out for opportunities and what if you fall down, and it doesn’t work out? Well, don’t quit too early. That’s our third and final step to overcoming fear of failure. The most common way people quit or give up is by thinking they don’t have the potential to achieve.

I’d like to share another story, and this is not off the internet. It’s more personal to me and something that changed me.

It was early 2006 and St Benedict’s College (my high school in Sri Lanka) had never been a force in theatre. For the first time, College planned to enter the prestigious Inter-school Shakespeare Drama competition, the longest running school-based Shakespeare drama competition in the world. I was dragged in by my friends and with little knowledge or interest, I instantly fell in love with acting. Fortunate to be coached by one of the best in the country in Jerome De Silva, we went for our first competition in 2006, failed. 2007 failed. 2008 failed again. 2009 failed. We never

made the finals, not even close. We were actually made a laughing stock by other competing schools.

The fifth year in 2010, I was president of the club. This excited me and I was so motivated to do something that has never been done before, to enter the finals for the very first time in college history. We put on a great show with *Macbeth*. We had special effects - flying heads, puking blood... you know...the whole nine yards. And people loved it! Or that's what we thought because surprise... surprise..! We didn't make the cut. Failed again. 5 years of taking part and not making the finals. I felt that was it, we did everything, and in my leadership position, I couldn't get the job done.

The following year, 2011, I was Head Prefect and drama was led by my close friend Divakar David, we were preparing for the comp with *Othello*. That year college had a science exhibition and everyone was so focused on that. No one paid any attention to drama.

So we get to a point where we were all casted and ready to rehearse. It was obvious that none of us were prepared. Jerome comes into direct and at this one rehearsal, and he absolutely lost it, told us off, gave up and completely left us. But before he left, he called me to a corner and said 'you have been in every Shakespeare this place has taken part, if you can't get it done this year, don't call yourself an actor, don't call yourself a leader'.

And there he went. And there we were a bunch of guys with scripts in our hands, the competition a fortnight away, helpless. I took this as a challenge and knew this was it, this was my final

chance and an opportunity to prove myself. One step at a time I thought.

That year we went all out, we were so motivated and committed that the entire cast shaved their heads bald! On the day of the competition, we went up did a stellar performance, and went up to the balcony of the Lionel Wendt for the judges' verdict. The judges came out gave their feedback and finally got to revealing the four finalists. One of the judges, Jehan Aloysius from St. Joseph's College, made the announcement 'and in no particular order that finalists are Merry Wives of Windsor St. Thomas' College, Coriolanus D.S. Senanayake, A Midsummer Night's Dream Ananda College,' by this time I had my head down, remembering scenes from previous years, thinking here we go again. Then, Jehan uttered 'Othello....' And paused. I was thinking it's probably some other school who performed Othello. But then the silence broke and Jehan's voice so subtly, almost like he was in an actual play, 'St. Benedict's College!'

I looked up and the whole place had gone crazy, the boys were all over screaming for joy! I remember the first thing I did, I looked directly at Jerome who was sitting two seats next to me. I looked at him, he looked me back and he said "You did it!", we did it.

And that was the single moment that changed me forever. It taught me an invaluable lesson. Life will test us with setbacks. Do not quit, these situations are not permanent. We have full control of our lives to move forward, one step at a time.

Maybe right now you are struggling with your day to day life, or maybe you are so prepared to achieve your next goal, but your head keeps telling you it's not possible. Achievement is not for the select few. Achievement is simply for those who never quit. It is

for those who set goals. It is for those who put the most steps in front of the others. Achievement is for those who can overcome the greatest obstacle of all, the fear of failure.

The only thing that keeps us from getting what we want, is the story we keep telling ourselves about why we can't have it. Failure stops us only if we let it. So I would like to end with a quote of my own,

"You are your own fear, overcome it, one step at a time."

Steffan Irugalbandara

Bachelor of Management | Master of Marketing

2015 Graduate of the Year, Deakin University

2016 and 2017 Student Excellence, Monash University

A Call To Attention For People With Severe Disabilities In Sri Lanka

Peter Gibilisco & Steffan Irugalbandara.

This article is respectfully dedicated to my many Sri Lankan friends whose friendship has been an inspiration. Though I suffer from a severe and progressive disability called Friedreich's ataxia which leaves me without the energy and capacity to easily make and develop friendship the Sri Lankan people of my acquaintance ignore this hurdle and unashamedly treat me with respect. They come from a country that admires intelligence, and I am the lucky recipient.

Sri Lanka and its major recent happenings.

Firstly, Sri Lanka became a republic in 1972. In a few years it will have its half-century anniversary! Before 1972 it was known as Ceylon.

Sri Lanka underwent a period of political and natural devastation during 1983-2009.

There was an intermittent insurgency against the government by the Liberation Tigers (the LTTE, also known as the Tamil Tigers) which fought to create an independent Tamil state called Tamil Eelam in the north and the east of the island. After a 26-year military campaign, the Sri Lankan military defeated the Tamil Tigers in May 2009, bringing the civil war to an end.

Sri Lanka was one of the countries struck by the tsunami resulting from the Indian Ocean earthquake on December 26, 2004. On January 3, 2005, Sri Lankan authorities reported 30,000+ confirmed deaths.

The south and east coasts were worst hit. One and a half million people were displaced from their homes. The death toll continued to rise as the threat of infectious diseases breaking out turned into a reality, with doctors confirming first cases of cholera.

And then Sri Lanka has suffered continued economic decline. The immense economic power held by the state provided the party in power with the opportunity for patronage, nepotism, and corruption. By 1977 unemployment had risen to about 15 percent. In July of that year the Sri Lanka Freedom Party (SLFP) was defeated by a reorganized United National Party (UNP) under the leadership of J.R. Jayawardene, who became Prime Minister.

Sri Lanka and the struggle for justice for people with severe disabilities

Currently, Sri Lanka has a large population of around 21 million and one of the saddest predicaments of this large population is the overwhelming belief that to have a child with a disability is simply "bad karma". Such fatalistic stereotypes simply confirm the problems of increasing socioeconomic injustice for people with severe disabilities.

Health worker estimates report that 30% of disabilities in Sri Lanka are caused by infectious diseases.

And for those with severe disabilities there is accumulated social

and personal devastation. For a family, having a child with severe disabilities, creates appalling socioeconomic hardships. That is, a child with a disability is simply viewed as a social and economic burden for the rest of the family.

With my "disability" I have had to wrestle with and overcome the fatalism of negative stereotypes, even the labels I stick on myself. So, I want to suggest that rather than giving up to the fate of "bad karma" what is needed is a conscious effort to help and increase the synergies for people with severe disabilities. They are simply going to have better facilities and kind carers.

How do we create change of this sort? The Sri Lankan government has not the means to do this on its own, and presently, the legacy of the civil war and the tsunami has emptied government coffers rendering the government "disabled" or "severely handicapped" so that the infrastructure and facilities are not there ... yet. Under urgency, Sri Lanka developed "National Policy on Disability for Sri Lanka" in May 2003.

Developing a national disability policy is a major objective for socioeconomic policy enhancement of people with severe disabilities in Sri Lanka.

This can be formulated through policy that enables an equitable direction that will also create socioeconomic stimulus for people with severe disabilities.

In following this procedure, policy makers in Sri Lanka have thought it wise to track the rights and responsibilities of people with severe disabilities in their country. To meet these demands the committee that had the responsibility

for drafting the policy had a very wide cross-section of members representing all the major types of disabilities, in all age groups, from Government, NGOs, those with expertise in Law and Human Rights and in reckoning with gender equality. The strength of the policy, however, lies in the process adopted for its development. This has been essentially a participatory process, with the Ministry of Social Welfare seeking collaboration from other relevant Government Ministries, NGOs, the Private Sector and UN and International Agencies as part of the consultative process.

Separate meetings were held with each sector regarding specific policy areas. Individuals who have disability and their organizations were given the opportunity to participate, as were civil society groups as well as a call going out to the general public through numerous notices and announcements in both the print and electronic media.

The views and representations of all those who participated and contributed in any way have been taken into consideration in the formulation of this policy. The National Policy is presented in two parts.

Part One provides the rationale underlying policy formulation, containing its scope, its underlying socio-economic considerations, identifying the barriers that exclude people with disabilities of some or other form from the socio-economic mainstream, and the resources available for policy implementation.

