

for and by people with disability



# starecase

Issue 3 • Springish 2013



## RESPECTE

SOUTH AUSSIES

FIGHT BACK AGAINST

HATE SPEECH

## DON'T DIS OUR DAY

INTERNATIONAL DAY OF

PEOPLE WITH A DISABILITY

- Locked up in WA
- Ableism
- The Right to be Fat
- Am I Disabled?
- Gary Kerridge the Gallbladderless



plus

STARECASE

ROUNDUP

- This month's unapologetic roundup of our 'likes' and 'dislikes'
- The future looks shiny - Suzy Keene talks about robots in healthcare

PRODUCED AT SPASMODIC INTERVALS WITHIN A MINISCULE BUDGET



## THIS MONTH

- 04 Deserving Respecte**  
Ben Paor on Respecte
- 07 Don't Dis Our Disability Day**  
PWDA President Craig Wallace on IDPwD
- 10 Locked Up In WA**  
Marlon Noble and the Mentally Impaired Accused Act
- 14 Ableism**  
Glenda Lee talks about Ableism and attitudes
- 15 The Starecase Roundup**  
This month in disability
- 16 A Bile Experience**  
Gary and Melissa's Big Adventure
- 19 The Future Looks Shiny**  
Robots in Healthcare
- 20 The Right To Be Fat**  
What IS the 'dignity of risk?'
- 22 Am I Disabled?**  
Allison on invisible disability
- 24 Sorry**  
Does the word make a difference?

## FROM THE GREEN CHAIR

Most of the disability sector will be celebrating International Day for People with a Disability - in a variety of ways.

There will be sausage sizzles, of course, and morning teas. Art exhibitions and swish breakfasts at \$100 a head, with important speakers.

A lot of people with disability question our involvement in the day - why do we celebrate at all?

The answer, of course, is to celebrate US.

We often get painted as brave or inspirational or hardworking or cheerful-despite-all-odds. And sometimes that is true - but sometimes we are just ordinary people.

Often, we are not. I have met hundreds of exceptional people with disability who could quite easily be classed as 'extraordinary', although they'd argue the point. They are people with extraordinary knowledge and understanding of the life they lead, extraordinary generosity of spirit and extraordinary strength of character.

What will YOU be doing on International Day of People with a Disability?

I propose this. If each one of us think of and do something that will make a difference for people with disability, imagine the impact on Australia. Something to make people value diversity, include others, make the world better. You don't need to do it alone. Do it with others - do it like a New Year's Resolution, but on IDPwD. As the slogan says - 'just do it.'

It's our day. Let's take it back. - Pretzel



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A bunch of people with disability

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HOW DISABILITY  
ADVOCATES TURNED  
HATE SPEECH  
INTO 'RESPECTE'



Ben says that the new teeshirts are awesome.

You can order your RESPECTE teeshirt or cap from [www.respecte.com.au](http://www.respecte.com.au)

By wearing the shirt, you are speaking up and telling people that hate speech against people with disability is not okay.

# DESERVING RESPECTE

Ben Paor was disgusted when he saw teeshirts with the words 'Retarde' in a local store.

Now he's helping change something bad into something good.

When Ben Paor saw teeshirts with hate speech on them, he felt like he was going to vomit.

'There's a shop called Globalize that runs teeshirts with really mean words,' said Ben. 'They should stop making them. Everybody hates those shirts.'

Ben and other disability advocates knew it was wrong.

They called the stores, protested at one of the stores that sold them and called the newspapers and television stations.

The owner of the Globalize store said that children who didn't like the shirts needed to 'toughen up'.

