

for and by people with disability

starecase

Issue 2 • Still Spring 2013

NOT JUST ANOTHER STATISTIC

MILLY PARKER

ON HAVING AN ABI

ITS OUR MOVEMENT

TAKING BACK THE DISABILITY

RIGHTS MOVEMENT

- All about contracts - how to avoid getting ripped off
- Whatever happened to Kyla Puhle?
- The Path to Inclusion
- A Liar and a Fake



plus

SURVIVING DISABILITY

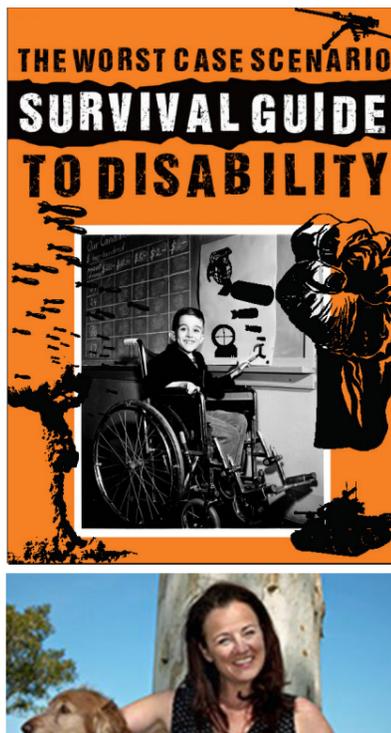
THE WORST CASE SCENARIO

SURVIVAL GUIDE

TO DISABILITY



PRODUCED AT SPASMODIC INTERVALS WITHIN A MINISCULE BUDGET



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FROM THE GREEN CHAIR

Great response from people with disability around Australia.

I should point out that this publication isn't a professionally produced marvel of technology and professionalism. Its a one person band with no funding, a Facebook window open on one side, Indesign on the other, and a marvellous group of random online contributors who are tirelessly writing and contributing for your reading pleasure.

We've had some marvellous feedback and a bunch of letters. My favourite comes from Stuart Mawbey, in response to Craig Wallace's article 'What happened to you?' It reads (partially) as follows -

'I reply to the question about my withered arm, saying...I got stuck in the dryer and it shrank... Great magazine. I would have liked "GIMP" as a title but that's just me. Gimpily yours with respect, Stuart.'

We also received some feedback about accessibility from Amber, a bunch of outraged complaints from some parents, an email from a web based disability mag called 'whats up in disability' (stay tuned for more info) and an email from a Mr. Leung Wing Lok, the credit officer of Hang Seng Bank of (Hong Kong) detailing 'a lucrative business proposal of mutual interest to share with you DETAIL OF THE PROPOSAL In June, 2001.'

Keep the responses coming. We need content - this isn't my magazine, or a magazine that belongs to any organisation. Its your magazine, and unless you're part of it, its just another bunch of words. Email us at starecasenews@gmail.com.

- Pretzel



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A bunch of people with disability

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IT'S OUR MOVEMENT - LETS TAKE IT BACK.

A NEW DAY IS DAWNING FOR DISABILITY RIGHTS

The last few days have seen mixed emotions as the new Government takes power in Canberra. The victors are jubilant while others are angry

or confused. Yet what is beyond doubt is that we are a democracy. We choose our leaders and hold them to account. If they get arrogant or lazy we ditch them. Democracy can throw up moments which crystallise the public mood in those moments.

The defeat of a candidate who didn't know his own policy in Greenway, the disendorsement of a bully in Hotham and that result everyone's talking about

in Indi. In Syria we see the results of a voiceless people as a government lobs poison at its own. Australia is lucky that we employ the government. And all across Australia in civil society - in

the clubs, the AMA, ACOSS, the NRMA, business councils, trade unions, professional associations, local councils, farmers groups, state and territory parliaments and in sporting codes - people can join, vote and elect those

who they want to represent them. Even the ALP is moving its leadership contests out of the shadows.



And yet somehow in disability, where we most need a voice of our own, it's all gone wrong. Almost everyone can vote for who represents them except people with disability ourselves:

- Service providers can join and vote for a funded organisation, National Disability Services, which represents them;
- Disability support workers can vote for organisers in unions; and
- Carers can vote for Board members in a funded organisation which represents them.

For us, the Australian Federation of Disability Organisations is the body officially recognised as "the primary national voice to Government that fully represents the interests of all people with disability across Australia". You heard it right. "Primary voice". "Fully represents". "All people". It's got some good hard working people in it. Genuine people. People I respect. But ordinary people with disability cannot stand for or directly vote for its board or decide who leads. Alone, out of all the business groups, trades, professions, movements, unions and causes, people with disabilities have no way of directly electing the leaders of the body that government appointed to represent us. That's not right, it's not fair, it's paternalism and

worst of all, it's not working. Even the organisational members of AFDO are voting with their feet. Some people haven't even heard of it.

This movement belongs to us and it's time we took it back, with a directly elected professional peak body recognised by government that's accountable to all of us. That holds power at the will of us, not imposed by government. That anyone with a disability can join, vote for and participate in. That's high profile and known. We need a body capable of harnessing the voice we now hold in the public square. That can grasp the momentum and goodwill we have following the introduction of the NDIS and make us run, wheel and shuffle like mad towards our future.

This is our moment. We have become the 98%, yet we still behave like we're in the attic with the 2%. But it doesn't have to be like this. We dominated the public square for an entire year in 1981, got wheelchair taxi subsidies and a PADP scheme, stopped a major airline from discriminating against us, made entire towns and cities change planning, freed people from institutions, shook up the ABC and wrote a Disability Discrimination Act. We were able to be all these things and do all these things because people stepped up. Leaders who are known and revered. Like Joan Hume,

Graeme Innes, John Moxon, Sue Salthouse, Ian Cooper, Christopher Newell, Robert Farley, Hazel Freed and Annie McDonald. Yet somehow we never took the next step. We never found a democratic culture. Is it any wonder we have so few people with disability in the Parliament? And where are our Ministers for disability with a disability? Why aren't the peaks a pathway for people to get into politics as they are for women, for unionists, for business?

This last week saw a group of advocates come together in Canberra to discuss where it's going wrong and how to fix it. These were exhausting discussions amongst people of goodwill trapped inside structures shaped by history rather than choice. Much of the two days was about what government might do to us, for us or be saying about us. Instead of talking about what others do, it's time we took the steering wheel.

All week I heard people frustrated by our lack of unity. They were right. Yet some also said that change is impossible. They were wrong. Some believe we have difference that can't be solved. That we are defined solely by our disability rather than our life stories, our genders, our common barriers and a lack of access to jobs, housing, relationships and resources within a world that

withholds its respect. And there is no denying some truths in all of this and it seems hard. Exhausting. But in throes of despair, I see the awesome stuff we CAN still do. And none of it has anything to do with what some doctor diagnosed us with. The campaign about Myer. The Divas busting a gut to develop a book of punchy stories in a single day to bring to Premiers at COAG. The people who let MP's into their kitchens and told their stories yet again. Those who told harrowing truths to the Productivity Commission knowing they would be repeated around the country. The gutsy YDAS team who stopped trams in the centre of Melbourne at peak hour and the bloggers like Carly Findlay who rewrite the ableist narrative of the world one post

at a time. The whirl of wonder that is Stella Young and ABC Ramp Up that's opened up a conversation in our community and got disability out of the box and onto Q&A. This Starecase magazine - dreamed out of nothing, done for free by people with no time. If we can do all these things then YES we can control our voice if we decide to. One that's filled with muscle and shows we can represent ourselves. A tuned up engine for change that is:

- modern, sharp as a tack and pushing out with social media, crowdfunding and the 24 hour opinion cycle;
- gutsy and never accepts comfortable mediocrity, ineffectual advocacy or tea and sympathy;
- democratic, muscular and able to attract the sharpest voices. Voices with ambition -

fighting to be part of what we are making who will wind up in Federal Parliament;

- respected and setting a high tone through probity, integrity and honesty;
- able to speak with one voice on great public issues that need weight of numbers yet champion voices of others in their own fields, especially campaigners for women, Deaf Australians, blind citizens and youth who blaze a trail for all of us; and
- inclusive enough to allow the unfiltered voices of people with intellectual disability to come through, along the lines of People First in NZ or the Our Voice initiative. If you want change, if you support a better voice for disability, if you have ideas - then join [facebook.com/wewantchangedisability](https://www.facebook.com/wewantchangedisability)

It's about democracy so we'll capture the discussions - even

the ones we mightn't agree with - and send them direct to the Minister for Social Services. There are millions of us and nothing can stand in the way of our voice unless we let it.

Craig Wallace is the President of People with Disability Australia.