This is the situation that has been taken into account in deciding this policy.

For each policy area, policy statements are made and strategies for their achievement are listed. The Policy also emphasizes the specific need that has to be addressed and suggests mechanisms for its implementation, monitoring and evaluation, and lists those Ministries that may take responsibility for these various aspects of policy.

But as Judeland Anthony in a YouTube video pointed out, Sri Lanka has a mindset that is stuck in the past, "they think many people with disabilities are also intellectually disabled". For example, Friedreich's ataxia is not an intellectual disability but the confusion it causes, allows a lot of people to reach for the stereotype.

When care becomes careless?

Dr Peter Gibilisco

The book's title is 6 and 1/2 years on a dung-hill; life in Specialist Disability Accommodation

It consists of edited versions of posts I have made to On Line Opinion (OLO) (www.onlineopinion.com.au), John Menadue, ProBono, The Conversation, DesignForAll, and my personal blog.

My aim is to affirm vital principles that need to be better understood and implemented if the National Disability Insurance Scheme (NDIS) is going to be of benefit and fulfil its mandate, so that care doesn't become careless.

What I have to say should be of assistance to people like myself who not only need heightened levels of care, but also encouragement to "keep going." If we are to maximise our potential, we need to grit our teeth (if we still have teeth) and rise to a big challenge even though we face severe deterioration. What I have to say is aimed to encourage people to keep on pushing the case for disability justice.

But my words are also aimed at those providing a service to people with disabilities. I'm addressing all who are involved in disability care, whether they are in one-on-one relationships, or professionals, social workers or those with medical and nursing expertise. My book is also aimed at those managing facilities that look after communities and groups of people. So, the book has a wide focus.

At times readers will say to me, "Hang on! That's a bit over the top!" I apologise if I hurt anyone with what I say, but my aim is not to win a fight, but to present a case.

And my case can be understood by the following points:

1. I write about myself as a severely disabled member of this community. I want to tell a story about my goals and about the hurdles I have had to overcome in recent times. I have already written and published about my earlier life (A Patient's Journey: Friedrich Ataxia <https://www.bmj.com/content/347/bmj.f7062>) Now I want to write as my strength and sight get weaker. In recent times I have had to confront further disappointments and want to share some of those to explain just how crazy life can be with the deterioration of my bodily condition, so that readers can better understand. I want to assist those who are keen to ensure that care doesn't become careless.

2. I also write about some negative tendencies I have encountered, and continue to encounter, and which need to be overcome. I have experienced these in the care that is given to support people like myself. I'm aware this might read as if I am simply just whining, and it's not always easy to explain what seems glaringly obvious to me. Some things need to be avoided if care is not going to become careless. Some of these tendencies are:

2 a. Stereotyping within the disability sector, which is often enforced by standardized policies.

2b. Treating people with disabilities as 'customers.' This is a very spurious term, especially concerning the care people with severe disabilities ought to receive.

2c. Treating people with slurred speech as if they have a mental deficiency. Adam Vogel (2015) wrote 'Speech disorder is an invisible form of disability.' How we sound influences how we are perceived physically, intellectually and morally. For individuals with a speech disorder (e.g., slurred/slow speech, stuttering), those biases are often intensified, leading to substantial social impact beyond the speech disorder itself.

3. And so I am giving advice not just to those I know but also to those forming policy, making laws and framing legislation. I am giving advice about the principles that should govern schemes like the NDIS. Disability is not easily lived with, let alone overcome. For success, the NDIS' will require a greater contribution from all citizens to support all who are directly involved. And this book is my contribution.

Friedreich's Ataxia does not affect my intelligence, but many working in the disability sector act as if they do not believe this. But the reality can be highlighted by my academic qualifications, which are a double degree from Monash University, Master of Arts from Monash University and a Doctor of Philosophy from University of Melbourne. My PhD was achieved late into the progression of my disease, when I was 43 years old. Many say to me that this was a huge achievement, and I am aware of some taken-for-granted misunderstandings about Friedreich's Ataxia.

However, there are many degrading effects to be battled with, such as blindness, very poor speech, hearing impairment, poor heart and limited mobility and coordination.

This book has been achieved with the assistance of two very good friends, Bruce Wearne and Christina Irugalbandara.

<http://petergibilisco.com.au/>



Bruce Wearne (1951-) is a doctoral graduate from LaTrobe University (1985), having also gained qualifications from Monash University (B.A. 1969-1971) and the University of Waikato, New Zealand (M.SocSc 1978). His scientific specialty is sociology and he has served as a lecturer in that discipline at Chisholm Institute of Technology and Monash University (1982-1998). From 1999 he has lived and worked from Point Lonsdale, Victoria, Australia. Having recently published essays on two major sociologists of the 20th century - Peter Berger and Talcott Parsons - he continues to work on various projects. He also walks a lot along the coast near his home since this stimulates his reflection of many things including his ongoing conversation with theoretical sociology. He is also involved as a volunteer in a local aged-care facility. With the decisive shift around the world making English the preferred language for global communication he also assists scholars and others in the editing of research reports, as well the translation and publication of vital documents and books. He is also active in developing public policy on many contentious political issues that give expression to a "Christian political option." He is married to Valerie, a social policy researcher, and has two grown up sons.

Pushing on for Justice: A Ghost-Writer's Perspective

Review of Peter Gibilisco 6 and ½ years on a dung-hill; life in Specialist Disability Accommodation CCB Publishing. 2019

(a shorter version of this article appears in the Foreword of the book)

This book brings together the reflections of a remarkable fellow who keeps on pushing for justice. This is a task that has preoccupied Peter Gibilisco in all his waking moments for decades. Observing Peter going about his 'work' - under the trials and tribulations that he has to surmount - causes many to ask a simple, but profound question: What keeps him going? How does he find the energy to persist?

In the pages that follow, Peter tells his own story. 6 and ½ Years on a Dung-Hill issues a call for greater awareness of the complex task that beckons as we seek to build just societies. As concerned members of innumerable polities we have a responsibility to ensure safe and just structures and processes of care for those whose abilities to contribute are severely constrained by bodily malfunction, disease or injury. We need to find ways to enable such contributions and, yes, we need to find ways to allow the voice of those who cannot speak - like Peter with his very slurred speech - to be heard. I'm privileged to be asked by Peter to write this review as I've been privileged, over the years, to also function as Peter's 'ghost writer'.

In recent times the load of helping Peter maintain his persistent efforts at public communication has also been shared by Peter's

'academic assistant'. From where I sit - perhaps 100km away from Noble Park where Peter resides on his 'dung-hill' - I have been able to observe Chrissy Irugalbandara's skills in providing our author with excellent advice and assistance with communication by innumerable emails. On occasion, she has also been an indispensable contributor at meetings planning Peter's care. Her astute advice and assistance has been a pre-requisite for bringing this book to publication. Not only has she kept the communication 'flowing', but her friendly advice and perceptive questions have kept Peter 'on message'; she has prevented serious miscommunication. As well, there's that 'indefinable' part of the economy that binds writer and us writer's assistants - it's what is generated by a shared trust between those working on the same project. Peter would refer to it as 'synergy'. It is a scarce but unpricable trust, perhaps best seen as a 'by-product' of ongoing friendship.

As I read this work, I find myself reflecting on the peculiar character of my own role as one who has regularly served as 'ghost writer' for this scholar's project. I'm also thinking of Chrissy's work that has ensured that Peter, the 'political activist', has now published another book that maintains his public policy 'voice' for the severely disabled. And all three of us know how each has contributed to this, and yet Chrissy and I also know very well that this is not our 'voice', this is not our contribution to 'public policy'. This is Peter's work, and we are glad for him that it be so.

It's a truly remarkable state of affairs in which we have participated, even as we have helped to form so many of the words that constitute Peter's communicative contribution.

Not everyone can publish material that openly draws attention to his or her own 'bag of bones', let alone one of bodily constraint that bring personal and intimate disappointment and frustrations. This is the daily reality for those with a 'disability'. Need it even be said that these are deeply personal issues? Well yes, but not simply to bemoan or complain. The 'bodily malfunction' presents silently as moan more profound than any thousands of words could configure.

Those who do make their contribution publicly and in publications, as Peter continues to do, have learned to do so without worrying too much about the image projected when 'talking' with the help of a computer robotic voice or describing one's situation on the page, or computer screen.