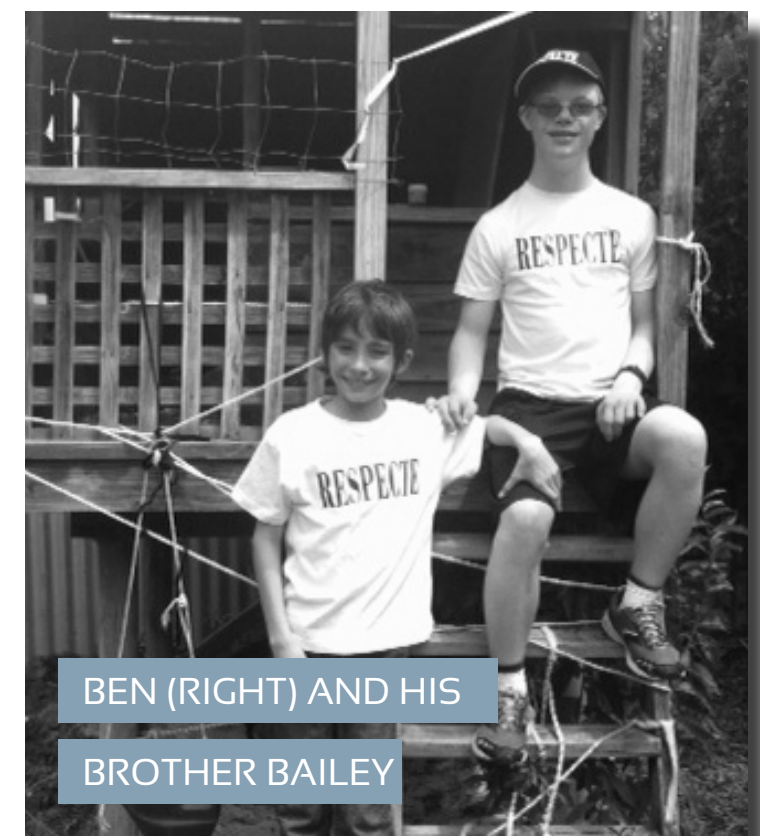
People across Australia were angry about what he said.

Finally, the shirts were taken out of the stores.

South Australian disability advocates say that they only won a small battle, not the war.

They want you to buy a different shirt - one with RESPECTE across the front.

If you wear a RESPECTE teeshirt, you are showing your support for anyone different, and anyone who has been bullied by hate speech.



BEN (RIGHT) AND HIS  
BROTHER BAILEY





“**Ningura Naparula with the Purple Truck of Western Desert Dialysis – an Award winner this IDPwD that’s worthy of respect”**

# DON'T DIS OUR DISABILITY DAY

**W**ell, it's nearing the end of 2013 - and what a year this has been.

Against all the odds we got the National Disability Insurance Scheme funded by a Medicare levy. A decision supported by over 70% of Australians in a Newspan. Then legislation to enact it was passed unanimously by both Houses of Parliament. That's right - a multibillion dollar measure sails into law with not a single vote against it in the dying year of the most unstable parliament since World War II.

And then Scheme sites were signed up to by the States and Territories, even the ones with really quirky Premiers who can't seem to agree on anything.

Then we had an election - with both sides of politics committing to the NDIS. And following a change of government we get Senator Mitch Fifield as our Minister. An experienced, smart, heavy hitter who carries the portfolio from Opposition rather than dumping us at the first available opportunity for some glam portfolio like "Minister for investigating sister city relationships in the Caribbean".

A Minister who is also Manager of Opposition business in the Senate - the one who devises tactics. Don't cross him or your only question in the next three years might be asking the Minister for Transport to reel off some stats about the financial impact of road tolls

CRAIG WALLACE  
SPEAKS ON  
INTERNATIONAL  
DAY OF PEOPLE  
WITH A DISABILITY

in the trucking industry.

A Minister who commits - strongly, publicly and unreservedly - to the scheme though it was an initiative of a former government. And who last week at the National Disability Awards also committed clearly and directly to the National Disability Strategy - the hugely important COAG agreement with the states and territories and local government in areas like education, health, infrastructure and employment.



In all this we need to be vigilant, yet our ability to do that comes from our profile during 2013. Examples include the controversy over Myer and then turning the spotlight onto jobs. And it will be a long time before the next fashionista flounces into a studio, writes disability hate speech on a whiteboard and says "well lets add an 'e' on that and stick it on a T-Shirt. These people are too weak to call us on it".

So at the end of such a year on Our Big Day - the International Day of People with Disability (IDPwD) declared by the UN who gave us the Convention - are we going to puff our chests with pride, claim the streets and put on a bash that combines the zing, exuberance and widespread traffic disruption of the Summernats festival, Mardi Gras and the running of the bulls at Pamplona?

Put simply, to borrow the phrase of the counter campaign selling T Shirts for

charity, are we going to get our Respecte on?

Hopeful. Or maybe we will arch an eyebrow, complain about the events and dismiss the Day with lofty disdain - the entire 365 days of the year should be disability day so why have it at all?

Well, every day of the calendar should be inclusive of GLBT communities too but that doesn't mean the organisers of the 2014 Mardi Gras are about to fling their sequined frocks onto a fire in the middle of Oxford St does it? Or that NAIDOC week or UN Womens Day have no relevance because they speak to issues across the year?