What should a peak body, a disabled person's organisation, representing ALL people with disabilities look like? It should include voting for our representatives, but voting isn't perfect and some of us are hard-pressed to compete that way. It needs to take that into account too. It needs to reach out specifically to groups that are historically disadvantaged: indigenous peoples, women, those with non-English speaking backgrounds, the homeless, those living in rural and remote Australia. It needs to reach out to disability groups that are usually not well represented

in groups like this: those with intellectual disabilities, those with psychiatric disabilities, those who are institution-alised, the deaf blind, those with complex communication needs, and those who are bedridden and housebound. People whose disabilities make it difficult for them to participate in disabled people's organisations need special attention: Those who need extra time to take in and think about information, those who need extra time to express their thoughts and ideas, those who require information in specialised formats, those whose disability makes it hard for them to access the internet or other means of communication. We need to

reach out to disability superstars - the people like Peter Gibilisco who have PhDs in this stuff but whose disabilities make it hard for them to contribute. I'm sure there are more superstars I just don't know about.

We need to decide how we will deal with certain types of members respectfully and usefully - those who are disabled by the "usual" diseases of ageing, and those who wish to join on behalf of a severely disabled family member. We need to decide ahead of time how this will be handled, paying special attention to making sure that those who are the least able to speak for themselves are still heard amongst the din. We need to reach out to people who don't usually join disabled people's organisations - those who are disabled by chronic illness but never identify as "disabled" because to them it feels too much like giving up. Those who think they have nothing to say, or think we have nothing to say to them.

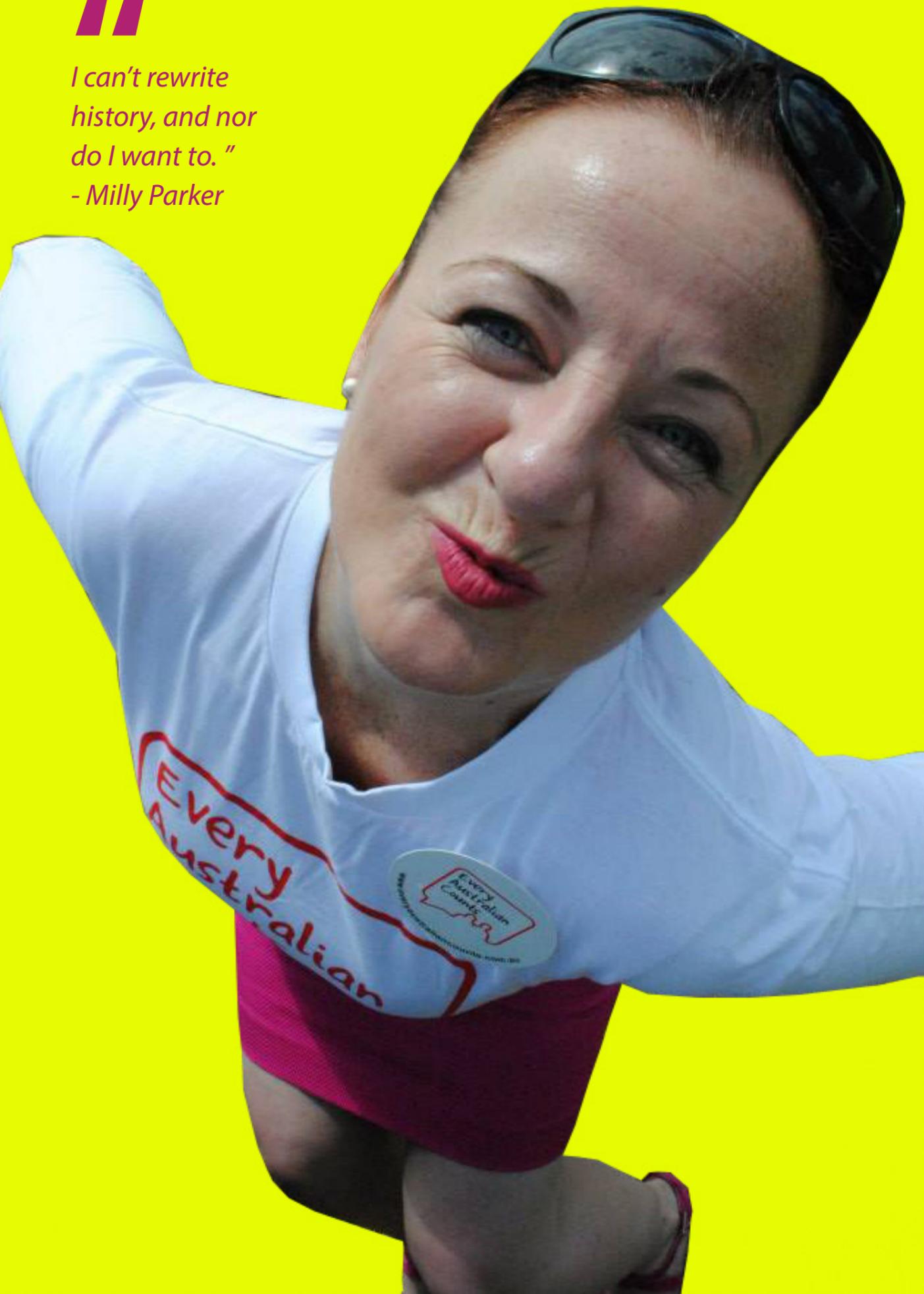
Just imagine - if all of us could listen to each other even when it was scary. If all of us could trust that others would listen when we said something. If all of us could communicate with each other and empower the best of us, we could move mountains.

- January J



I can't rewrite history, and nor do I want to."

- Milly Parker



NOT JUST ANOTHER STATISTIC

There comes a point in many relationships when the couple realise that they've spent more time with their significant other than they have with their family of origin.

It's a milestone that can unnerve people who struggle with the emotional consequences of change. I've achieved a milestone of sorts as well. It also involves a relationship. In this case it is the passing of my original self to the person I became in 1992. In September of that year, at the age of 21, I was involved in a horrific car accident. The result was an Acquired Brain Injury that changed my life more profoundly than if I had left home to cohabit with another person.

This year I will have lived half of my life with a

disability.

Living with an ABI affects different people in different ways. In my case, my short term memory is poor as is my emotional control, especially when I get tired. I am impulsive, have trouble reading and retaining information, my organisational and complex planning skills are affected, my decision-making ability can be poor, I suffer from fatigue and my brain can't cope in loud noisy places.

I can't drive and I can't take public transport. I've been accused of being a princess because I'm a taxi junkie and, even worse in their eyes, an abuser of the MPTP Card (half price taxi card). I've tried using public transport but my brain can't cope with the lights, colours, noise or the planning needed to remember the right stop or

MILLY PARKER

TELLS US ABOUT

LIFE, BRAIN

INJURY AND DOGGY

TREATS

I can honestly say that after a long period of mourning for the life I had planned for myself, I've come to accept that the 'new and improved me' is someone I actually like.

connecting transport. The last time I tried I got off at the wrong stop and ended taking a taxi home. I'm not the only one like this but what worries me is that there are many people in our community who aren't self aware about the limits of their ability, be it for reasons of age, disability or whatever, who continue to drive, putting themselves and others at risk.

Taxis are not without their problems, either. I was abused by one driver when I showed by MPTP Card because "you don't look sick!" I wanted to argue but my brain closed down. So I ran from the car, which is not my preferred way but my brain was in no mood to engage. The reverse of that is my experience with people who think a brain injury renders me deaf, dumb and stupid. How do I know? They insist on talking very loudly, very slowly and very, very close to my face.

All of the above means I have to plan ahead.

I can honestly say that after a long period of mourning for the life I had planned for myself, I've come to accept that the new and improved 'me' is someone that I actually like. I can't rewrite history and nor do I want to. I know that I am a good and decent person; to that extent nothing has changed.

Each day brings a new challenge

Daily life can be frustrating, but I've learnt to live with it. I don't really know when I wake up what the day will bring. There are some days when I wake with pain and others when my brain won't function at its optimum.

I began my life with an ABI as a statistic. Of course, I will always be a statistic, but I pushed myself to become so much more. It started with a beautiful dog and from there to a small business creating dog biscuits. I didn't intend starting a business; I didn't think I could. But when Riley came into my life I wasn't happy with the quality of treats that were available.

A friend suggested a recipe using human-grade ingredients and Riley loved it! I



gave it to friends and got the same reaction. I felt excited and empowered and against my better judgement I asked the local pet shop if they would stock my products, which I called Happy Yappers. I walked out of the shop with a \$15 sale. The cost of a pack of cigarettes today, but a million dollar contract to me!