There is something inspiring here and I would invite readers to think deeply about this communication problematic, in its full compass, as they consider Peter's persistent push for justice for the severely disabled.

Here in this new compilation of previously published articles, newly edited, Peter broadcasts his 'beef' about the ideology that propels the management of supported accommodation. The word 'ideology' is appropriate since that word suggests a much repeated violating effort in recent history to change social structures by engineering the way vulnerable people think about themselves. In this sense Peter's appeal, as a critique of ideology, is a firm appeal to those providing 'Specialist Disability Accommodation' to think again about how easy it is to respond to a person with severely slurred speech as if he or she is mentally deficient.

This book is an appeal for a fresh, more patient, wiser approach to intra-organisational communication. In fact it may well be that

Peter's contribution, while in the main made possible by the IT revolution, the disclosure of which has coincided with his own academic career since the early 1990s, is to provoke SDA's to rethink their communication so that "face to face", "eyeball to eyeball" interaction is given top priority.

As much as this book is advice to social policy researchers and managers of 'disability services' - published strategically at a time when NDIS is being rolled out nationwide across Australia - it is also autobiographical, drawing upon his own experiences. His contribution assumes that much more is at stake than merely ensuring his own sense of satisfaction at having given voice once more to his critique and suggestions for reform.

I have known Peter for over 25 years, since he first knocked on my door at the Frankston Campus of Monash University when he struggled to negotiate the ill-equipped elevator in his wheelchair to get to my second floor office. In two successive years he asked to be included in the Summer Semester "Introduction to Sociology" courses I was teaching. One thing led to another and, as he tells it, he became an enthusiastic student who eventually concentrated on sociology and even developed the outrageous long-term aim of bringing the disciplines of sociology and economics together in some kind of creative symbiosis. These days he would say that sociology and economics need to overcome a loss of "synergy". That was also the start of our friendship.

First off, our friendship grew from a relationship of lecturer and student; then I became his Honours supervisor and when he pushed on further up the higher education mountain-range, I became his MA dissertation supervisor as he chose to write a Masters Thesis on Hugh Stretton (1924-2015), the critical

historical economist who had done much to bring economics and sociology together. During this time (1999) I departed from the University, but we kept in touch.

Since then, Peter went on to gain a PhD and a reputation among prominent economists for his brazen jet-setting willingness to knock on academic doors around the country as part of his refusal to allow his condition to prevent his mobile mind from pushing ahead with what had to be done. In more recent decades, as (I have said, I have acted as his proof-reader as we have looked carefully at social policy, as fellow members of this Australian political community doing what we can to promote public justice.

In March 2006 he graduated with a doctorate from Melbourne University, and from then on became a regular contributor to various web-based sites including Graham Young's On Line Opinion. He has also launched his own blog and contributed elsewhere as well.

Recent years have not been all plain sailing for Peter. And what we have here are the ongoing reflections of a social justice activist from within the difficulties, as he continues to live as one of the "21st century precariate" on top of his "dung hill".

Peter works. His body may be inert and incapable of what we might say are 'normal' physiological responses, but the arrival of this publication is evidence of his persistent effort to "push back" against the frustration that such restrictions bring with them. Readers, like myself, can have little knowledge of how frustrating a day-by-day experience under these conditions can be. So I counsel readers that when what you read seems tinged with bitterness keep in mind that Peter is "pushing back" against being overwhelmed by the debilitating of Friedereich's Ataxia. His aim is

clearly to keep his own responsibility as an advocate for social justice on his and our horizon.

Well done, Peter. Thanks for continuing to remind us all of our responsibility to contribute to social justice!

Bruce C Wearne

Point Lonsdale

Social Aspects of a Complex Neurological Disability.

My friend Peter Gibilisco has, over many years, taught me about the social aspects of Friedreich Ataxia (FA). It has been a large part of Peter's life and it plays a big part in our friendship. Ever since I first met him, this weighty intrusive bodily condition has annoyingly shaped his social life and has been "present" in that social sphere we call "higher education" or "science". FA demands an ethic of patience. Things take time! In that professional sector of social science, Peter's involvement has taught me that though FA doesn't go away, Peter hasn't gone away either! So I've learned that FA is something to "resist"!

Consider the social act of "resisting". Recall the "demo"! "What do we want? When do we want it?" No, this resistance is no demo like that. We might even say that in Peter's case it's more "radical" than that. This "resistance" to FA comes to expression in "keeping going" in a day-after-day determination to "stick at it".

But thinking about FA should be sobering: what happens when you need someone else to get you out of bed in the morning? What is life like to have to wait until your PCA arrives? And then, what about the intimacy of taking a shower, let alone how to adequately perform other bodily functions?

I mention "ordinary things" like waking up and having a shower to note how these things are not taken-for-granted when FA struts its stuff! What is life like if you have to eat from a spoon someone else puts to your mouth?

Take wheelchairs. They are marvellous inventions; they augment mobility. It's great to motor down to the shops on your own, but how do you get out of the way of the person you don't want to see?

Then there's communication - you want to laugh with your friends but how do you discuss politics when your speech is badly slurred?

There's much more to say but let me conclude with this: the day to day "resistance", that is part-and-parcel of life for people like Peter who are afflicted with FA, has great potential to reorient our social vision, to soften and sensitize and make us all more gentle and thankful for the lives we have been given. That "resistance" has unpriceable social value across the entire horizon of social responsibility.

Bruce C Wearne BA, MSocSc, PhD



Adam is A Professor and Director of the Centre for Neuroscience of Speech at The University of Melbourne, Australia, where his team work towards improving speech, language and swallowing function in people with progressive and acquired neurological conditions.

SPEECH THERAPY

Professor Adam Vogel, University of Melbourne.

Speech (how we sound) changes in people with Friedreich ataxia (FRDA). FRDA is a multi-system degenerative brain disorder that results in difficulties coordinating arms and legs, and the muscles that control eating and talking. It also affects vision and hearing. As the disease progresses, speech becomes slower, pitch and loudness are harder to control, breath support for speech declines and words and sounds are less clear. This speech disorder is called dysarthria. Speech can become unclear and difficult to understand. It sounds different to healthy speakers. Dysarthria often results in changes to peoples' esteem, their employment opportunities and their ability to form and maintain personal and professional relationships.

The complex nature of FRDA, including vision and hearing difficulties, combined with difficulties controlling arm movement, make the use of alternative communication devices (in place of speech), a challenge. Some intensive speech treatment programs that build on biofeedback technology show promise for improving speech in this life changing disease group.



Associate Professor Louise Corben started her professional career as an Occupational Therapist working with people with complex neurological disability. She is now a MRFF Next Generation Career Development Fellow based at the Murdoch Childrens Research Institute, Melbourne Australia. Her research is focused on clinical interventions designed to improve functional capacity in individuals with Friedreich ataxia. She also coordinates the clinical service provided to individuals with Friedreich ataxia.

Physical supports and equipment related to Friedreich ataxia.

Associate Professor Louise Corben.

Friedreich ataxia (FRDA) is progressive, currently incurable, and has devastating consequences for mobility and quality of life, necessitating the provision of appropriate physical supports that will improve, or at least maintain health, well-being and functional capacity. Symptoms including reducing balance, hand function, vision and hearing; muscle weakness; fatigue; spasticity; scoliosis and foot deformity all interfere with the ability to mobilize, attend to personal daily tasks such as dressing, toileting, showering, eating and using a computer and, ultimately community and social participation. The progressive nature of the condition is particularly challenging. Dealing with the grief and frustration of losing yet another skill such as feeding oneself presents a never ending challenge to both the person living with FRDA and the clinicians who are responsible for the appropriate prescription of adaptive equipment or physical supports. Compounding this issue is the presence of little evidence regarding the provision of adaptive equipment or physical supports for people with FRDA. Individuals with FRDA require access to clinicians who are either experienced in the requirements of someone with FRDA, able to incorporate evidence from similar progressive, neurological conditions into their clinical practice but most importantly are able to listen to and incorporate into their clinical practice, the experience of a person living with FRDA. By way of example getting the prescription of the first wheelchair right is crucial both

in timing of the wheelchair (not too early to encourage walking for as long as possible) and the type, dimensions and adaptability of the wheelchair (to accommodate the current and changing needs of the person living with FRDA). As such a successful wheelchair prescription is the combination of the expertise of an experience clinician and the lived experience of the person with FRDA. This is critical for a person who faces a progressive and seemingly inevitable loss of function. Maintaining the capacity to participate in self-care tasks can provide the critical difference between autonomy and dignity, and complete dependency which, in the context of this unremitting, unforgiving and devastating disease will be inevitable if appropriate physical supports are not provided.