At best, IDPwD is about pride, ownership and respect. And this year's International Day has it in buckets if you look. I've got respect for the winners of the Excellence in Accessible Communities Category in the National Disability Awards who run the Western Desert Dialysis otherwise known as "the pur-

ple truck" which travels boggling distances in the Northern Territory and Western Australia providing accessible mobile dialysis to remote communities. I've got loads of respect or the late Lesley Hall who was recognised with the PMs Award as well as from Sue Salthouse, John Moxon and Ann Proctor; the three finalists in the Lesley Hall Award for Lifetime Achievement in Disability. I've got it for the participants in this year's 21 Up project for IDPwD. 21 year olds marking the 21st anniversary of IPWD talking about their lives and coming of age in an honest and empowered way. Cool.

And an education kit produced in association with the Australian Government that's available to every primary school in Australia and is backed up by a mainstream newspaper supplement that hitting a readership of over 100,000 decision makers in the nations capital

next Tuesday morning. Ice cool.

So you don't like the Lady's auxiliary tea sculling event held up a flight of stairs or the segregated bowls event?

Well don't just dis it and snarl in a corner. Let's create our own! Like the divas in WA creating their own Breaking Doors and Opening Barriers Counter event.

The same should go for the rest of the year. Annoyed at a swanky commercial conference with a price tag equivalent to the GDP of a small country full of usual suspects talking about the NDIS?

Fair enough, but why waste energy complaining about what others when we can build our own that's worthy? Build webinars, hold social media forums and take other spaces like ABC Ramp Up.

They'll be better, richer, deeper and more noticed by the opinion makers anyway.

It's time that we shook off the dregs of victimhood. And I don't mean that we're victims. I mean that it's possible to be portrayed as victims by other people and to define ourselves by what other people think of us. Or simply by inaction and imagining our lives as created by other people.

The opposite is ownership, where we grab the steering wheel with our hand/s, fingers, toes or whatever bits we have in working order and fling it back in our direction.

And we're NOT victims anymore. Victims would have seen a T-shirt with 'Retarde' on it and said isn't it awful and there's not much we can do about it really. Tut. Let's write a thesis and moan about dominant paradigms. Maybe

Government can help with a soft touch campaign to educate fashion designers? Quick, let's find a designer champion who has a person with a disability as his PA.

A community of proud doers, people worthy of jobs, rights, voices and opportunities, cries enough, takes on the t-shirt retailers and then creates and sells our own t-shirt with twice the class before the smoke clears. Respecte indeed.

And that control and respect is what the NDIS is about really. And we're doing it. We really are.

Happy International Day. We have people to respect and things to celebrate.

*Craig Wallace is the President of People with Disability Australia.*





IF YOU LIVE IN WA AND  
HAVE AN INTELLECTUAL DISABILITY,  
YOU CAN BE DISCRIMINATED  
AGAINST BY THE LAW

*Marlon Noble on  
leaving his home  
without permission  
- 'You'll go back in,  
quick as mud.'*

# LOCKED UP IN WA

The law in WA says that some people with an intellectual disability or mental illness can't go to court like anyone else - and some people spend years in jail.

In Western Australia, there is a law called the 'Mentally Impaired Accused Act'.

A man named Marlon Noble was locked up in jail for more than ten years because of this law.

Marlon has never been found guilty of a crime.

The law says that some people who have an intellectual disability or a mental illness can't go to court like other people do.

They call this being 'unfit to plead'.

People are locked up in a 'declared place'.

The only 'declared places' in WA are jails or mental hospitals.

A lot of people think this law is wrong. People who haven't been accused of a crime shouldn't go to jail or hospital.

Graeme Innes, the Disability

Discrimination Commissioner, says that there are problems with the law.

"If the law allows a person who has not been convicted of a crime to be in jail for ten years, then there's got to be a huge problem hasn't there?" he said.

Because of this, the Government in WA has now opening a 'declared place' in a place called Lockridge in WA.



People in Lockridge are angry. They do not want the 'declared place'.

They say that the people who have been accused of crimes might hurt them.

In 2012, the Mentally Impaired Accused Board made a list of people who were not 'fit to plead'.

Some people were accused of murdering or raping people.

Other people had driven without a drivers licence, stolen something or had trespassed on another person's property.

But none of them have been found guilty of a crime.

Marlon is out of jail now.

But he is not allowed to leave his home without asking first.

He is not allowed to leave his town without asking first.

He is not in jail, but he is still not free.

WATCH MARLON'S

STORY HERE -

<http://is.gd/marlonnoble>





# ABLEISM

## LET'S PUT AN END TO IT

Glenda gives a frank and ironic take on ableism - from <http://gleecrip.blogspot.com>.