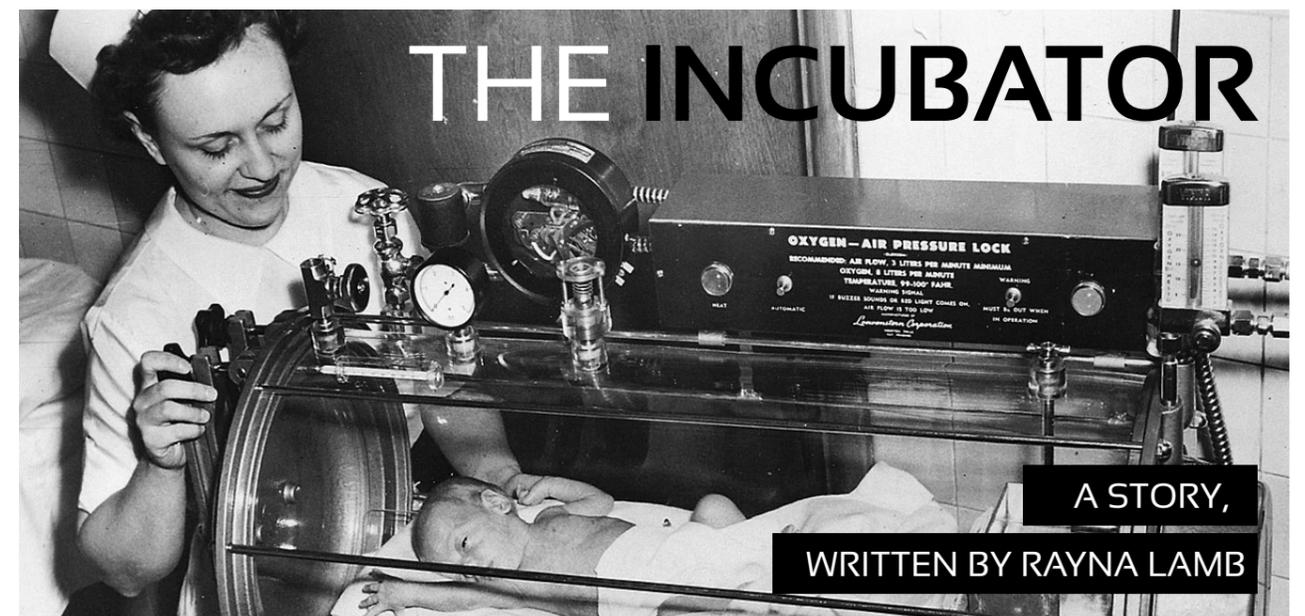
While a business was born, the outcome was to affirm my independence from the welfare system and to tell the world, at least my very small part of it, that I was capable of making a change.

Today, I value my story as a businesswoman and as the first Disability Ambassador for Yooralla, one of Australia's oldest and largest disability service organisations. Yooralla clearly appreciated the work that I was doing as a disability advocate and asked me to support them in their efforts to advocate for the rights of people with disability, their families and carers.

I'm not sure if anyone sees the irony in that: Australia's foremost disability service asking ME to support THEM!

There are parts of me that are different to the way I was born and will ever be thus. But the challenge I've been given has inspired others in ways that wouldn't have been possible had I arrived safely on that fateful night.

Quite honestly, I wouldn't want it any other way.



There is a connection between the loneliness I feel now and what I must have felt as a baby in the incubator. I realized that newborn babies have no sense of time whatsoever. Three days must have seemed like three lifetimes and then some. With no awareness of the events that break up time, that separate day from night, hour from minute.

No knowledge that care continues. Each feed the first and last, each brief physical contact the only one in a lifetime. And always the desperate aloneness that stretches for eternity, the panic that there is something that I desperately need, that I cannot put into words and ask for. And now I know that because I never had it then, now I can never really have it at all. So the loneliness that I feel now

echoes what I felt then, and seems to stretch beyond time, and will never end. But I don't know how it is possible that I have survived this, what I went through when I was younger, and what I am still enduring. I don't think that any human being should have to go through life feeling this fundamental lack, this emptiness.

Enclosed in a bubble like a bug caught in amber, trapped and at the mercy of those whose power far outweighed mine. They had the power over life and death, survival and..... The only power I had was that of resistance. I could resist their insistence on my lack of value, resist their doom laden proclamations of a worthless life, nothing more than a vegetable (and I always wanted to know - what kind of a vegetable? Carrot, cauliflower, cabbage - what?), and fated to be inferior in thought,

feeling, movement. I resisted their expectations that I would lie placid and accepting of whatever they did to me.

Scooting endlessly up and down, up and down, testing out the confines of this plastic bubble they condemned me to. I pulled out the wires and needles attached to me, these insulting non-human things that were meant to help me live. I knew I could live without those substitutes for reality. They say that the nurses could never keep a nappy on me, I moved around so much. So I crawled up and down endlessly through my own shit, the only thing in the silence, that was me, that was real and human, and didn't beep and hum and pour chemicals into me. I was the one who was in control and I showed it. The nurses nicknamed me 'the little abortion'. Three months too early, and very inconvenient.

THE WORST CASE SCENARIO SURVIVAL GUIDE TO DISABILITY



WHAT TO DO WHEN YOU'RE STUCK

Have you ever been really stuck because of your disability?

This is not an existential question about feeling stifled or filled with existential angst in some airy fairy 'Waiting for Godot' kind of way. No. I mean being physically stuck in a 'Holy-vat-of-super glue-Batman, how-are-we-going-to-get-out-this-time?' kind of way.

An example. The other week I was silly enough to charge front first into a narrow washroom cubicle with a heavy inner opening door. This was in a deserted underground carpark after closing time. Getting in was fine. Hooray! But there was no turning space so I had to reach behind to get out. But the door was so heavily sprung – and closing so quick - that wheeling backward while holding it to get out just

wasn't working. After about six attempts it dawned that Plan A wasn't going to work for a long time. Possibly ever. Mobile phone? No reception. Anyway I've got Y

chromosomes so recoil from asking for help or directions, even when it's the logical thing to do. We'll sort it - if there's a way in, there's a way out. In the 40 minutes or so it took me to swear, scream, bang on the wall and think up Plan B it struck me that what situations like this call for is a Worst Case Scenario Survival Guide for disability. You know the sort of thing: like What would McGyver Do? or the SAS survival handbook. The sort of jolly blokes guide that tells you what to do if: you find yourself in a deathroll with a croc, your tie gets sucked into the shredder or you have to scam your way through an interview for a job, like a

CRAIG WALLACE
ON FIRST WORLD
PROBLEMS AND
HOW TO SURVIVE

Craig Wallace is the President of People with Disability Australia. Craig has a disability and uses a wheelchair for mobility. He denies writing this while stuck in a loo.

brainsurgeon, you're hopelessly unqualified for. But this one would be 'disabilitised'- just for us. No "proper process" or referrals to tea sipping social workers – just swashbuckling "cut through" methods with hints and tips for the novice. So here's a few boys own solutions – and yes they are real things that people I know have done. They come with a certain risk of breakage and/or scary consequences but who cares – at least they made things go pop, bang or splatter:

Worst Case Scenario #1: What to do if unable to attract attention at a shopfront or deli counter because it is too high and/or their low 'special access counter' is covered with cobwebs and hasn't been personed since Whitney Houston last warbled out a good tune:

Step 1: Take a ticket from their silly touch screen machine (which you probably can't reach or see anyway – in which case a business card will do just as well).

Step 2: Fold this in half longways.

Step 3: Fold flaps on either side.

Step 4: Invert flaps at the edges.

Step 5: (optional) decorate the wings of your paper device with a suitable message like "Are you free?" or "I'm down here".

Step 6: Using a long forearm stroke throw upwards through the window of the service

counter (try not to actually hit a member of staff with it – Hint refers)

Step 7: Look up 90 degrees, speak loudly to the tall people and commence your friendly transaction. Hint: Don't use your solicitor's business card as construction material– you may need this if you hit a customer service person in the eye. Check where the exits are beforehand so you can leave in a hurry.

Worst Case Scenario #2: Make tea with cup on high shelf in motel with half-arsed access

Step 1: Take an inventory of the contents of the kitchen.

Step 2: Find a long implement, like a spatula or a serving spoon (knife not recommended). Step 3: invert implement holding the business end;

Step 4: Poke upward, hook implement handle under the handle of your cup and lift - letting the cup gently slide down the handle of your makeshift reaching device.

Step 5: Steep, stir and enjoy. Hint: Keep your credit card handy should the whole set crash out onto the floor. Hot tip: Avoid this method entirely if: a) the words 'Ming' or 'Royal Dalton' appear on the crockery or; b) the Motel manager combines the customer service sensibilities of Basil Fawlty & Mark "Chopper" Read. And back to where we started ...