Professor Martin Delatycki is the Medical Director of Victorian Clinical Genetics Services and Co-Director of the Bruce Lefroy Centre at Murdoch Children’s Research Institute in Melbourne Australia. Martin has clinical and research interests in neurogenetics and genetic screening. He heads the Friedreich ataxia research program at Murdoch Children’s Research Institute. He has more than 100 publications related to this disorder. He is currently overseeing clinical trials of resveratrol and rehabilitation for ataxias.

Friedreich ataxia

Professor Martin Delatycki

Director, Bruce Lefroy Centre, Murdoch Children's Research Institute

Described by Professor Nikolous Friedreich in the 1860's, Friedreich ataxia is severe, progressive genetic disorder of the nervous system. Friedreich ataxia has an average age of onset in the early teens and causes worsening incoordination (ataxia). Affected individuals require increasing support for activities of daily living with a wheelchair being required for mobility on average 15 years after the onset of symptoms. Friedreich ataxia affects multiple body organs. The heart is affected in most (cardiomyopathy). Diabetes, scoliosis (curvature of the spine), impairment of vision and hearing, issues with bowel and bladder, swallowing problems and speech articulation problems are all more common in people with this condition. Life span is reduced with the average of death being in the mid-30s. Heart failure and irregular heart rhythm are most common causes of death.

Friedreich ataxia occurs due to a person having a fault (mutation) in both copies of a gene called *FXN*. About 1 in 100 people have a single faulty *FXN* gene and about 1 in 40,000 people have Friedreich ataxia. There are many interventions that can improve quality of life for people with Friedreich ataxia. These include physiotherapy, occupational therapy, speech therapy, orthopaedic surgery, use of hearing devices and medications to treat symptoms. There are, however, no medications that have been shown to slow the inexorable progression of this condition.

Since the genetic basis of Friedreich ataxia was discovered in 1996, the mechanism by which this leads to cell death in vital organs is increasingly understood. This has led to therapies being developed and tested in clinical trials. In addition to medications, genetic therapies are being developed that will be tested in humans in the coming years.

Since its description in the 1860s there have been huge advances in understanding Friedreich ataxia and we are now entering the era of discovery of therapies. Hopefully in the not too distant future, the diagnosis of Friedreich ataxia will result in treatment being introduced to prevent its progression and to allow those affected to have a life little different to those without this condition.



Letter from the Chairman's Desk

By Sunil Bhatia PhD

I was watching the television and my favorite actor was performing for whom I was considering best actor among current lot of actors . Suddenly there was breaking news that his mother has expired and he was crying on dead body of his mother. I found what he performed on screen from what he is behaving in reality was completely different. I was shocked by his behavior.

Another incidence has happened to me that my reaction to death of my mother was completely different to when I go for cremation of known people. It was extremely painful and I am still under that effect of death of my mother on 18th August 2018 and I attended others cremation and came back to normal daily life.

Dr Rain Scott was my philosopher and guide and helped me in establishing this publication who also died in the month of April and before that I received his email that was not legible and was reflecting as someone in extreme pain. I replied his mail but he could not answer my e-mail. Recently I received email of Prof Dr Peter Gibilisco that was with font size of 72 points. That made me to think for inviting him for Guest Editor and requested him to highlight his medical problem and world designers should work for attending this serious issue. Our publication has never attempted in highlighting the problem but focusing on problem with solution with design. Why did I explained different situation in above paragraph where we behaved in never expected manner because we were never passed from that phase of life what others were passing. It is easy for anyone to imagine problems from the distance but when it strike us our perception entirely changed.

I request our readers that they should feel the pain of shoes when you step in your feet into

Prof Peter accepted our invitation of Guest Editor and we are starting a new segment of raising the real issue in our publication. This is a new beginning for us and new for our readers. If your response will positive then we will formulate the policy that in a year we will dedicate two special issues by inviting Guest Editor who are in reality facing the problem. Prof Peter is facing acute problem of Friedreich ataxia (also called FA). It is a rare inherited disease that causes progressive nervous system damage and movement problems. It usually begins in childhood and leads to impaired muscle coordination (ataxia) that worsens over time.

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

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

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

With Regards

Dr. Sunil Bhatia

Design For All Institute of India

www.designforall.in

dr_subha@yahoo.com

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Forthcoming Issues

April 2019 Vol-14 No-4

Ms Ruth J Clark, Fashion Moves will be the guest editor and she will highlight on special dresses



April 2019 Vol-14 No-4 (special)

"B.Arch (1999) from Government College of Architecture, Lucknow. Doctorate in Infrastructure Financing & Planning (2011)



from Indian Institute of Technology Roorkee (IITR).

She has a professional experience of more than 18 years. Presently, she Professor & Acting Director in Amity School of Design, Amity University Noida. Apart from this, she is researching extensively in the area of urban infrastructure development and policies she has conducted academic research in the area of 'Accessibility'. She is 'MASHAV' scholarship holder, granted by Republic of ISrael. Earlier, she had worked with Administrative Staff College of India, Hyderabad (ASCI, under Ministry of Human Resource Development, GoI), as Faculty in 'Centre for Energy Environment Urban Governance & Infrastructure Development'.

She has extensively indulged in 'training of trainers' for senior executives of the Central Government, State government and PSUs, as program director, coordinator and resource faculty.

Also, she has experience of leading the team for capacity building program organised by government and multilateral organisations jointly with ASCI in the area of PPPs in Urban Infrastructure. She had the privilege of working for the nomination process for social infrastructure projects for Prime Minister's Award.

She has worked with Central Government, State Government department and multi-lateral organisations. Prominent among them is Department of Economic Affairs Ministry of Finance GoI, ADB, Department of Personnel & Training GOI, Government of J&K, NTPCL, ULB of Bangaluru etc.

She has comprehensively reviewed the existing regulations and trends in the infrastructure sector both domestic and international at length. Further she has been closely scrutinizing the on-going national and state policies pertaining to regulatory issues.

She has published book chapters with renowned international publishers and refereed research papers in the scopus indexed journals.

May 2018 Vol-14 No-5

Emilio Rossi is CEO of Emilio Rossi Design Consulting (Italy) and Adjunct Professor of Industrial Design in the Department of Architecture at the University of Chieti-Pescara (Italy).



He got a PhD Industrial Design (Architecture and Urban Planning Programme) and a Master in Architecture at University of Chieti-Pescara (Italy); he also completed a Master in Euro-Project Management at Europa Cube Innovation Business School (Italy). In 2013, he was a Visiting Research Scholar at Brunel University London (UK), where he conducted studies on Inclusive Design, HCI Design and Design Research.

His research interests revolves around four areas: 1) Inclusive Design in new product development; 2) Human-Computer Interaction and new forms of natural gestures for digital and tangible products, with a focus on the development of new technologies, tools and methods for sharing knowledge and know-how (i.e. tacit knowledge); 3) Ergonomic Design for Sustainability and, recently, 4) 3D Printing and Additive Manufacturing.

He serves as Scientific Advisory Board Member for AHFE (Applied Human Factors and Ergonomics), where is Co-Chair of the International Conference on Additive Manufacturing, Modeling Systems and 3D Prototyping, for IEA (International Ergonomics

Association) in the Technical Committee on Human Factors and Sustainable Development and, till 2014, in the National Board of SIE (Italian Society of Ergonomics and Human Factors).

His works has been published in more than thirty peer-reviewed publications, including: The Bloomsbury Encyclopaedia of Design (six items), Proceeding of AHFE, Proceedings of IEA, Proceedings of NES (Nordic Ergonomics and Human Factors Society) and Proceedings of SIE.

Professionally, he has 10+ years' experience in new product development; currently he works as a Designer and Consultant in R&D and Innovation. His works have been awarded and produced by many companies, both in Italy and abroad. Specifically, his products and researches have been realised in Italy, UK, Germany, China, Taiwan, Nicaragua, USA, Canada and Chile.