**W**e must call a spade a spade and put Ableism right

on up there next to Sexism, Racism and Homophobia and many other scared weird hate isms. We must stop calling it 'disability discrimination'. When the general public hear the word disability they think of it (us) as someone else's 'problem'. They pop a coin in the beggars tin. They think Special Needs People need to be 'dealt' with by Specialists in a Special Place (away from them) and they especially do not particularly want to hang out with us. For of course they have no Special Skills to be able to approach the Special People. Those 'Spastics'. Those 'Retards'. Those 'Deaf and Dumb'.

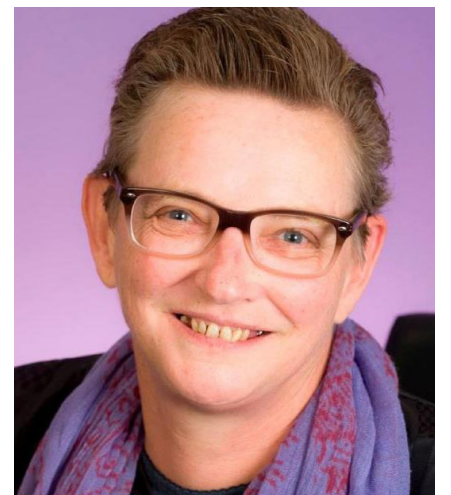
Do NOT use the D word. If

we keep referring to their label for us then that is where we will stay. Disabled.

THIS discrimination belongs with those who do it. Call it after the people who discriminate. Call it Ableism. Put it where it belongs!

I believe that it has become very difficult for white people to say that black people are lesser than they are. Or for men to say that women are inferior to them. It is easier cos it is just gender and skin colour.

However, with us crips the story is different. The 'Able' people, the self-appointed Normal people can point to us and say - "you can't walk or see or speak or understand LIKE ME so you must be inferior. It's obvious! You are not Normal."



GLENDAL EE  
GIVES US THE GOSS  
ABOUT ABLEISM  
AND CALLING A  
SPADE A SPADE

What they fail to see is that they have never built the world or their attitudes to include US with equal



opportunity. When it comes to our access to equal opportunity, it suddenly costs too much. Never mind what it costs to accommodate sighted people's need for lighting or hearing people's need for hundreds of noise emitting devices, or chairs sitting around empty most of the time everywhere, in trains, waiting rooms, theatres, public transport, aeroplanes, offices, schools. Altogether this tip of their iceberg costs trillions of dollars worldwide. And that's ok. Because that's NORMAL. But when we need a wheelchair, the only chair we will use in public, it is suddenly too expensive and we will have to go on the waiting list. I said to the train driver who was putting out the ramp for me to get on the train. "They should get automatic ramps." He "Oh no that would cost too much." Me "Well get rid of the

seats! They cost thousands upon thousands. I bring my own chair so get them to bring their own chair!" He giggled as if I was talking nonsense. That is Ableism. That is why we do not function well with our "impairments". And what IS normal and who got to decide what normal is anyway? The people in control, the men over the women, the white people over the black people and the "normal" people (who had physically built the world to exclude us) over the abnormal people. For too long we have tolerated this and still tolerate this. We need a united front in the rejection of Ableism to get rid of it. While it is only a few of us fighting Ableism we will be pointed out as the 'bitter twisted cripples' as opposed to the 'sweet disabled people who are sooo grateful and

lovely'. Too many of us are too oppressed or frightened to rock the boat yet. When the new generations of feisty aware crips and non-crips come on things will gradually change. But people will have to die and then their kids and their kids will have to die before Ableism is eliminated. We must gradually educate out and fight out and breed out the defect that causes Ableism! We must all make a stand. Even if it is only in small ways. Have it YOUR way.

//  
*For too long we have tolerated this...we need a united front in the rejection of Ableism."*

## TOP FIVE SIGNS THAT YOU ARE STUCK IN DISABILITY SERVICES

- YOU'RE CALLED A 'PARTICIPANT', NOT AN 'EMPLOYEE'
- IT'S PERFECTLY OKAY FOR YOU TO BE PAID \$2.75 PER HOUR
- PEOPLE CALL YOU AND OTHER PEOPLE WITH DISABILITY 'THE GUYS' \*
- YOU ARE WAY TOO GOOD AT BOWLING
- THE PEOPLE YOU GO OUT WITH ARE PAID, FAMILY OR ALSO DISABLED

\* NO MATTER WHAT AGE OR GENDER YOU ARE

*Policy Divas*

# THE starecase ROUNDUP



THUMBS UP TO WONDERBRA AND THEIR AD - 'LOOK IN MY EYES. I SAID -IN MY EYES!'