Worst Case Scenario #3: Escape in reverse from a narrow loo with heavy inward

opening doors

Step 1: Take off your shoelaces, belt or tie.

Step 2: Tie a knot around the end to create a loop – if they aren't long enough try tying both sets of laces together.

Step 3: reaching back loop the end of your makeshift rope over the door hand and wedge it back to the part of the handle nearest the door jam.

Step 4: Tie the other end to your chair in a secure area such as near your brake or your footplate.

Step 5: Push forward quickly and when the door is nearest to the wall, wedge it between your wheel and the wall while reversing out.

Step 6: Untie.

Step 7: Celebrate your freedom by shouting 'Hooray' and get out fast before something else goes wrong. Hint: Do not tie the laces/clothing material round a) your wheels or b) your neck.

I can't be the only one with makeshift disability tricks for getting out of scrapes, so share them with us all in the comments. I'll bet one of you has worked out some ingenious, complicated way to get your clothes up and down from those annoying hangers they have in hotels or reach the beer nuts right at the back of the bar fridge.

Write to us and tell us your survival tips at starecarenews@gmail.com



TICKING ALL THE BOXES

Remember our feature article on Tom Softly? Thank you to Jackie for sharing this picture of Tom proudly voting for the first time ever. Tom is a role model for other young men with Down Syndrome, and we think it's awesome that he's leading the way for other young people to vote.

A few years til the next one, so check out the AEC's plain English resources and teaching tools. How many young men and women with disability exercise their right to vote, and how many people with disability are discriminated against when it comes to voting? Let's change that.

Expect the Respect

Own your ownself. Roll into the room like you own that too. Style what it is you got, crazedness or gimpiness – the move is your own, darlin'. Drool like you mean it. Spasm like it's good to you. Stumble, stutter, then flash one long, wicked grin.

Never apologize. Never explain – unless they're sayin' how they got like they are. Could be they fear you. Use that. Let your speciality say, *Hey dog, show us somethin' real yourself.* **Don't you wait for respect.** Take it, as much as you want. And don't let anybody call you slow. You're showing all of us the way to go. We can wait.

Expect the Respect

Lifted almost legally from Mouth, a premier disability rights web magazine (with thanks)

what to do

- Read the contract carefully
- Understand the contract
- Only sign the contract if you agree with it.
- You can get help if you need it



CONTRACTS

HOW TO MAKE AND KEEP THEM

What is a contract?
A contract is an agreement or promise that is legal.

That means that the courts and the law can make sure the promise is kept.

An example of a contract is when you buy something. You have promised to buy it and the store or person has promised to sell it to you. If you don't pay for it, or if you don't get what you are paying for, the contract or promise has been broken.

If one person breaks the contract, they might have to pay a fine (money).

The new NDIS (DisabilityCare Australia) scheme means that the way people buy things will change.

This means that you may have more choices. You may also have more control over the way you spend your money. You should get the type of service that you pay for. You can ask questions about what type of service you will get. And you can ask your service provider to prove how they will do what they promised to do (provide evidence).

You can also have a contract (a service agreement) between you and your service provider. The contract will say what you expect will happen and what the service provider expects will happen.

It should also say what will happen if things go wrong and how they will fix it.

A contract can keep you safe, but you need to read understand what is in it.

WHAT SHOULD YOU DO IF YOU HAVE TO SIGN A CONTRACT?

- Read the contract carefully
- Take your time
- Only sign the contract when you understand it AND agree with it
- Get help if you need it.

You can read the fact sheets from Consumer Affairs Victoria on the next page to find out more.



What is a contract?

- Two people make a promise to each other
- Most contracts can be verbal
- Some contracts must be in writing, for example, when someone sells land
- A contract is a legal agreement. If one side breaks the rules in a contract there may be a fine. For example, paying extra money.



What should you do with a contract?

- Read the contract
- Understand the contract
- You can ask a support person or family member to help you
- Make sure you understand everything in the contract
- If you do not understand the contract ask a **lawyer** or **Consumer Affairs** in your state for help

- Write any **special rules** on the contract.

A **special rule** will protect you.

For example, a special rule might be “I can only buy this product if I get a bank loan”.

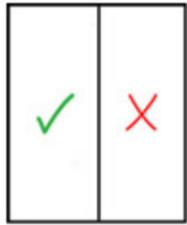


How to stop a contract

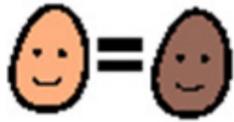
- Some contracts will give you a set time to change your mind and stop the contract. This is called a **cooling off period**. You might have to pay a fee
- You cannot stop a contract after it starts. If you stop a contract you might have to pay a fee.

A **cooling off period** is when you have time to change your mind.

Ask how many days you have to change your mind.



Rules for contracts



All contracts must be fair

A fair contract is equal for both sides. For example, there are 2 cakes and 2 people. Each person gets 1 cake.

That is fair.

An unfair contract is against the law.

If you think you have an unfair contract you should contact Consumer Affairs in your state.

Consumer Affairs makes sure businesses follow the rules.

There are also Tribunals and Courts, who have the power to;

- Stop an unfair contract
- Give a fine to a business who writes an unfair contract.



Rules for contracts



A contract must

- Use a clear font. The font in this book is called Arial
- Have short, easy to read sentences
- Use plain English
- Explain hard words.

The business must show you any other documents they talk to you about, for example, a warranty.



IMPORTANT NUMBERS

- Northern Territory** - Consumer Affairs 1800 019 319 SMS : 040 111 6801
- Tasmania** - Consumer Affairs and Fair Trading 1300 65 44 99 TTY users Phone 133 677, then ask for 1300 13 55 13
- Victoria** - Consumer Affairs Victoria 1300 55 81 81 TTY users: call 133 677, then ask for 1300 55 81 81.
- South Australia** - Consumer and Business Services - 131 882
- Western Australia** - Consumer Protection
Call 1300 30 40 54 or 13 36 77 for the National Relay Service for the hearing impaired.
- Australian Capital Territory** - Fair Trading (02) 6207 3000
- New South Wales** - Fair Trading 13 32 20 Language assistance Telephone: 13 14 50 TTY 1300 723 404
- Queensland** - Fair Trading 13 74 68

COMPLY OR DIE

JANUARY J. TALKS ABOUT BEING SICK - AND COMPLIANT

I was going to write this awesome article about fragility of support for Starecase ... it was going to be a masterpiece of literature and theory and you would have laughed and cried reading it. But unfortunately for my masterpiece, on Thursday I went to see a new specialist. This new specialist had a new set of treatments she wanted to try, and it's no exaggeration to say they take up the entire day. There are specific exercises to do every 45 minutes for the whole time I'm awake, and the other 45 minutes - at least at the moment - is pretty much taken up with recovering from the exercise part. It's hard and it hurts and it's very much not any fun at all. The specialist said it would be very hard and that I would need to persist for at least six to eight weeks at least before there was any noticeable benefit to my health - and that's the best possible case, I don't know what her worst case was because I was too afraid to ask.

So, with zero notice, I've had to cancel everything I had on for the next several months, basically. I've had to cancel my attendance at the family pizza night on Sunday - my only chance to see my brothers and my adored baby niece. I've had to cancel my trip to the local park to be with my friend and her toddler. I think I'll have to cancel the appointment with the haematologist on Monday. I'm trying to figure out what to do about Thursday's dental appointment because I can't sanely cancel that but I also can't figure out how I can possibly find the energy to attend it.

I wanted to write about this not because it's

extraordinary, but because it's not all that uncommon. In my twenty years of chronic illness and disability it's something that doctors have asked me to do many times - anybody with a chronic illness will be familiar with it. You have to be willing to turn your entire life upside-down with no notice, or be labelled "non-compliant". If the treatment that's been prescribed is something you've already tried multiple times with no improvement, that's probably not good enough (I went through inpatient rehab six times before admitting it was never going to work). If the treatment is something you think won't work for you, even if you have good reason to think that, that may not be good enough for the specialist. The treating doctor absolutely has all the power here - if they don't want to listen to your perfectly logical scientific reason why their treatment won't work or has not been helpful, they don't have to. If you're labelled "non-compliant" then you put at risk your ability to receive any treatment in the future. In terms of chronic illness, it's like the kiss of death - if a doctor thinks you're non-compliant then they think you don't want to get better, or at least you don't want it badly enough, and many times this turns around into abusive victim-blaming. If your file says you're non-compliant, anything that goes wrong in the future is automatically your fault.