June 2019 Vol-14 No-6

Design for all specialist consulting public and private sector how to expand their innovation capacity and add value by deep understanding of people-centered design approach and qualitative research. Trainer on how to use human diversity to create social inclusion and develop sustainable solutions.

Experienced coach, passionate opportunity developer and visioner.

Ivelina is the founder of Design for all Bulgaria Foundation, which is part of Design for all Europe. She is also the co-founder of Service Design Network chapter Bulgaria, member of Global Service Design Network. She is currently Research Associate at the Helen Centre of Design at the Royal College of Art in London. Ivelina has a vast experience in delivering training for



professionals, business and non-government organisation on how to use design for social good and life improvement. Her projects include research in access to health information, creating a space for social innovation, conducting research for the first tourist wayfinding system in Sofia, Bulgaria, consulting inclusive playground, consulting technology Startup Company developing robotic devices for people with paraplegia and many more.

July 2019 Vol-14 No-7

GONZALO RAINERI BERNAIN

Assistant Professor | Design School

Universidad Finis Terrae | Chile

PhD (c) in Design

Universidad de Palermo | Argentina

More than 30 years of experience in all fields

of visual communication design and 24 years of experience in the field of interactive design. Permanent formal education and continuous research in the fields of design, interactivity, experience design, new media architecture, market trends, new technologies, bioclimatic architecture and environmental issues among others. Advisor and consultant in strategic and communicational aspects for middle and large companies and organizations. Proactive entrepreneur in new trend media, creating the first Film Animation Festival, first cyber café, first 100% visual magazine and first ECO friendly shop in Chile. Worked for companies and organizations in Amsterdam, Dublin, Madrid and Santiago. Graduate & postgraduate professor and lecturer in design related matters. Actual Product and Spatial Design Studios Coordinator, Member of the Research in Design Committee at Universidad Finis Terrae, Design School. O yeah! Did I say I'm doing a PhD in Design in Buenos Aires at the same time?



August 2019 Vol-14 No-8

Mugendi K. M'Rithaa ,Transdisciplinary Industrial Designer/Educator/Researcher with a passion for Afrika, Design and Innovation.

A widely traveled transdisciplinary designer experienced in design education and research. Skilled in various socially conscious fields including: Industrial Design, Human Factors Engineering/Ergonomics, Advertising and Marketing, Building Research, Design Research, Universal Design, Design Thinking, Communication Design, as well as Design Strategy and management



New Books



ISBN 978-613-9-83306-1



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 man made designs was a significant attempt of thinking beyond survival and no

doubt this contributed in establishing our supremacy over other living beings. Somewhere in journey of progress we lost the legacy of ancestors in shaping minds of future generations and completely ignored their philosophy and established a society that was beyond their imagination. I picked up such drivers that have contributed in our progress and continue guiding but we failed to recognize its role and functions. Even tears, confusion in designing products was marvelous attempt and design of ladder and many more helped in sustainable, inclusive growth.

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Rosemarie Rossetti, Ph.D., teamed with her husband Mark Leder in creating this unique Toolkit. They bring ten years of research, design and building expertise by serving as the general contractors for their home, the Universal Design Living Laboratory– which is the highest rated universal design home in North America.

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From Principles to Practice

Second Edition

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Foreword by Michael K. Young



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EDITED BY SHERYL E. BURGSTAHLER • FOREWORD BY MICHAEL K. YOUNG

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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.

“Sheryl Burgstahler has assembled a great set of chapters and authors on universal design in higher education. It's a must-have book for all universities, as it covers universal design of instruction, physical spaces, student services, technology, and provides examples of best practices.”

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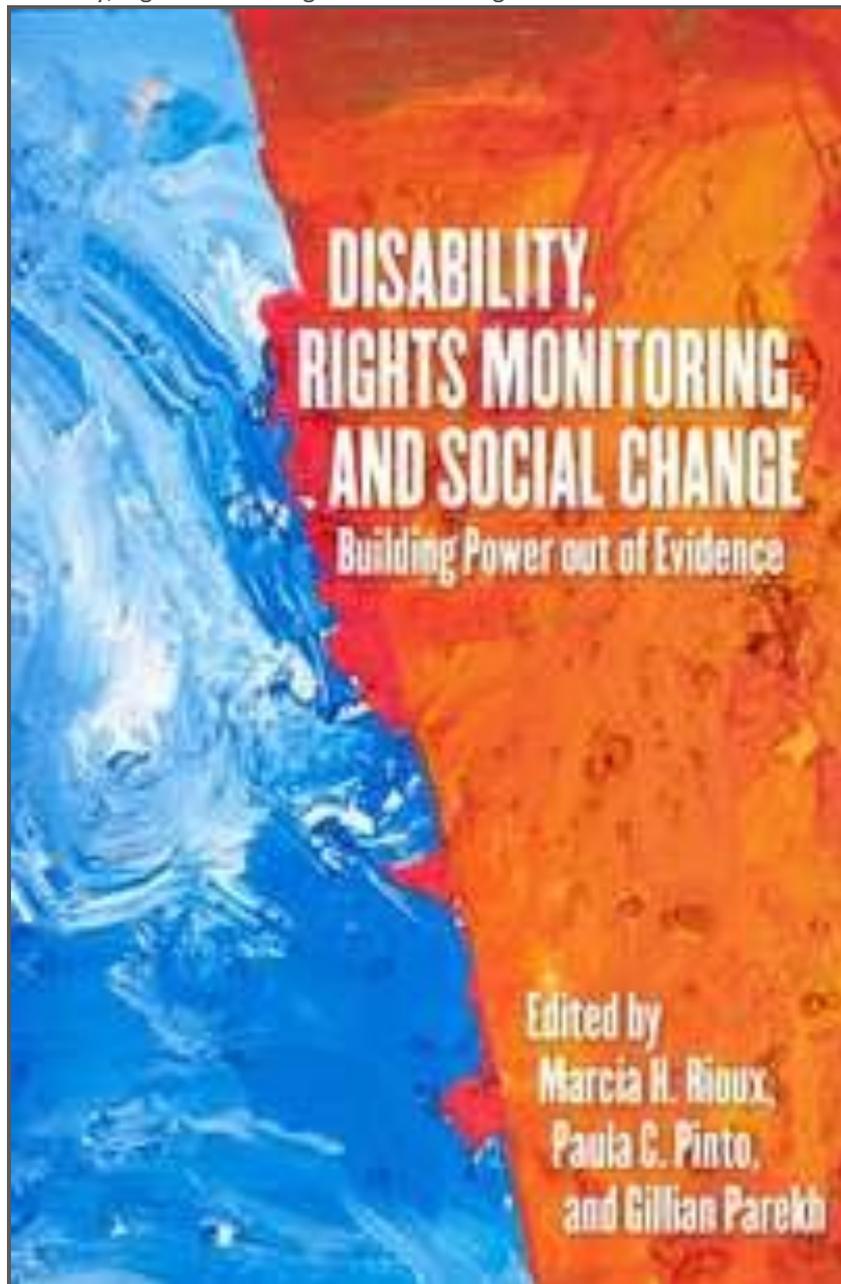
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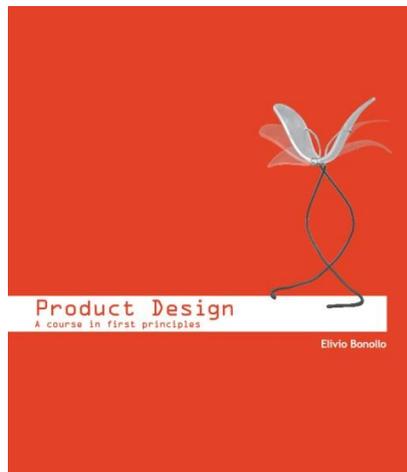
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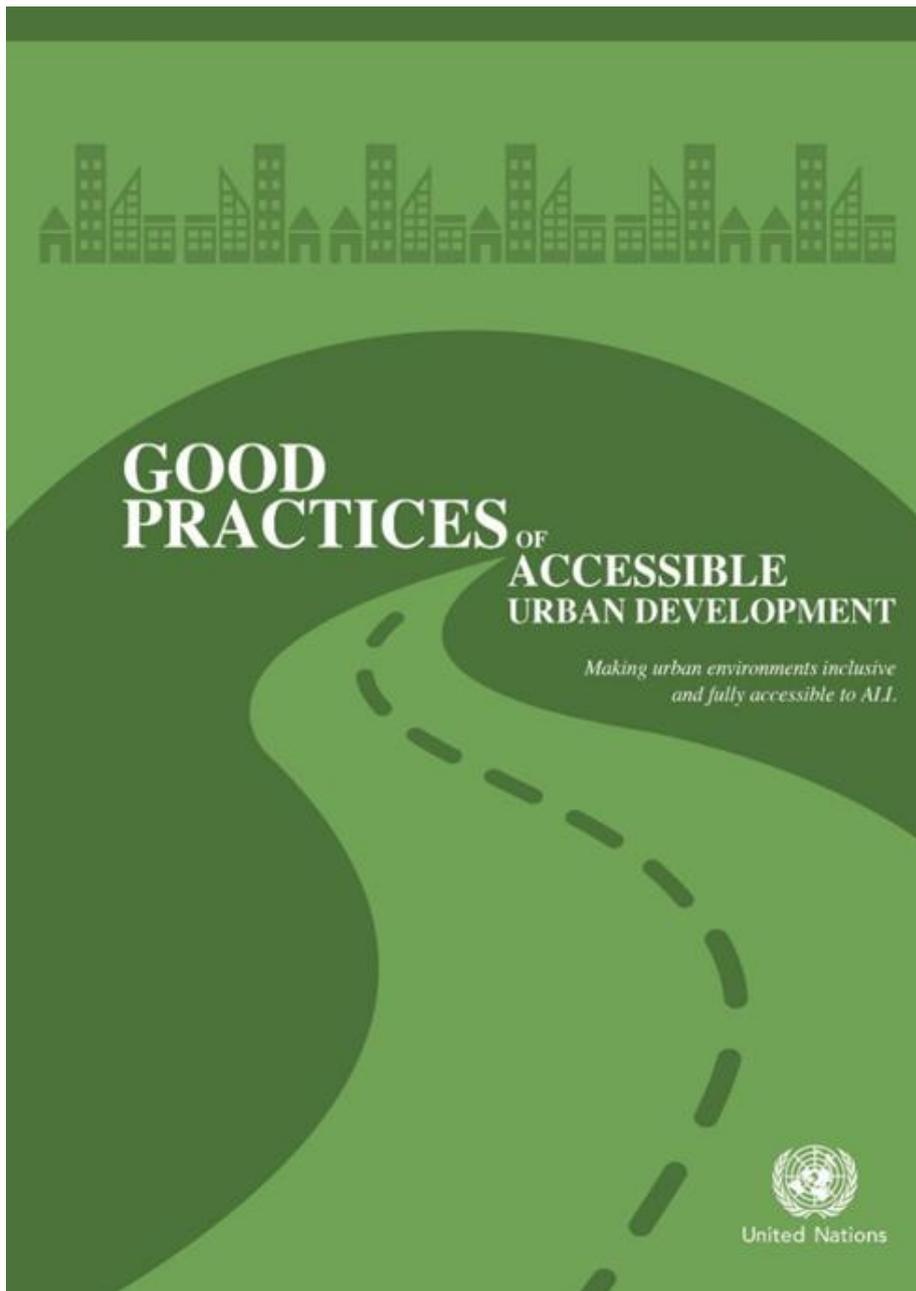
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TAPPING INTO
HIDDEN
HUMAN CAPITAL