THUMBS DOWN TO INSTITUTIONS THAT ARE PRETTIER AND HARDER TO RECOGNISE AS PLACES THAT SEGREGATE AND ISOLATE PEOPLE WITH DISABILITY



THUMBS UP TO YOUNG PEOPLE WHO FIGHT AGAINST HATE SPEECH



Description	one of the largest non-government disability service providers in Australia. We support more than 3,350 people with a disability from 30 locations across Victoria and Western Sydney. To celebrate 21 years of International Day of People with a Disability, a morning tea will be held in each of our Recycled Clothing Stores. Bring your family and friends and help celebrate this momentous occasion.
Accessibility details	Street parking. No wheelchair access.

SIX INACCESSIBLE EVENTS HELD FOR INTERNATIONAL DAY OF PEOPLE WITH A DISABILITY - ALL FROM THE SAME PROVIDER

THUMBS UP THAT A RAPIST WHO WORKED AT YOORALLA WAS JAILED FOR EIGHTEEN YEARS AFTER RAPING TWO CLIENTS....

BUT



THUMBS DOWN THAT THE TOP BRASS MISSED THE TRIAL AND ATE LUNCH AT THE AGM A KILOMETRE DOWN THE ROAD





# A BILE EXPERIENCE

GARY AND MELISSA'S

EXCELLENT ADVENTURE

I awoke at 5am. I was feeling queasy and a little bloated. I had a big day ahead of me at work and I was also flying out to Sydney to attend the Deaf Sports Australia AGM. I went to the couch to watch some cooking shows on Foxtel. I thought this preferable to tossing and turning and keeping my wife awake. None of them were captioned so I gave up and went back to bed. I slept fitfully.

By 7.30am I knew this was not some small tummy bug. The pain was worsening. I emailed work to let them know that I would not be in. I decided to rest in the hope that things would settle in time for my 4.30pm flight. By 2pm they had not settled but they were no worse. I decided to chance it in the hope that it was a 24 hour bug. I packed my bag and went to the airport.

At the airport I was meeting Melissa, the Prez of Deaf Sport Recreation Victoria. (DSRV) We were both representing DSRV at the AGM. The flight was delayed an hour because there had been storms in Sydney. Not that we actually knew this for sure. It is something I deduced having seen the weather on Sunrise that morning. There was nothing on the

airport screens to let us know. If there were any PA announcements we had no access to these either for obvious reasons.

The flight was uneventful. Apart from the fact I was in a bit of pain. We landed uneventfully. In fact it was a beautiful landing. Melissa and I agreed that it was one of the softest landings we had ever experienced. It is ironic that from that moment onwards everything became a nightmare.

We were to be trapped in that plane for almost three hours. Problems caused by the storms earlier had seen an enormous amount of cancelled or delayed flights. Planes were banked up for miles awaiting an opening at the arrivals gate so that passengers could get off. Initially Melissa and I just shrugged and attributed things to the storm.

After an hour we both became a little anxious. We were tired and hungry and I was in a lot of pain. Obviously we had no access to the PA announcements so had no clue as to what was happening and when we might be able to escape the plane. I tried to grab the attention of a flight attendant with no success. I tried lip-reading them as they were talking to

passengers in the aisle. In the end I just asked the guy next to me, which I should have done in the first place.

I told him that we were deaf and asked if he could fill us in. He was not an easy guy to lip-read either but he did his best. I managed to get a little of the story. Long queues of planes that were all waiting for a berth at arrivals and that it was not known how long things would be. The guy was great from then on. If he heard something he would tell us how much time it was going to be before the plane moved on.

Of course, my pain just got steadily worse. I was cramped up in a small seat, never a nice thing for a big guy. I was steadily getting dehydrated too. In short I felt like crap. I tried sleeping, deep breathing and rocking. Melissa thought the rocking made me look like a praying guy.

Eventually after about two hours I got a flight attendant's attention. As luck would have it he was very camp and spoke at 100 miles per hour. Even though I told him I was deaf he must have thought that I was the worlds greatest lip-reader because he yammered on,

fluttered his eye lids and gesticulated excessively. About the only thing I understood was that there were lots of planes, we just had to be patient and he had no idea for how long. Come to think of it that's probably all he did say but in 10,000 words.

So we were stuck in the plane for almost three long, tedious and painful hours. Even when we berthed we had to wait half an hour until they managed to get the plane doors open. But eventually we did get off and I was in a bad way.