Potentially worse, if you DO decide to turn your life upside-down to comply with their requests, but it turns out that the treatment doesn't help you, the doctor may not like hearing that. Logically, they may accept it when you report (with written logs and checklists galore) that you did exactly what they prescribed ... but they may also decide that their treatment couldn't possibly be at fault, so therefore you must be lying. Yes, I've had this experience too. Where I did all the exercises prescribed, exactly as prescribed, and my body did not do what the doctor thought it should. And the doctor could not imagine that their theory might be wrong, or might not apply to me, and concluded that I must have lied when I said I'd done all the exercises. And bingo, simple as that I'm written off in the "non-compliant" wastebasket even though I had complied perfectly!

Once you're labelled as "non-compliant", you will either be ignored or shipped off to the psych department where they try to address your "unwillingness to get well". If you try to claim that you're perfectly willing to get well they'll have to address your denial too, of course. These both generally involve cognitive-behavioural therapy doesn't take into account your actual disability in any way, and frequently involves a lot of victim blaming. So how is it reasonable that specialists can demand that you drop everything in your entire life with zero notice to follow their untested regime? How is it reasonable that - if patients question this - they're told they are "not serious" about getting better and labelled "non-compliant" and sent down the hall to a psychiatry department that's primed to be as

unhelpful as possible.

I want people to look at this from a social justice perspective: Patients need to be able to say that a burden of treatment is more than we are willing to accept without being written off as not wanting to get well.

The world isn't divided into "good cripples" and "bad cripples", it's never that simple. We need to have the right to question things and ask "why" without fear of reprisals. We need to be taken seriously when we report what's happened, even if it isn't what the doctor wanted or hoped for. We need to be able to see what the medical profession is writing in our files and seriously challenge or change it when we think it's wrong. And, sad to say, I can't see how we get there from here.



WHATEVER HAPPENED TO KYLA PUHLE?

WHAT HAPPENS WHEN SOMEONE AT 'THE MARGINS OF PERSONHOOD' DIES IN OUR COMMUNITY?



“
Kyla was brought up as a member of the family.”
The Honorable Justice Sulan, in his sentencing address

I wanted to write a story about Kyla Puhle. Most people with disability, I thought, will know about Kyla, whose mother pleaded guilty to her manslaughter after she died at their family home in 2011 from malnutrition and dehydration.

At the time of her death, 27-year-old Kyla weighed only 12 kilograms.

So I googled Kyla's name. To my surprise, there were a paltry 2,070 results.

For many disabled people, Kyla's story is a source of outrage. Her parents withdrew her from her day service, refused her medical attention and left her to starve in a beanbag, unattended for eight hours a day. For others, the story is more complex – many argue that this is the sign of a broken system which allows parents to care until they crack. Angela Puhle will never serve time, and she was given a suspended sentence and a \$1000 fine.

So...where's the story?

I googled 'Koda the police dog'. Koda was stabbed twice during an incident in Elizabeth Vale, and his attacker was jailed for three months. There were 19,300 results, including the SA Police page, where Koda reports that he has made a full recovery.

A year after her death, there are 1,010,000 Google search results for 'Jill Meagher', the dark-haired beauty whose life was cut short when she was brutally murdered in a Brunswick lane.

There's even a book.

"I think it has changed Melbourne," said Brunswick writer Michaela McGuire, who has written a short book about the ABC broadcaster's murder.

"It was easy to get swept up in that and forget that it happened to a real woman who had a real family who were really suffering. But the strong reaction that most people had has also made us view other crimes against women in

the same way."

Really?

It's an interesting thing, community outrage. People took to Facebook in the wake of Jill's death, with one group – like the others, named 'RIP Jill Meagher' – hosting an impressive 285,778 members.

There's even a Jill Meagher Day.

But Kyla is conspicuously absent. As a person with a severe and profound disability, she didn't have a facebook page, or friends, or support. Kyla's photograph is missing from every news report, which mostly bear the image of a harried Angela Puhle rushing to or from court. Kyla

wasn't even at the margins of personhood – the media coverage was one tenth that of the stabbing of a German Shepherd. It's almost as though she never existed.

In 2012, an estimated 30,000 people marched along Sydney Road, Brunswick in memory of Jill Meagher. Nobody will march for Kyla, nor hold a candlelight vigil. A bitter irony that Kyla Puhle is also far better known in death than in life.

In September, 2013, members of the Disability Clothesline group wrote to the Director of Public Prosecutions, South Australia, to ask if Angela Puhle's sentence would be appealed. From the

response -

'The value the community places on human life and the standard of care that is expected of every person were matters referred to during those submissions. The fact a judge has disagreed with a prosecution submission as to penalty is not, of itself however, a basis for the DPP to appeal against that sentence... The Director has taken into account all the factors in this matter, including the fact Crown Appeals will only be allowed in specific and limited circumstances. It has been determined that there are no reasonable prospects of success with respect to an appeal in this matter.'



DIY PAPER PLANE

WITH A LOGO
DESIGN COST OF \$130K,
IT SEEMS LIKE A
WASTE TO NOT RECYCLE
YOUR OLD DCA FORMS.
WE SHOW YOU HOW.



DisabilityCare Australia will shortly be rebranded to 'NDIS'. We show you to save money on expensive toys, and keep the NDIS green.

1. Take your DisabilityCare Australia flyer, fact sheet, information sheet or other advertising material. Fold it in half like a **hot dog**.

Subversive disability fun fact - 27.4% of people with disability are currently living below the poverty line of 50% of median household income. The cheapest place to buy a hot dog in WA is IKEA, where you can buy them for a dollar each.



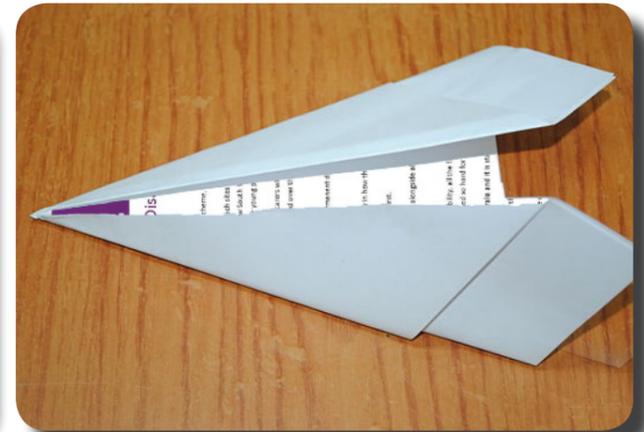
2. Take the top right corner of the paper and fold downward towards the left side into a **triangle** shape. Repeat on the other side.

Subversive disability fun fact - The black triangle was a badge used in Nazi concentration camps to mark prisoners as "asocial" or "arbeitsscheu" (work-shy). More recently it has been adopted by UK disabled people's organisations responding to increasing press allegations that disabled benefit recipients are workshy. Australia ranks 21st out of 29 OECD countries in employment participation rates for those with a disability.

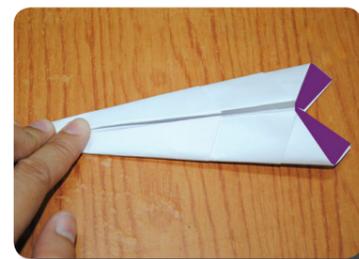


3. Flip the paper so the pointed top of the plane is facing the left. (this will be the nose of the plane).

Fun fact - we could have added more facts, but we didn't want to waste the paper :D



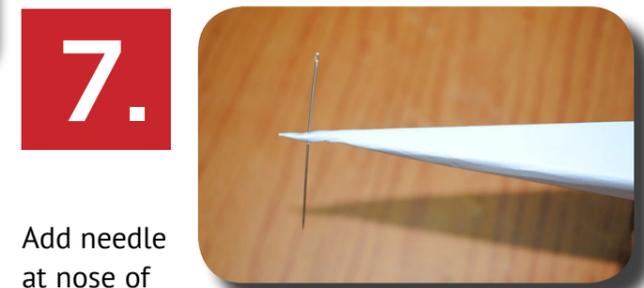
4. Fold the top down in half, starting at the nose. Repeat on the other side.



5. Fold both sides down again in the same way as above.



Pull the folds up to form the top of the plane. It should be flat and look similar to a platform.



7. Add needle at nose of plane. Fly.



A LIAR AND A FAKE

GARY KERRIDGE

FESSES UP

Gary Kerridge is a disability advocate, a liar and a fake. He also happens to be Deaf.

I am a liar and a fake. I lie and fake on a daily basis as do many deaf people.

It's what I do when I can't be bothered with communication. Sometimes the effort of lip-reading and intense concentration involved with communicating with hearing peers is a drag. So rather than make this effort I lie and I fake. If you are deaf I am betting THAT YOU DO TOO!!