How Leading Global Companies Improve their
Bottom Line by Employing Persons with Disabilities



DEBRA RUH



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.

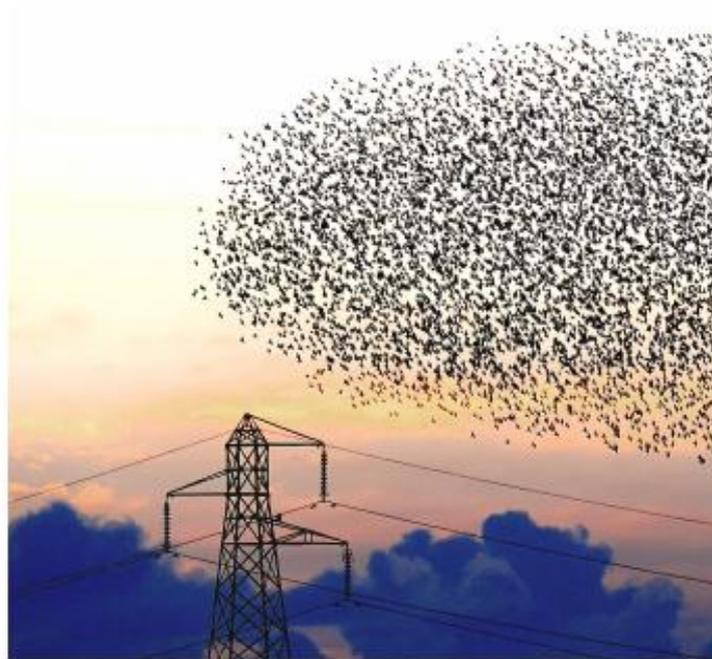
The advance unedited text is available

at:http://www.un.org/disabilities/documents/desa/good_practices_urban_dev.pdf

FROM MODULARITY TO EMERGENCE

A PRIMER ON THE DESIGN AND SCIENCE OF COMPLEX SYSTEMS

Chih-Chun Chen and Nathan Crilly



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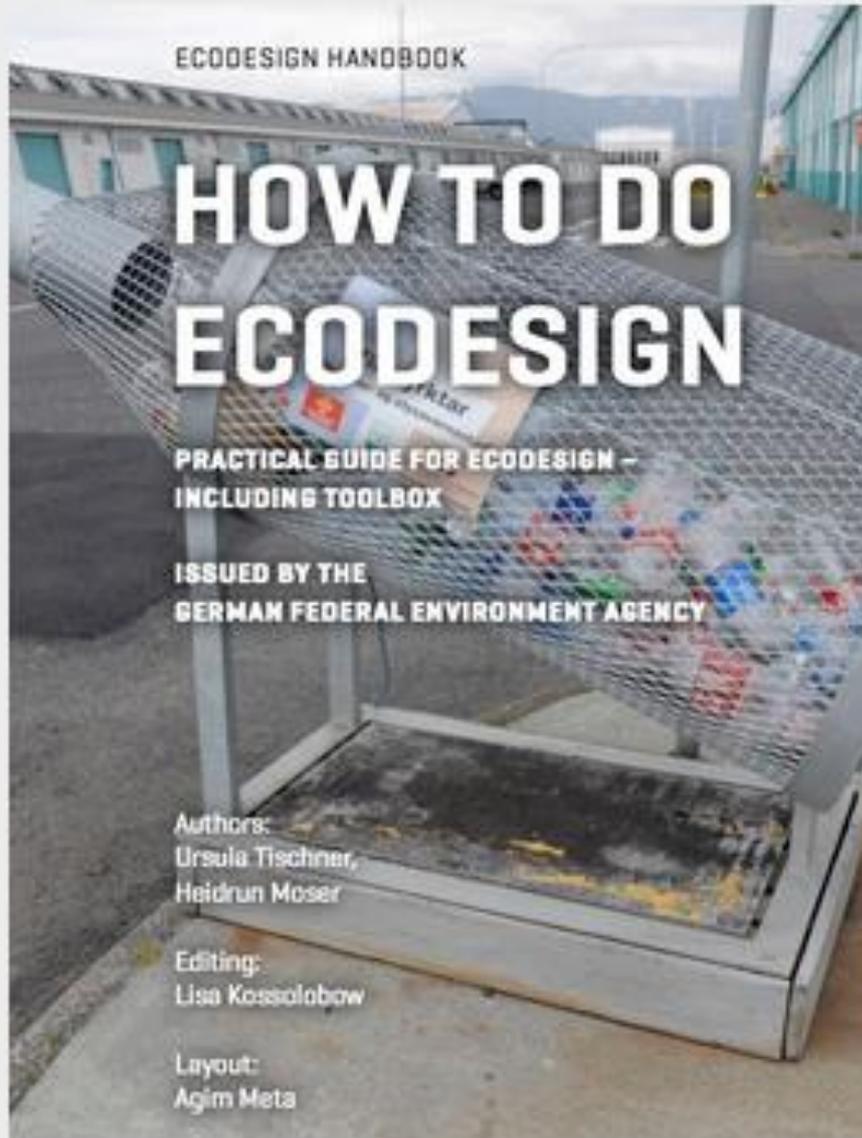
Dr Chih-Chun Chen and Dr Nathan Crilly of the Cambridge University Engineering Design Centre Design Practice Group have released a free, downloadable book, *_A Primer on the Design and Science of Complex Systems_*. This project is funded by the UK Engineering and Physical Sciences Research Council (EP/K008196/1). The book is available at URL:

<http://complexityprimer.eng.cam.ac.uk>

Changing Paradigms: Designing for a Sustainable Future



New iBook / ebook: HOW TO DO ECODESIGN



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TRANSFORMATIONS

7 Roles to Drive Change by Design



Joyce Yee / Emma Jefferies / Kamil Michlewski

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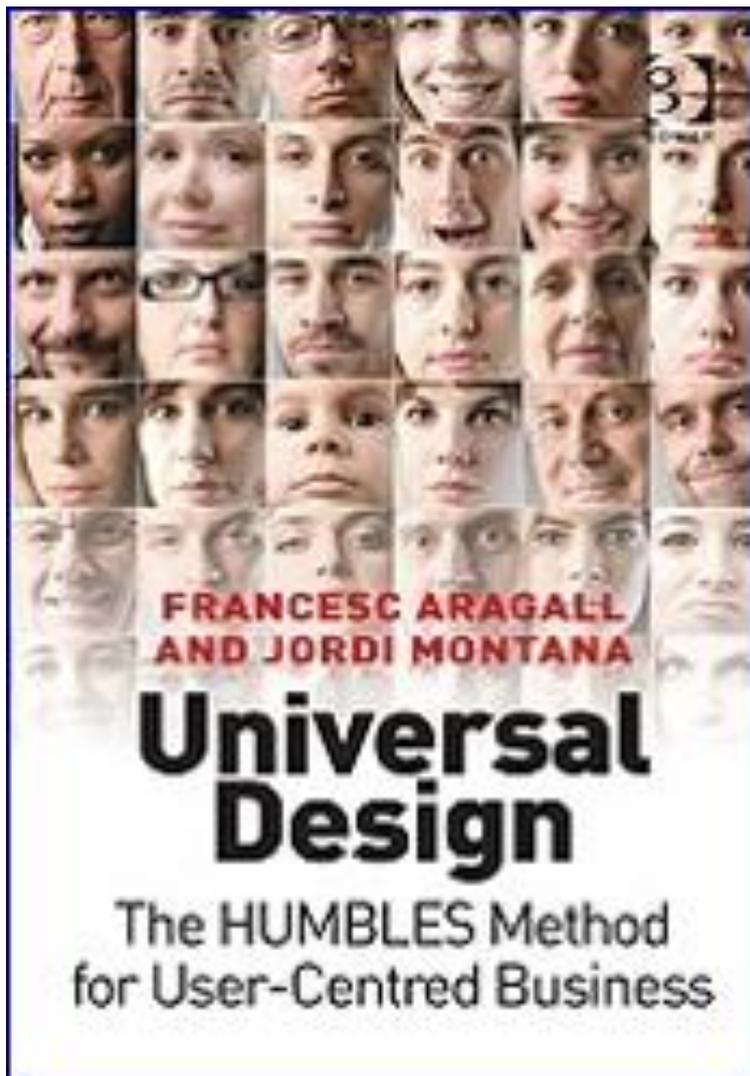
Amar Arnason and Sigurjón Baldur Hafsteinsson

DEATH AND GOVERNMENTALITY

Neo-liberalism, grief and the nation form

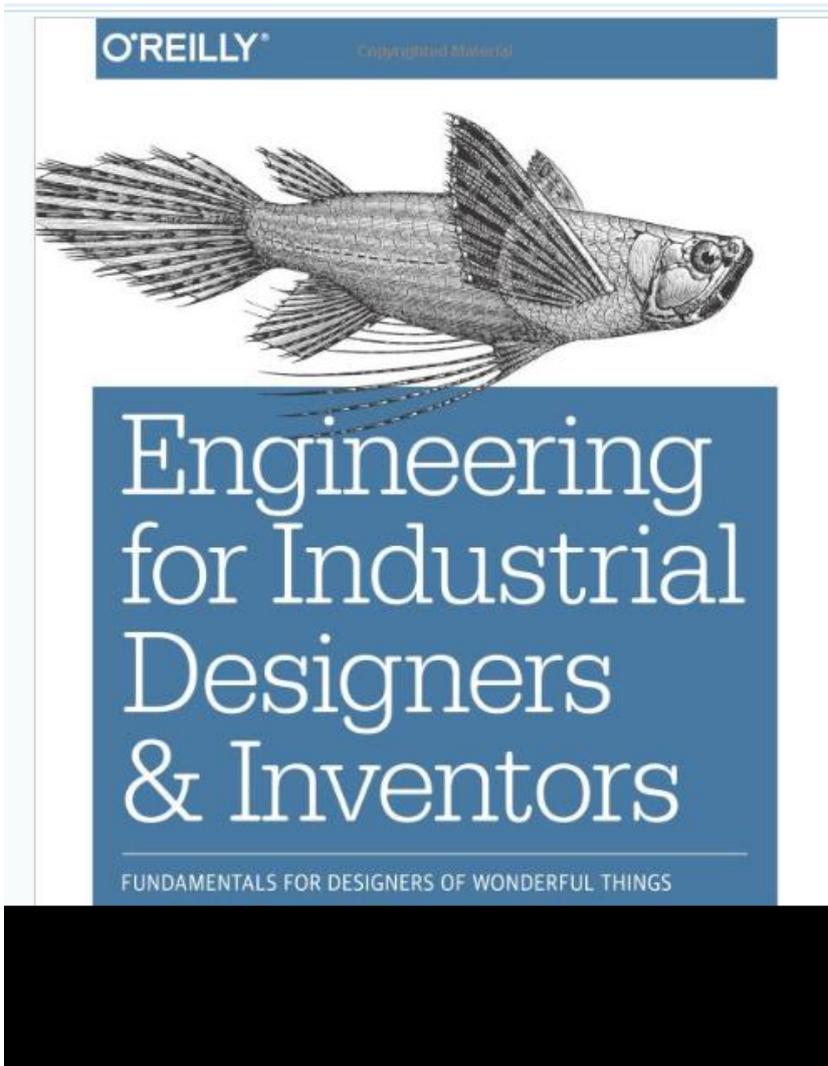


Universal Design: The HUMBLE Method for User-Centred Business



“Universal Design: The HUMBLES 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 HUMBLES 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**



I have a new book that presents fundamental engineering concepts to industrial designers that might be of interest to you. This is the link:

https://www.amazon.com/Engineering-Industrial-Designers-Inventors-Fundamentals/dp/1491932619/ref=sr_1_1?ie=UTF8&qid=1506958137&sr=8-1&keywords=engineering+for+industrial+designers+and+inventrs



News

1.

Can Design Help Prevent Electronic Waste From Ending Up in a Landfill?



Simone Farresin, co-founder of Studio Formafantasma, speaking at the 2019 Fortune Brainstorm Design conference in Singapore.

The research-driven approach of design duo Studio Formafantasma might typically result in beautiful, poetic objects ranging from lighting and vessels to furniture, but the studio has been recently applying its efforts towards tackling a very contemporary problem: the recycling of electronic waste.

“In this moment, electronic waste is the fastest stream of waste growing globally. Only 30% is being correctly recycled while the remaining 70% is being exported to developing countries or simply ends up in the landfill,” said studio co-

founder **Simone Farresin** on **Wednesday** at the *Fortune and Wallpaper** **Brainstorm Design** conference in **Singapore**. **"The obvious question here is why."**

While it may seem like stating the obvious, the recycling of electronic products is actually highly complex. Not only is the issue worsening thanks to the increasing number of circuit boards present in electronic products, but the fact that most copper and metal elements are covered in black rubber for safety also means that they are harder to detect by recycling systems that use imaging to identify and isolate various components by color.

Studio Formafantasma has drilled down into the problem by collaborating with experts in Europe, India and Kenya to conduct extensive research through analysis of different levels of the recycling chain. Their design-led process included speaking with legislators, activists (who use GPS to track electronic waste), recyclers, non-governmental agencies (which support responsible recycling workshops), and manufacturers.