Melissa and I decided to catch a train to our destination. We purchased our tickets and headed to the platform. The

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*To witness Dr  
Henry throw  
everything he  
had into  
communicating  
with me was a  
thing of joy."*



screens said the train was to arrive in 3 minutes. Half an hour or so later no trains had been sighted. In fact, in that time at least four should have arrived but they did not. I asked a guy what was going on. He had no idea. We checked the screens but there was no information there either. It is apparent that no PA announcements had been made so we were all in the dark. So much for Disability Commissioner, Graeme Innes, suing Rail Corp for the lack of audio announcements for the blind at train stations. Mr Innes was awarded \$10,000 and donated this to charity. It seems that the charity is the only entity that benefitted from the whole saga.

I was feeling so bad that I told Melissa we had no option but to catch a taxi. This was going to be expensive because Parramatta is

a long way from the airport. Of course there was a long line up for the taxi. Eventually, almost an hour later we got into a taxi. As I do, I told the taxi driver I was deaf and needed to lip read him. He wasn't from an English speaking background, and was impossible to lip-read. - it is difficult for a deaf person to lip-read a foreign accent.

Eventually and after a bit more messing about I got to the hospital. This was the Westmead Hospital in Parramatta. And I have only the highest praise for them. Of course the nurses and doctors there were not without their comical moments. When it came to communicating with me.

To witness Dr Henry throw everything he had into communicating with me was a thing of joy. His miming of diarrhea and projectile vomit

were things of absolute comic relief. Henry was probably of Chinese origin and dressed immaculately with a collared shirt and tie. So his pantomime to communicate with me was all the more funny to watch. I made a joke with the other doctors that I preferred Dr Henry because he was walking theatre. Three days on it's been an adventure, but perhaps not an excellent one.

Tomorrow I head to surgery to have my gall bladder removed. An interpreter will be present so hopefully it will all be plain sailing from here on. As for Melissa the rest of her weekend was uneventful. As for me, the adventure continues.

*Gary successfully had his gallbladder removed last week and remains in hospital, complaining bitterly and posting pictures of bad hospital food on Facebook.*

# THE FUTURE LOOKS SHINY

SUZY KEENE ON

ROBOTS IN HEALTHCARE

As a geek and a nerd I have always been fascinated by robots and once the stuff of science fiction, robots are now essential tools in manufacturing industries and have been utilised in medical surgery. The surgeon operated Da Vinci Surgical Robot for instance has been in use now for over 10 years with great success and in Montreal in October 2010, the first fully roboticised operation was performed on a patient combining the Da Vinci unit with an anaesthesia robot (nicknamed McSleepy). However, the field of robotics in healthcare is still quite young but the potential is excitingly enormous.

In late 2008 the European Commission published Robotics for Healthcare Final Report, the result of a study into the potential for robotics in healthcare. The report identified the need for research and development to achieve practical outcomes by 2025 and the major outcome of the report is the identification of six representative areas of potential robotic applications in healthcare. Those areas are

- (a) smart medical capsules (mini robots that are placed inside the body as diagnostic tools)
- (b) robotised surgery (such as the Da Vinci robot and anaesthesia robot)
- (c) intelligent prosthetics (natural movement controlled by the brain)
- (d) robotised motor coordination analysis and therapy (to create tailor-made plans to build motor skills)

(e) robot-assisted mental, cognitive and social therapy (to build and maintain social skills) and (f) robotised patient monitoring systems (for monitoring of a patient at home without the need for a nurse to visit).

Various prototypes currently exist in research laboratories around the world, for example, Toyota's Balance Training Assist, a two-wheeled balancing game utilising a monitor, a game and a balancing machine, which may be available to buy as early as next year. The potential for the use of robotics in assistive technologies is huge and as many utilise technology found in household machines such as a mobile phones or computers, the likelihood of this technology becoming relatively affordable, if not for individuals, then for hospitals and rehabilitation centres is very high.

The EC report importantly recognises that ethical, legal and social issues have to be explored.

I have great faith in technology to open up my friends' abilities but we need to consider affordability, reliability, and the possible consequences. Greater reliance on machines or financial pressures within the healthcare sector could result in the loss of care workers and bring subsequent social isolation; malfunctioning or unmaintained robots could lead to devastating accidents where machines topple or misinterpreted data cause injury or death. I share the enthusiasm that the scientists have for the technology, but we have to temper this with a consultative process between the scientists, the manufacturers, lawyers, the health care sector, and society at large. But most importantly they need to consult with people who have disabilities.

*Suzy Keene is a Director on the PWDA Board. She has an interest in technology and how this can improve people's lives by increasing independence, give greater creative expression and bring greater inclusion.*





# THE RIGHT TO BE FAT

FIGHTING FOR THE RIGHT TO BE FAT?

SAM CONNOR TALKS ABOUT THE 'DIGNITY OF RISK'



I know a lot of fat people.

