

Presentation to New England Complex Cases Conference
Armidale, 20 September 2016

I acknowledge the traditional owners of this land.

My brother, Brian, and I had just bought our first car. We had the perfect combination: I was about 22 and had saved a little money; he had just got his licence and was desperate to drive. So I paid for the car — he paid me back half the money later — and he drove. It was a blue Chrysler Gallant, five years old, with a few miles (yes, they were miles back then) on the clock, but we thought it was the best thing since sliced bread. We never missed an opportunity to take it for a spin.

I had been asked by a social club in Wollongong to give a presentation to their afternoon meeting on people with disabilities. So Brian and I decided to drive. For him, four or so hours behind the wheel of our little beauty was worth the tedium of listening to one of my presentations.

I spoke about the importance of including people with disabilities in all aspects of society. I encouraged people to focus on the person, not the disability and to ask if assistance was needed rather than making assumptions about what we couldn't do. During question time I commented how critical it was to talk to the person themselves rather than about them.

At the end of the meeting we were invited to afternoon tea and were happy to partake of the excellent cakes and biscuits on offer. One of our hosts approached me, and said to Brian, who was standing right next to me, 'Would Graeme prefer tea or coffee?'

I winced in disappointment, given the point of my presentation. However, 'coffee' was Brian's calm reply.

'Does he take milk?' she asked.

'Yes,' Brian replied.

'And what about sugar?' she continued.

'Two sugars, please,' was his calm response.

In contrast, my temperature was rising, steam was beginning to trickle from my ears, and I was planning the tongue-lashing he would receive during the drive home. His actions, I thought, had completely undermined my presentation.

'By the way,' Brian said with a wry smile, as our host was about to leave with the coffee order, 'Would you like me to drink it for him as well?'

Suitably chastened, she apologised to me, and my recompense was an excellent cup of coffee and an extra lamington. She had worked out the way to my heart.

So, good morning. It's exciting to have a chance to speak with you at this conference. The NDIS, and the choice and control it is beginning to offer, is a very positive step forward. Not only for the scheme participants and our families, but for our whole community. Because our whole community will benefit significantly from the greater inclusion of, and input by, people with disabilities. As both Premier Baird and Minister Ajaka have said, NSW cannot afford not to have the NIS. Australia will become a more sustainable community. And all of you, as service providers, are contributing to that more sustainable community. So you should share my excitement.

But let me go back to my coffee story. Why have I told it? Firstly, because it's one of the stories from my recently-launched autobiography; *Finding A Way*. And Paul from Collins Booksellers in Armidale is here to sell you one if you would like one. And for

those who have them I am happy to sign them today. I should warn you, though, that an event in Melbourne tonight means that I am leaving relatively soon after I speak.

But, despite my shameless self promotion, I did not really tell the story because it, along with many other stories of my life, is in my book. I told it because it typifies the way people with disabilities in our community are viewed in a negative and limiting way. We experience the soft bigotry of low expectations. And I want to talk more about that today.

Now I'm not one of those conference presenters who asks you to turn off your phone before I start. In fact, I encourage you to leave it on, and comment about this presentation — and my book if you plan to buy it — on social networks like Facebook and Twitter. If you like what you hear I am there as graemeinnes. If you don't like it my name is James McNeill.

So, how many of you are tweeting. Come on, that's not many. With all these heroes of New England disability in the room, you're just a selfie stick away from a photo opportunity.

So, let's talk about pollev. impressive software. I've used version 1.0 for years. it used to be known as putting up your hand. But I want to tell you something else about me as a conference presenter. It's a behavioural fault — at least the one I'm prepared to admit. If you put up your hand or use pollev 1.0 to answer one of my questions I'll completely ignore you. So you have to go to pollev 1.2 and use your voices.

So, let's get back to how I have my coffee, and who drinks it. This was just a very minor example, which did not change my day much. In fact, I scored an extra lamington which has got to be a good result.

But these sorts of incidents happen every day to those of us who have a disability. All of you here with a disability could tell us similar stories — and if you can't remember them, its not because they didn't happen, it's because they happen so often that you don't even notice. Elizabeth Hastings, the first Disability Discrimination Commissioner, used to say that people with disabilities swim in a sea of discrimination.