It happens everywhere. Where I work there are thousands of people walking around everyday. They come from all walks of life. From overseas, from up the road

"I am a liar and a fake. My question to my fellow Deaf folk out there is – are you?"

from regional Victoria ... you name it we have it. At least four times a week someone will stop me, lost in the vastness of the campus and ask for directions. Now sometimes it is a simple ask like, "Where's the loo?" and sometimes it's more elaborate and detailed like, ".Where is the X room in the Y building?"

Now generally I can assist but from time to time I get an Asian person asking for directions. Now, I am not racist but I can not lip-read many Asian accents. Some Malaysian student will come up and ask me a question and I just will not understand them. So I fake it and answer, "No idea mate, the office will be able to help you." And point them to the office. Sometimes they give me weird looks. They probably asked something like, "What's your name?" and I answer, "No idea mate, the office will know."

McDonalds and any like fast-food place are the pits. It's noisy and the person serving you just can not accept your order. You specifically say what you want and they ask if you want more. "Large chips?," "would you like an upsize?," "Desert with that?" -It's worse than the Spanish inquisition. On occasions I will fake it, look a my son and say, "What do you reckon?" This is a mistake because he will always say "Yes", "Large" and "More". The consequence is I end up spending 20 bucks more than I intend to!

Then of course when you have ordered, they have to repeat your order to you. It's noisy in McDonalds, you know. I have a Deaf voice and have trouble monitoring my volume in noisy areas. I either scream or whisper but very rarely get the right volume for the moment. What this means is I am often misunderstood. The person serving me will read back my order of a Big Mac with a large fries as a "Kids pack and an apple pie" I of course - fake it and nod vigorously. Mind you its fun to play with the toys. I guess you reap what you sow.

I am a liar and a fake - My question to my fellow Deaf folk out there is - ARE YOU?

AFFLATUS

THE INVISIBLE BODY

When you will not hear my pain
You cannot share my joy

When you will not acknowledge my hate
You cannot feel my love

When you will not allow my weakness
You cannot be supported by my strength

When you will not accept my difference
You cannot appreciate my beauty

When you will not see me
That does not mean I don't exist

- Rayna Lamb

WHAT MAKES US HUMAN?

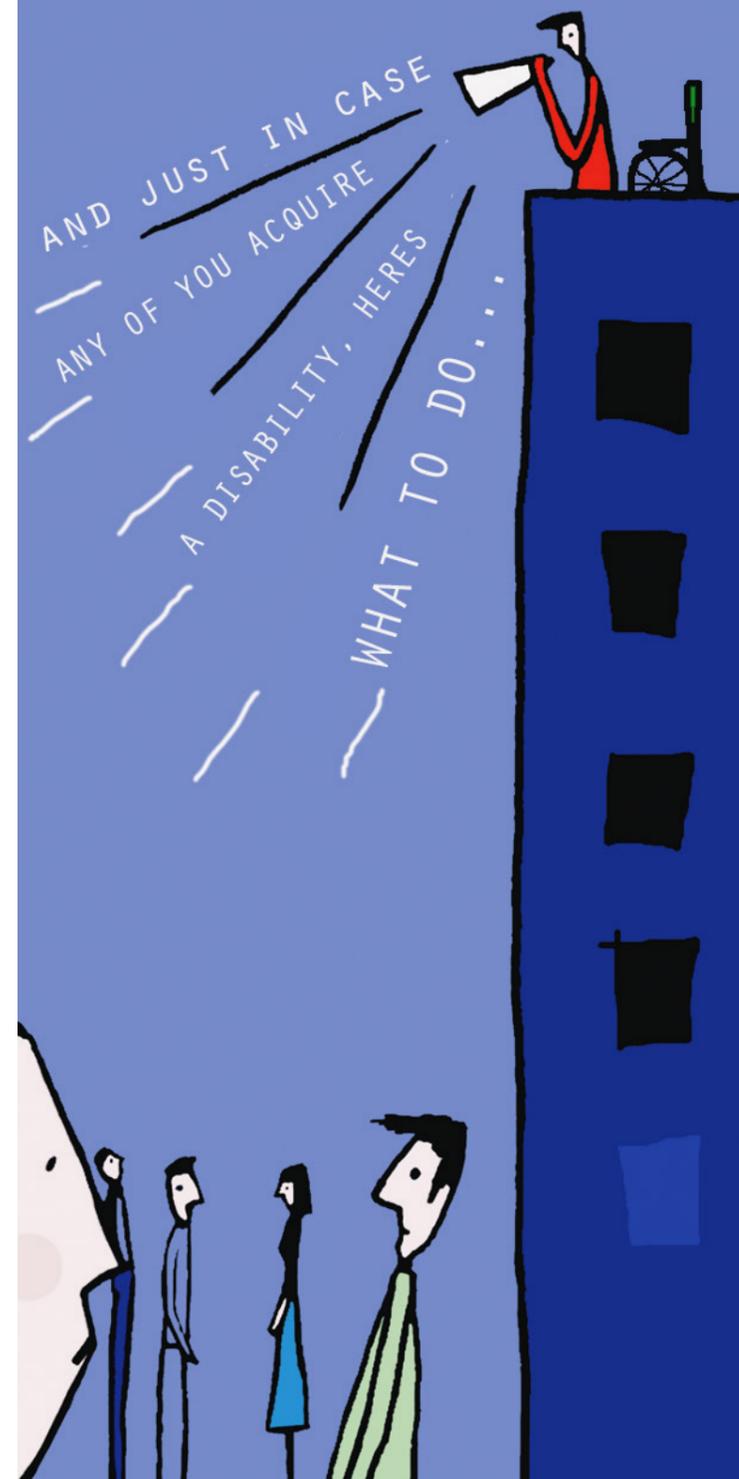
Is it our minds and our emotions
Or compassion for another?
Is it our capacity to love
And our need to be with others?

What do we have in common?
Lets be real about our functions
Stuff goes in, stuff comes out
We hope there's no malfunction

I may have a different shape
But I'm part of our diversity
Stuff still goes in, and out it comes
But for me with a suppository

- Samantha Jenkinson (upon being
challenged to write a poem
using the word 'suppository')

I WISH I'D KNOWN...



WHAT DO YOU WISH YOU'D BEEN TOLD ABOUT DISABILITY?

- * That people would use me as a coatrack.
- * That it doesn't make me less of a human being and and I don't need to justify my existence
- * To get used to being treated like I don't exist, or as a charity case - not much in between
- * Avoid the people with attitudes that are even more disabling
- * That large numbers of people people will never learn the difference between blindness and low vision!
- * That as somebody with an invisible disability I'd have to fight harder to have people acknowledge my disabilities than my abilities ... and then as my disability became visible it abruptly reversed and I had to fight to have people acknowledge my abilities not my disabilities.
- * Not to bother studying and having aspirations for a career. I'll never get a job or be acceptable.
- * You don't need designated words like 'special' and 'brave' to pick out the positives of disability. Beauty is beauty and courage is courage no matter who you are.
- * It was so damn expensive, waiting lists and how many fricking forms there are!
- * Support does not mean support unless you throw endless tantrums and then you risk extra labels and pills.
- * Life is still good.

THE PATH TO INCLUSION

SAMANTHA JENKINSON TALKS ABOUT THE BIG ISSUES - SEGREGATION, ISOLATION AND INSTITUTIONALISATION



In 1989 at the age of 20, I was involved in a car accident where I acquired a disability. Well, what actually happened, for those who want the gory details, was that the van I was in hit a tree when we skidded on a dirt road and I broke my neck. I became a quadriplegic and my life completely changed.

Now usually when you read a story like this it tells you all about how the person was a wonderful, fun loving, active member of their community until tragedy struck. In my case of course this all goes without saying. Then the story usually turns to how the person triumphs against the odds to live a normal life. Here is where my tale differs, as I want to tell you about my experience and observations of how our society can isolate - or include people with a disability, regardless of how hard the individual is trying to 'triumph'. About how community can safeguard people from abuse

– or allow it to happen. And about the importance of knowing what norms and values we are using in our different communities.

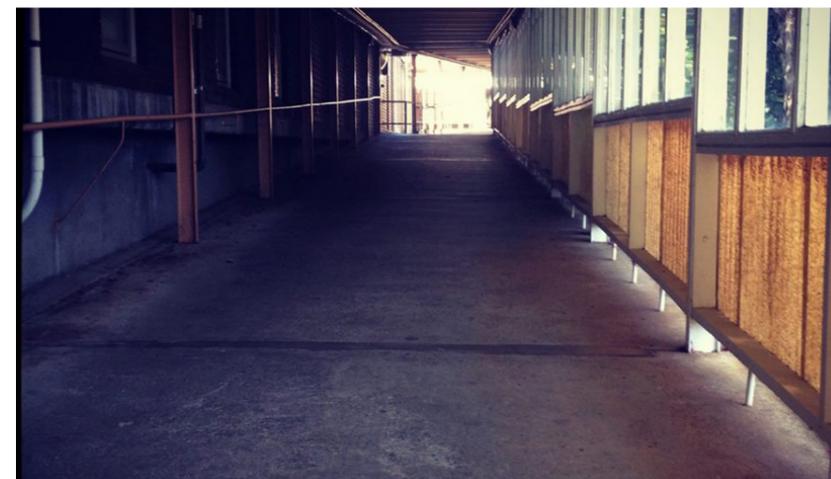
The story starts with the realisation that as a person with a disability I was finding it very hard to still see myself as a part of that all encompassing community.