Call it what you will. Morbidly obese, overweight. And some, downright fat.

My friend Su laughs with her head thrown back at the notion that she's a lesser woman because of her weight, then drinks another Coke. She's been known to call herself Fatty McFatfuck, thanks to the movie Ted. Su knows that she is a glorious specimen of womanhood and she will bloody well eat and drink whatever she likes, thank you very much.

Clearly, Su doesn't have a disability.

If she did, her choices would probably be severely restricted – a menu of limited options. You want a Coke? Is that a good choice, Su? You know you're watching your weight. That takeaway? Is that the best choice you can make? It's hardly nutritious. And that shirt

– well, it's not actually appropriate, is it? We don't want people seeing your cleavage, do we?

What time are you going to go to bed tonight? Well, the attendant won't be able to work past nine, so it looks like you're going to have to miss going out with the girls. Sure, other people go to bed at eight or nine. It's not unusual.

Who is going to give you a shower today? Do you want it to be someone you know, or like? A man, or a woman? Does it matter who sees you naked?

God forbid you should want to have sex with a partner of your choice, let alone a partner of the same sex. And try telling your religious service provider it's okay for you to be gay. I dare you.

In Serviceland, they call it 'The Dignity of Risk'.

But it doesn't seem to impact on the way there are always single beds in group homes, nor the way people's diets are monitored and administered, nor in the way people are restricted in spending their own money in the way they want.

We need new language around human rights.

- *The Right to Sexuality (including the right to have sex with someone of the same sex)*
- *The Right to Be Fat*
- *The Right to Be Promiscuous*
- *The Right to Take Up An Adventure Sport*

- *The Right to Live With Who You Want*

- *The Right to Get Horribly Drunk and Fall Down*

If you have a disability, it doesn't mean you don't know what you want to do or when you want to do it or who want to do it with.

The Dignity of Risk. The language of risk says, 'What if something terrible happens?' But it doesn't allow people to make their own mistakes, to experience life, to be free.

But what if we said, 'What if something wonderful happens?'

Let's find out.

//  
*Living at risk is jumping off the cliff and building your wings on the way down.*  
- Ray Bradbury"





# AM I DISABLED?

ALLISON ASKS -  
ARE PEOPLE WITH  
INVISIBLE AND  
EPISODIC DISABILITY  
STILL DISABLED?

I was diagnosed with multiple sclerosis in January 2000 at age 34, after two decades of symptoms. I won Gimp of the Year (not real name) in 2006 for working to help improve disability inclusion within my workplace. No one knew I had MS unless I told them because I worked hard and worked to create an environment where I did what I could, when I could. I

continued to work full time for my employer until my 45th birthday.

Then I ran away to the country and for a whole year lived the life I dreamed I could; far away from the city and stress. I lost 20kg started running again, felt a million dollars.

Winter came and something happened. First pains in my arms, then legs, then fatigue that was very different to MS fatigue; a

mental lethargy that was similar too, but also different, to MS brain fog. I felt so awful I could not even go on the internet (my second home!).

I live in a country town of 3000. There's not much choice in doctors and none in specialists (my neuro is a 3.5 hour drive away) and in the 15 minutes I had with the first GP I felt like a freak listing off symptoms that were getting more and more

bizarre (kidney pain, breathlessness on laying down, flashes in my eyes, itchy ear holes). I ended up having an iron infusion and told to take Vitamin D, and that was that for him. Once I was signed up for all the added extras that his practice gets paid for in the country, I was left to ...put up with things.

The weather warmed, the symptoms eased and I went on with life. Not as good as I was before, but functioning. Then along comes the next winter and things deteriorate further; incredible fatigue, confusion, pain, more bizarre symptoms and my new female GP says I am 'weird' and has no idea what is wrong.

Being bedridden and too confused to drive I finally felt ready to put the label 'disabled' on my forehead. I could not lift my arms over my head, the chronic pain was crushing my personality, I felt hopeless. Surely is is what being disabled is all about? My guy works full time and 50km away - I needed some kind of support, help from services, something to remove some

of the stress of not wanting to overburden him. Not one professional had any suggestions. They have no answers, and seemingly unwilling to put anything forward beyond medication. No wonder people turn to the woo-woo artists, they at least appear to care.

I tried to take the upper hand, the next appointment I had with my GP I took in the paperwork for her to fill in so I could apply for Disability Support Pension. She decided that she wasn't going to say I was permanently disabled, and that my case should be reviewed after 90 days. Better than nothing, I thought. I tried to fill in the paperwork for my side of the application. I found the process overwhelming and confusing. I sent a request for assistance from the department - three months later I still have not heard back.