People park in accessible parking bays, removing the only parking option for people with mobility disabilities.

People leave obstructions such as shop displays, tables and chairs on footpaths, which people who are blind or have low vision run into, or who have mobility disabilities trip over or can't get past.

People at meetings don't use microphones when they are available, and exclude people with hearing impairments.

People stare at our difference — our skin condition, our wheelchair or our mobility aids.

People use words without pictures on signs, and exclude some people with learning or intellectual disabilities.

People use words like Mental, Insane, Retard or Spastic, or describe others as "turning a blind eye to my problem" or being "deaf to my concerns". Language which hurts

us, and sends a message that we are diminished because of our disability. When after all, normal is just a setting on a washing machine.

I'm sure that people who treat people with disabilities in these ways do so with the best of intentions. But in doing so, they disempower us, they take away our decision-making, they deal with our disability first and us second.

But you know what — I don't blame them. Because they behave just the way that our society teaches them to behave. They demonstrate a negative, limiting attitude towards people with disability. People with disabilities experience the soft bigotry of low expectations.

Why am I talking to you about this at a forum aimed at complex cases in this area, because people with disabilities make up 20 % of the population. And we are the group upon whom your work is focused. So I am challenging you, both in your work and your broader lives, to be part of the solution rather than part of the problem. Because changing attitudes change lives.

Do some of you find my statements about the limiting of people with disabilities, and that you are part of the problem, challenging? Remember; answer with your voices not your hands. Well, let me back it up with some facts and research.

People with disabilities are employed at a rate 30 % lower than the general population. And those of us who are employed are often under-employed. These figures have not improved for a couple of decades. And when there are 15 % of us of working age in the population we are employed by governments at a rate of under 3 %. Australia comes 23rd out of 29th on the OECD index for employment of people with disabilities. So whilst we have — as a nation — just celebrated the achievements of our paralympians in Rio, as they won lots of medals, in the race of life we are at the back of the pack.

We are all aware of the socio-economic impact of employment. The first question you were asked at this forum this morning, by someone you met for the first time, was "what do you do?" Employment, or more relevantly for people with disabilities, the lack of it, determines our social status. But the economic impact of lack of employment is also very clear — According to Deloits, if just one-third of that 30% employment gap moved from welfare benefits into jobs, the National Disability Insurance Scheme would run at a profit in a decade. But here's the key question. Does your organisation employ 15 percent of people with disabilities?

45 % of us live in or near poverty. We come 27th out of 27 on the OECD measure for this. A pretty poor effort for one of the strongest economies in the world. Again, no where near that paralympic gold.

Australia's own Peter Singer, who interestingly appeared on Q and A several weeks ago, rates us as lesser beings, in many cases not worth keeping, and perhaps not worth counting. But was there a person with a disability on the panel to counteract his appalling views on murder of people with disabilities, I refuse to euphemise it with the word euthanasia — even though we make up 20 % of the population. No.

People with disabilities experience worse education outcomes. Our year 12 completion rate sits at around 25 %, when in the general community it is at around 50 %.

People with disabilities have less access to health care services, and therefore experience unmet health care needs.

The lack of height adjustable couches in GP's surgeries until fairly recently meant that those of us with physical or mobility disabilities could not be properly examined, or that doctors and nurses joined the disability cohort by injuring their backs lifting us. Health and medical literature is only available in print, and not in easy English, excluding people such as myself with a print disability, or those with intellectual or cognitive disabilities.

Hospitals do not have wards with hearing augmentation, thus making communication more difficult for people with hearing impairment. My mother, who has hearing impairment, was in hospital recently. I was told that I would need to stay with her, as she could not understand what the nurses were saying, and must have dementia. When I asked if she was wearing her hearing aids, they admitted that they had not thought of that.

Because we are viewed as asexual, these sorts of problems particularly occur in the delivery of sexual health services.

Also, people with disabilities require more general health care services than the general population, and experience greater levels of unmet needs. "Health promotion and prevention activities seldom target people with disabilities."

We are also disproportionately represented in the prison population. This particularly impacts on people with intellectual disabilities and people with mental health issues. This is caused by the lack of equality in the justice system for these groups.