My first experience as a person with a disability was when a friend took me out into the city for shopping and a meal while I was still in rehabilitation. It was like a slap in the face. The reality of people looking at you because you were different; the reality of a built environment, which was not friendly to someone with mobility issues; the reality of a community that was not very inclusive. All of this on top of the feelings of embarrassment and shame that my friends needed to help me. This was when I had my first experience of being a person with a disability. This is when I recognised my label.

Leaving the hospital was difficult but I was fortunate enough to have found accommodation at the 'Quad Centre'. The Quad centre was like a hostel with nursing staff specifically for people with physical disabilities, mostly

spinal injuries. It was a one hundred bed facility with 24-hour care.

I lived in the Quad Centre for three years and in that time I never felt isolated in the normal sense of the word, as there were lots of other



It was a 100 bed facility with 24 hour care...I lived there for three years."

people with disabilities and staff around always; in fact I was often trying to find my own space. I was lucky enough to have a room in the wing for those who were more independent. It was a bit like I imagine boarding school to be, with communal dining at set times and shared bathrooms. I had made good friends with some of the other residents, who like me were young and waiting to find somewhere to live, and I made friends with some of the staff. I also had a supportive family who visited me often and friends who visited me and took me out. The year after my accident I also went back to university and made new friends.

None of this was as easy as it sounds of course. Making friends at university was very hard given my inability to participate in spontaneous trips to coffee shops or pubs i.e. I had to be ready for my taxis or carers. Also, friends I had from pre-accident slowly dropped off to a faithful few. Within twelve months my life revolved around being at the Quad Centre studying or having a drink with other residents, or going to lectures and classes at university.

The staff and residents at the Quad Centre soon became my community. However it was a community I wasn't sure I wanted to be too much

a part of. I knew some of the people had lived at the Quad Centre for twenty years, eating in the same communal dining room every day, who worked at the Quad Centre or the sheltered workshop nearby, who attended classes in pottery, art, cooking etc. at the activity centre located in the middle of the Quad Centre, who got books to read from the Quad Centre library. Some of these people had acquired brain injuries, some spinal injuries, some other physical disabilities like multiple sclerosis and cerebral palsy, however they were mostly intelligent, ordinary people. Yet they probably only went out into the broader community once a month if that. The idea of actually moving out to live in the community was just too scary.

Not all of these people who had lived in this setting for twenty years were people who needed 24-hour care. Many did not. Many were in their 40's or 50's and had been told twenty years before hand that they would be unable to live in the community. This was a reflection of the values and norms inherent in our society at that time. So they had become part of this segregated community with its own norms and values.

These were some of the norms that I noticed in the community at the Quad Centre:

- People were in bed or in their own rooms by 8pm usually each night unless they were going out somewhere special.
- You always let staff know if you were going out.
- No one could stay overnight in your room and sex was never talked about or seen as something that might seriously happen.
- You didn't meet other people's family or friends and they didn't meet yours.
- During the day your bedroom door is always open
- Staff don't need to knock when they are doing rounds
- You don't talk back to staff or 'make waves'
- Staff are there to help so you don't do things yourself like make a drink or your laundry
- Conversation and socialisation during meal times is limited
- It's too hard to get out so you get things you need brought in eg. Books, food, drinks, movies.

This way of living starts to slowly sink in to how you act and interact. You start to accept that staff can come in and out whenever they want. You don't make the effort to go out anymore because you can get what you need without going out. You accept limited or no choice because

it's just too hard and too much trouble to get choice. It is very easy to see how some people's social skills could be severely set back, as well as many other life skills. Even the language and communication used between staff takes on these norms, and many of the staff had also been working at the Quad Centre for ten years or more.

I was aware that I was becoming isolated from the broader community, so I used every opportunity I could to work towards leaving the Quad Centre. I didn't want to become like the people who had lived there for twenty years.

What would happen to someone in this situation who had no family who visited? Or who never had the opportunity to go out? This was a facility, which allowed for interaction between residents. This was also a facility, which although it was segregated from the wider community, had a choice of things to do, was reasonably well staffed, and did not have abuse to my knowledge.

I saw the development of norms and values that were not the same as values in the broader community, and within those norms the development of low self-esteem and reduction of social skills among residents in this institution. What would happen if there weren't

enough staff? Or initial training of staff was flawed, or there were not enough resources for proper maintenance and hygiene. We have all heard the stories of nursing homes that gave residents kerosene baths because it was the cheap and easy way of stopping body lice and fungal infections. How long do these things happen in these isolated settings before someone sees that it's not normal?

I believe that the key elements, which influence these characteristics of an institution, are isolation and segregation. Segregated communities develop their own norms and because the people in the community are kept isolated from the rest of society the norms that are developed are not challenged.

I truly believe from my experience that de-institutionalisation is a good thing, but does closing down these types of institutions stop the isolation and segregation of people with a disability? My experience and that of many others would say 'no'. What is important is not only is isolation as a factor but segregation and isolation can be attributable to institutional systems which can cause abuse and neglect, not just institutions as facilities.

Currently our institutional



In 2012, Samantha won the Minister's Award for Excellence in Disability Reform at the National Disability Awards



You accept limited or no choice because its just too hard and too much trouble to get choice."

systems include shared accommodation facilities, day placement centres where people with a disability go to do 'meaningful activities' during the day, and a variety of support programs with small amounts of funding for usually specific purposes. Groups homes or 'shared supported accommodation' (SSA) are usually houses in the community that have four to five residents and, depending on the needs of the residents in the house, a number of staff to support residents. Group homes have become the replacement of large institutions for accommodation of people with a disability, with the supposed advantage of being ordinary homes where people live in the community. The Senate Report (2005) showed otherwise based on its submissions:

...despite being in the community, group homes do not mean greater participation in community activities, better quality care or necessarily that individuals have their needs met or are protected from abuse and neglect; an incompatibility of residents often leads to injury, aggression, hostility, threats, intimidation and fear.

I support this statement based on my experience as a case manager dealing specifically with accommodation and support issues. Many of the people I worked with were trying to stay out of group homes or move out of group homes they were currently living in. However as the following statement from a parent in the Senate Report (2005) shows, isolation can also occur in the family home.

A view was put by a parent of a severely-intellectually disabled child that contemporary ideology which promotes 'that the best place for children with a disability is with their family, supported by services from within the local community to meet their particular needs', rings as hollow as any populist slogan. This parent advised that: Because of the almost non-existent support to families of children with difficult behaviour or disabilities...the 'inclusionist' ideology has led to many families becoming institutionalised. It has increased the new 'mini-institution' the family home. Of great concern is that these 'mini-institutions', these families, are invisible to the policymakers and ideologues. Their isolation and loneliness is not factored into policy because they neither have the time nor the energy to agitate and be heard...this holds true for most families who have the difficult task of not only

meeting the challenges of life in the modern world, paying the mortgage, meeting expectations/commitments of work and relationships as well as raising children and the special challenges presented by this unique task. Add to this the difficulty of a child with difficulties either medical problems, behaviour problems or a disability and the task of keeping a family in tact seems almost impossible. Is it any wonder these families are endangered. (2005, section 5.59)

Much of the literature on people with intellectual disability living in the community, be it in group homes or other alternatives concurs with these statements from the Senate Report. The initial report on 'Power Sharing and Direct Care Staff Interaction with Residents of Disability Accommodation Services' (2002) done by the Victorian Department of Human Services states in its literature review that:

Placing people with an intellectual disability in the community does not necessarily mean that there will automatically be increased community participation, decision making and self-determination. (p24)

Isolation and segregation is occurring for people with disabilities in group homes, in family homes, in day centres and even in their own homes.

When there is isolation, all of these settings can lead to the development of norms and values, which in other circumstances would be considered abnormal. This does not mean that being in any one of these settings is automatically going to lead to a person with a disability becoming isolated. However, segregating people with disabilities from the rest of the community, even in their own homes does lead to isolation and a higher risk of abuse and neglect.

I believe that when people have natural (informal) supports in the community, there is an opportunity to reduce isolation and an extra safeguard is in place for a person with a disability from the abuse and neglect of the institutional system. Institutional norms can be challenged when a variety of other community members are in a persons life.