"Design can be used to mediate conversation," Farresin said. "One of the problems we had while speaking to recyclers was the need to gain the information from them to actually design. What we did was dismantle electronic products which we placed, almost as a taxonomy, into different elements so that we could speak with them about the problematics in recycling very specifically."

One of Studio Formafantasma's solutions includes the implementation of a color-coding system that identifies recyclable metal elements and helps separate them from hazardous components. When an electronic device is opened, there is currently no universal design language to indicate which materials are harmful or not.

Another idea calls for the introduction of a labeling system that would be enforced by legislature. This system would require manufacturers to outline the shelf life of each product, rather than concealing its obsolescence, thus allowing consumers to make an informed decision of whether it is worth purchasing or not.

Yet another suggestion is the creation of a digital passport for different types of plastics in the form of a QR code that will enable recyclers to know the composition of the type of plastic they are recycling. "A lot of recyclers struggle to understand exactly what they are recycling because plastics are being engineered daily," Farresin explained.

Studio Formafantasma's measures may seem simplistic, but they offer tangible, conceivable solutions to a mounting problem of a mammoth scale. "We needed to be very pragmatic," Farresin said about his firm's strategies. "Rather than to completely rethink the system of recycling, we chose to operate within it."

(Source: Fortune)

2. New boards for Aiap, Italian association of visual communication design

The association faces contemporary challenges and aims to define new directions and purposes for the profession of graphic designer

Aiap new boards members for 2019-2021 triennium have been elected on Sunday 18th November 2018 at Spazio MIL in Sesto San Giovanni - Milan, during the annual assembly.

Aiap President is Marco Tortoioli Ricci. Executive Board Members are Laura Bortoloni (vice president), Paolo Buonaiuto, Dario Carta (general secretary), Manuel Dall'Olio, David Gil, Francesco Ermanno Guida.

Panel of Arbitrators: Matteo Carboni, Elio Carmi, Francesco Dondina, Carla Palladino, Stefano Tonti. Auditors: Vincenzo De Rosa, Giangiorgio Fuga, Luciano Perondi.

Executive Board's Agenda seeks a deep renewal for Aiap. The association must gain back its central position in the professional path for graphic designers. Aiap needs to craft a contemporary view on graphic design, looking for new definitions on the job.

Executive Board's Agenda will cover these topics:

- **Defining directions and purposes of Aiap**
- **Supporting magazine "Progetto grafico" as a central asset for the association**
- **Promoting new relations with design schools and universities**
- **Developing Aiap Archive "Graphic Design Documentation Centre"**
- **Cultural growth for Aiap members**
- **Consulting activities for organizations and companies**

Aiap Executive Board wants to increase listening and dialogue activities among its members, in order to bring back the sense of belonging and the idea of Aiap as a platform for sharing knowledge and experiences.

Magazine "Progetto grafico", Aiap "workshop publication", is pivotal in this renewal process, a tool to nourish the discussion around the profession from a cultural perspective.

Design schools are today in Italy the place where research and experimentation are happening; Aiap mission is to strengthen dialogue, propose research topics, suggest workshops and activities.

Aiap short courses and seminars offer will be designed keeping in mind the idea of high-level expertise and quality

not just in the strict graphic design field, but in neighboring disciplines dealing with contexts and scenarios.

It's crucial to Aiap to improve, develop and exploit its Archive "**Graphic Design Documentation Centre**"; Aiap Executive Board will take this project as essential in its mandate. The historical archive of design culture preserves an estimated 50,000 real artifacts (including books, posters, documents and other materials) which have been (and still are) collected with the aim of sharing with a varied public the stories and experiences of graphic design in Italy.

In the end, Aiap will continue its consulting activities towards companies, organizations and other associations in order to help them with the proper launching of call for contests and competitions.

Cinzia Ferrara, past president, and Camilla Masciadri, former president of the Board of Arbitrators, will help for one year the new boards.



Marco Tortoioli Ricci, Aiap new president

Marco Tortoioli Ricci (born Perugia, Italy, 1964) is a communication, brand designer and Design Professor. Graduated from ISIA, the High Institute of Industrial Arts in Urbino, he is the founding owner of renowned Bcpt

Associati / Comodo studio in Italy. His work ranges from the design of brand identity for private and public companies to strategic design consultancy and communication for cultural events, publishing design, exhibition display and retail identity. He is also the author of several international design projects for products and interiors.

He has developed a considerable international experience with his studio and his collaborators' team which, together with the projects carried out throughout Italy, has led him over the years to develop projects in Europe, United States, Brazil, Argentina, Canada, Jordan and China.

He has been an Aiap Executive Board member for two terms. Since 2006 he is Design Methodology professor at Isia Urbino and since 2014, Design professor at Fine Arts Academy in Perugia. Since November 2018 he is President of Aiap.

(Source: Aiap)



Programme and Events

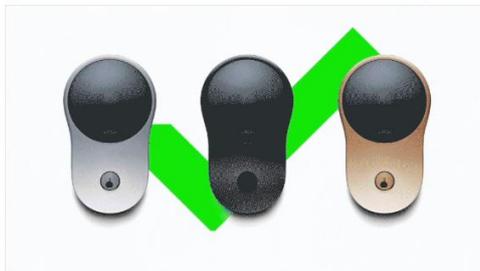
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Click on photograph for details.



THE SEARCH FOR EXCELLENCE IN DESIGN

Good Design Australia is calling for Australian and international entries to the 2019 Good Design Awards. Through the annual Good Design Awards program, we recognise and celebrate excellence in cutting edge design and breakthrough innovation. Entries close 28 March 2019. [Find out more about the 2019 Good Design Awards here.](#)

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NEW FOR 2019 - THE WOMEN IN DESIGN AWARD!

Good Design Australia is extremely proud to announce the new Women in Design Award, that will be presented as part of the 61st annual Good Design Awards.

The inaugural Women in Design Award seeks to recognise and celebrate women who have made significant contributions to the industry and hopes to encourage a more diverse and equal representation within the industry and leadership roles in particular within the design and creative industries.

The Selection Committee for this Award will comprise of Australian and international leaders in the design and creative industries. Confirmed Selection Committee Members include:

Liza Chong, CEO INDEX:Design to Improve Life (Denmark)

Margaret Petty, Executive Director of Innovation and Entrepreneurship UTS (NSW, Aus)
Sarah Weir, CEO Design Council (UK)
Claire Beale, Executive Director of Design Tasmania (TAS, Aus)
Eunjo Maing, Director / Head of D-TEC at Korean Institute of Design Promotion (Korea)
Trish Hansen, Founding Principal Urban Mind (SA, Aus)
More to come...



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www.aaate2019.eu

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Deadline for submission:
28 February 2019

Call for other contributions

Educational sessions
Policy sessions
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See website for deadlines



Conference topics

- ↓ Assistive technology (AT) for cognitive, sensory and motor disabilities
- ↓ AT service delivery systems, practices, quality and outcomes
- ↓ AT education, training and professional development
- ↓ AT in low- and middle-income countries
- ↓ Emerging and innovative AT
- ↓ Alternative and Augmentative Communication
- ↓ AT and social assistive robotics
- ↓ AAL, smart environments and IoT
- ↓ eAccessibility
- ↓ Universal Design
- ↓ Mobility and seating solutions
- ↓ Ageing and technology
- ↓ AT for rehabilitation
- ↓ AT, virtual and augmented reality
- ↓ AT, digital health and innovation in care
- ↓ AT in education
- ↓ Policy and social aspects related to AT

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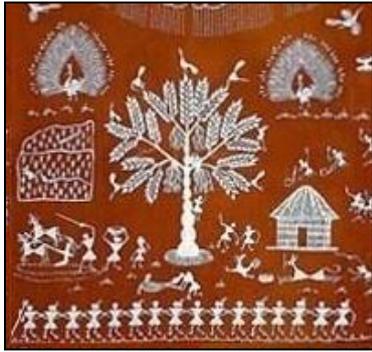
aaate2019@aiasbo.it



International conference on 'Designing for children' with focus on 'Play and Learn'

Saturday 7th to Sunday 8th of December 2019

Venue: VMCC, IIT Bombay



Job Openings

Job Opening

Looking to get development quotes for the redesign of a WordPress website. We are designing the site and need development support. Please email me at shagunster@gmail.com to learn more about this opportunity



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