And we are excluded from communities by lack of access. Building and transport standards are starting to have an impact on that, but progress is slow. For example, how many council facilities in Armidale exclude people with mobility disabilities, print disabilities, hearing disabilities or cognitive disabilities? Or another question is this stage accessible?

What is the emerging theme here?

People with disabilities are significantly disadvantaged across a spectrum of measures in employment, education, poverty, health outcomes and imprisonment. And when you add the negative and limiting attitudes within the general population towards people with disabilities, that is a pretty negatively toxic cocktail in the hotel bar of life.

But this should not be the case. The vision should be about quality service, especially for those people who are challenged by the choice and control that the NDIS is beginning to provide. The vision should be underlined by the human rights ethos that expects equity and inclusion for all. Service providers should correlate the outcomes for people with disabilities with the investments they make in items such as staff education. And these investments should be measured not by the services delivered, but by the outcomes achieved by clients, and the improvement in their quality of life. The NDIS is a shift to a rights based support system, and was tirelessly fought for

over many years. There is a chapter in my book about the campaign. This type of shift will change the disability culture of Australia to one where all of its people, including those of us with disabilities, are respected and treated equally. We know it will take time to have it functioning at full capacity, but we will get there. NDIS is the opportunity to challenge the status quo, and the foundation for a truly inclusive community. You should be part of that change. The work you do in promoting individual rights, and the strategies you develop will assist services to change, and become resources for those positive outcomes rather than just meters of compliance targets.

So, back to my question. What are you, as advocates for people with disabilities, doing about it. Because, as David Morrison recently said, in relation to the Australian Defence Forces, the standards we walk past are the standards we accept.

I'm firmly of the view that our obligation — all of us here and many others who are not — is to knock down that attitude barrier which is a major cause in the list of disadvantage I have outlined. Because until that attitude barrier is removed, and people with disabilities start catching the rest of you on the measures I have outlined, people with disabilities will not be equals, and will not be fully included in Australian society. We have to re-imagine normal, and ensure that our systems deliver for everyone, not just the 80 % of people without disabilities.

That's my challenge to you today. Because; inappropriate treatment of people on the margins, or people with disability, should also be the responsibility of us all. We all need to think about the ways we can change our society to include everyone. Not just making our school buildings and buses accessible;
Not just better resourcing kids with mental illness in our community;
Not just finding supports for students who are homeless;
It's about changing our approach.

What should we do? Not disempower people by reinforcing their marginalisation. Not accept that there is nothing we can do if a student cannot get school books because they — or their family — are living on the street. Not expect that everyone will behave in the same way. Because you can hear a question asked in a noisy restaurant, don't get cranky with the person who asks you to look at them when you're speaking to them. They may have a hearing impairment. Give some thought to why your employee is asking to work less hours for a month or two. With a few careful questions, you may discover that it is as a result of their mental illness.

We won't have a fair and well functioning Australian community, until we include all of its different members. That's what you should work to achieve. And we won't include everyone until we challenge the negative assumptions that are made about people with disabilities.

One of the ways we might do that, or at least start to do that, is by turning some assumptions upside-down. For instance, I want all of you who did not bring your own chair with you today to please stand up. Come on, up you get. Now you all cost the region extra because we had to bring you in a chair. Ok, sit back down on that lovely comfortable chair. Are you relaxed? Good.

Now, let's go a little further. Can we dim the lights? Can we actually turn them off? Are you ready to continue this conference in the dark? I am what's your problem? Ok, all of that light which we are providing for you comes at a cost.

Finally, (move lips) did everyone understand that sentence? You all did. What did I say? Oh, you can't lip-read? Ok, another cost for the region is the public address system.

You see, the problem with our society is that all of you able-bodied people are costing us so much extra, because of those chairs, lights, and loud-speakers. If we could cut out those costs, the economy would be zinging along. Perhaps we should show a little humanity and respect for your difference — I think I'll start a campaign for a national able-bodied insurance scheme. But seriously, while ever those negative assumptions are made, we need to challenge them. Because if we don't we're walking past, and accepting those standards. And we're continuing to maintain a non-sustainable community where people with disabilities are prevented from participating. Inclusion: it's everyone's problem.

Thanks for the chance to speak with you today. I'm happy to take questions.