None of this is new and as the quote from the parent of a child with a disability points out the idea of community inclusion can easily become a populist slogan while funding bodies reduce support for people with a disability. Across Australia the policies of person centred approaches are leading to a changing perception of how support for people with a disability can be provided, yet service providers, people with a

disability and the community are not necessarily changing as quickly as the rhetoric. Those who are leading this change need to look carefully at how they are bringing everyone along.

So the big question is how do we do community inclusion so that people with a disability are not isolated or segregated, while maintaining the support that people with a disability need in their lives. I think it is important to remember that discouraging segregation in life is not just about reducing the risk of abuse, but also about reducing the development of norms that can be restrictive and impede the personal growth of people with a disability.

At this point I would like to say very strongly that I am not suggesting people with a disability shouldn't socialise or do things with other people with a disability. For me the community of similar people with similar experience was important for the grief process I was going through. It is still important to me, and to my identity as a person with a disability, that I have good friends who have disabilities and I am involved in the disability movement. The reasons that continuing to have these links and friendships are important to me are:

- Other people with a

disability 'know'

- I don't have to explain the why and how
- I'm not embarrassed about needing help or looking 'gimpy'
- They are in on the jokes (sometimes really bad jokes, if there are more than two or three Sams in the room)
- I believe that jointly we can change the community

The links I have made in the disability movement and friends I have are ones that I have made myself. They are groups and people I have actively made an effort to be involved with and are simply one part of my life. This has also been a part of my life that has developed over time. Like any person there are lots of aspects that make up 'me'.

Earlier in this article I talked about how I could see isolation from the rest of the community happening to me when I was living in the Quad Centre, and this also continued when I first moved out into my own home. What did I do to counter the feeling of isolation? I still felt that people in the community stared, and were unsure of how to talk to me but I was determined to do something. I kept going to university, which helped a lot as over time I did make a couple of very good friends. I also went full time so there was continuity with the other students and

more opportunity to build a friendship, although this is not something that everyone can do.

The biggest thing that I did to try and make some connections to the community was attending Adult Community Education courses. Each semester I would sit down with the paper and see what courses I could do that interested me. I would ring and find out if the venue was accessible and then do one course a semester. Over a couple of years I tried life drawing, watercolour painting, short story writing, film script writing, poetry and voice. Doing the poetry course was the only one that led to a friendship outside of the course, but each time I did a new course I grew in confidence.

Finally I got the courage to ring a community choir that had advertised for members in the local paper. The conductor was a wonderful person who made every effort to ensure I could participate. He was interested in people who loved to sing and the disability was not an issue. From this beginning I ended up on the committee of the community choir and then joined a bigger choir that was more my own age group at the time. In both choirs I made lifelong friends. The majority of people I met didn't know about disability, but

they made an effort to ensure I could participate. They encouraged and supported me to attend social events and even to participate in trips interstate for concerts. My participation in a national choral event led me to meet my husband and move interstate.

Not once during this time did I think that I would need to go to a disability specific music group. Of course I know that not everyone can do this, even people without disabilities. It does take confidence and courage to turn up to something by yourself and hope people will respond to you when you say 'hi'. In fact I think it is probably harder for me to do know that I am older. So if this isn't your way of making new friends then what do you do?

This is not a rhetorical question. Making the first connections in the community are so important and there are lots of ways to do it. A resource on community connections for people with developmental disabilities states: When we're trying to help people with disabilities meet new people, it helps to identify our own strategies, what's worked for us in the past. We can ask ourselves what we did, or how would we do it if we had to figure it out ourselves. The simplest question is, 'If this were me, what would I do?'

This is only one part of the community inclusion equation, albeit an important one. I was also studying and then working, which made me feel like a valued member of the community.

Even though I feel that I am part of the wider community I still get shopkeepers, bus drivers, real estate agents etc. who stare, treat me with pity, and make a wide berth to get around me. I hope that every time I look them in the eye and talk to them, I am breaking down their stereotyped view. I think that as an individual with a disability I can, and do, make a difference whenever I meet someone and challenge their view on my being there.

Structural and systemic barriers do still isolate me. I cannot visit my neighbours because they do not have accessible houses. I don't meet the other parents at school because it is too difficult for me to find parking, get up the curb, and get someone to open the gates for me, plus only half the school is accessible. Many of these barriers are ones that I cannot easily change as an individual.

I feel that for me to be a part of the community takes a great personal effort, and some days I wonder if its worth it, but then I remember the Quad Centre and look at the friends and family I have know.

On a final note I must let you

know that after myself and many of the other young people who were at the Quad centre left to move in to our own places in the community, a few of the residents who had lived at the Quad Centre for many years also moved out. It seems that our example, and the change in support available to people living in the community had made them rethink how scary it was to be part of the community again.

Samantha Jenkinson is a WA disability advocate and Chair of the Ministerial Advisory Council on Disability in Western Australia.

DECRIMINALISE

DISABILITY NOW!

They'll act all shocked. Nobody says disability is a crime! Then how come we get a **placement** like criminals get a sentence? For the crime of disability, hundreds and thousands of us are serving out a life sentence in nursing homes or loony bins or state 'schools' - lockups with fancy names. Or sentenced to group homes or sheltered workshops - hard time, for life. There's even a death sentence for disability - they're calling it our 'right to die'. Yeah, but they never did call shit by its real name. Look how much crime gets done in the name of **help**. Expect the respect.

- Mouth Magazine



ANDREW HEWITT IS A DRUMMER

AND AUSTRALIA'S FIRST TRAP FACILITATOR

Andrew Hewitt is a busy man. He's a drummer from Sydney, has cerebral palsy - and is Australia's first TRAP (The Rhythmic Arts Project) facilitator.

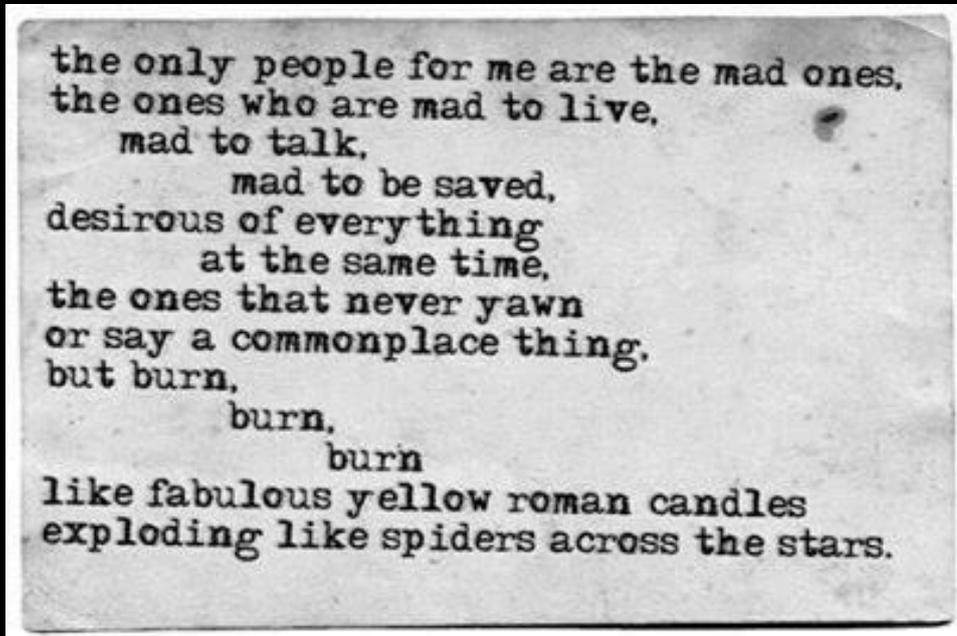
TRAP is an educational program which teaches people with disability to read, spell, count, identify colours and share and interact using drums and percussion. Andrew and his wife went to the USA in March to attend a TRAP seminar, and haven't looked back. He's delivered his first workshop to a workshop with some young people through the CP Alliance, and hopes to continue spreading the word.

Andrew says that his trip opened up some other avenues for him as a drummer. "Another part of my trip

was to go to New York. While there, I attended a meeting at Dom Famularo's studio in Port Jefferson. Dom is known as drumming's global ambassador and travels the world. We talked about the frustrations of getting a real gig.. being offered real opportunities."

You can find out more about TRAP by visiting the TRAP Australia page at www.facebook.com/TrapAustralia.

Andrew is also part of a collective of musicians with disability who support and guide each other. Its a global movement called 'Can-Do Musos' - they are looking for musicians from all over the world to feature on their site. For more information, go to www.candomusos.com



THINK THIS IS AWESOME?

WANT TO SEE MORE EDITIONS?

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 starecasenews@gmail.com