The papers are on my coffee table.

I developed a nice case of vertigo and fell over a few times. I tried to go shopping and sat on the floor for a while in the aisle because I could not get

up from getting something from a lower shelf. I gave up going back to my doctor who had no answer other than change to a new antidepressant.

As the weather warms I am feeling more energetic. The confusion has cleared and I ignore the pain. I am still having to sleep a few hours extra each day, and the light still burns my eyes. I spent 20 years labelled a malingerer before ending up in a wheelchair for a while (thanks Royal North Shore hospital!) and here I am again...wondering what it takes for an intermittent, invisible disability to be recognised and accepted with some kind of compassion. I am not a malingerer. I am not a drug seeker. On my good days I work as hard as anyone you know.

I wonder why I have to look for help when surely it is obvious I need someone who knows what to do. Someone to offer a helping hand and to acknowledge that what cannot be seen can still be as debilitating as the most in-your-face disability.





# sorry.



# SORRY.

SUCH A LITTLE WORD. BUT DOES

IT MAKE ANY DIFFERENCE?

//

Would 'sorry' have made any difference? Does it ever? It's just a word. One word against a thousand actions." - Sarah Ockler, Bittersweet

In Australia, Sorry Day is an annual event to remember and commemorate the mistreatment of the continent's indigenous population. The Australian government's most controversial policies resulted in an entire 'Stolen Generation' - Aboriginal children separated, often forcibly, from their families of origin in the interest of turning them into white Australians.

I'm thoroughly sick and tired of the word 'sorry'. I can't begin to imagine how Aboriginal people feel about it - not about Sorry Day itself,

but about the meaningless apologies that the disadvantaged receive every day.

'I'm sorry that we removed your grandmother from her family two generations ago and told her she could never see her family again or use her language or keep her identity or live at home instead of out on a mission way out at Mogumber' might be an appropriate response, but 'I'm sorry that we will not let you go to your mother's funeral' or 'I'm sorry that we will not give you a job' is not. I was proud of our country when we delivered the National Apology - not so much when discrimination against Aboriginal people continued on a daily basis - will we be apologising for the Northern Territory Intervention fifty years from now?

That got me thinking about disability and the word 'sorry'.

I have a cool game that I play when I go to Carousel Shopping Centre.

I enter the store, and the clock starts ticking. I start counting how many people say 'sorry' to me.

Some leap out of my way, even if they are a metre or more away, muttering 'sorry', red faced. I'm never quite sure whether they're apologising for being in my way or whether they're apologising because I'm disabled. My record is 23 'sorries' over the

course of an hour. I'm collecting 'sorries' like Pokemon cards.

- 'Sorry, we cannot provide an accessible toilet for you in your workplace.'

- 'Sorry, you cannot visit this restaurant - it has steps.'

- 'Sorry about the wait - although you fly regularly, we have a new pilot today and he really wants to make sure your wheelchair is safe to fly. Just wait here at the back of the queue.'

- 'Sorry about the lift breakdown.'

- 'Sorry - you are different from other people, and it is a huge inconvenience having to accommodate you, even though you are a paying customer.' And the apology never reaches their eyes.

I'm not even exceptionally disadvantaged. If we disabled people collectively made the 'Sorry Pokemon' card collection, it would look something like this.

- 'Sorry that we will not employ you.'

- Sorry that we will not let you in.

- Sorry that we will not let you out.

- Sorry that we will not educate you.

- Sorry that we will lock you up in a prison, without charge, for ten years.

- Sorry that we will fail to support or protect you.

- Sorry that we will not allow you to testify in a court of law.

- Sorry that we will paint your rape or murder as an administrative error or an act of mercy.'

I don't want a National Sorry Day for People with Disability. I want change. I want people to stop discriminating against people. I want our Pokemon collection of Sorry Cards to be as irrelevant as Pokemon is today (and as collectable).

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*one thing I don't need is any more apologies i got sorry greetin me at my front door you can keep yrs i don't know what to do wit em they don't open doors or bring the sun back they don't make me happy or get a mornin paper didn't nobody stop usin my tears to wash cars cuz a sorry."*

*- poem by Ntozake Shange, for colored girls who have considered suicide/ when the rainbow is enuf "*



# THINK THIS IS AWESOME?

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WANT TO SEE MORE EDITIONS?

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We don't exist yet. We're people with disability who want to have a voice. But if you're not a sheltered workshop, if you don't run an institution, if you believe in inclusion and if you think we're worth supporting, let's talk. You can also buy this back page for whatever sum you think is reasonable.

**Email us at [staircasenews@gmail.com](mailto:staircasenews@gmail.com)**