

The value of advocacy – Building a bridge between theory and practice

DANA Conference

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Introduction

May I pay my respects to the traditional owners, of the land on which we meet today the *Jagara tribal nation, south of the Brisbane River* and the *Turrbal tribal nation, north of the Brisbane River*, I would also like to acknowledge Elders, past, present and future.

Thank you to the organisers of today's event for inviting me to contribute. It's fantastic to be here at the fifth DANA conference. DANA has certainly come a long way since moves were made in 2007 to create and build a national voice to support the development of independent advocacy in Australia. I congratulate the board, the staff and members of DANA of the progress you have made to date and I look forward to witnessing and hearing about your future progress. It is also fantastic to be amongst those who advocate in myriad ways for vulnerable Australians with disability to live their lives with dignity, justice, equality, and freedom from discrimination.

The value of this work should not be underestimated – serving, as it often does, as a bridge between individuals and the fundamental support to which they are entitled. Sometimes, however, those conducting this work can feel as if they are engaged in a titanic struggle– small figures standing in the path of bureaucratic Goliaths a bit like rubber boats trying to turn around an oil tanker. In fact, the barriers vulnerable people with disability encounter daily can often make the pursuit of rights like climbing the insurmountable hill.

Today, then, I want to talk a little about the foundation on which the work of advocates in the disability arena should be built – the basis on which members of this audience already advocate for vulnerable people with disability are, whether overtly articulated or not. In essence I want to remind you – and, by extension, those bodies to which you advocate – that, though often very pragmatic and local actions, the claims you make for vulnerable people with disability rest upon a very global bottom line.

I draw upon the vision and wisdom of Eleanor Roosevelt's to draw the relationship of thinking globally and acting locally in the context of human rights.

'Where Human Rights Begin'

*"Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world".
Eleanor Roosevelt 1936.¹*

What is the value of advocacy?

So what is the real value of advocacy? After all, in any social policy area, the funding focus is often directed primarily towards direct service provision, with advocacy perceived as a luxury item when faced with competing budgetary demands.

Yet, as this audience well knows, without advocacy to build a bridge, too often services can remain inaccessible to the people who need them. Equally, problems connected with service provision can become intractable without advocacy to forge a way out.

This is illustrated in the simple example of Bella's story.

The Adult Guardian had been appointed to make decisions about Bella's accommodation and Bella had resided in a Department of Housing unit until it was decided that it was in her best interests to move to alternative accommodation. When Bella moved, some of her belongings were left behind. The Department of Housing emailed the appointed guardian to advise that Bella's possessions were being removed and placed in storage. If Bella's possessions were not collected by a date nominated in the email that was approximately 12 months away, then the possessions would be destroyed. The appointed guardian was asked to pass this information on to Bella.

¹ http://quotes.dictionary.com/Where_after_all_do_universal_human_rights_begin

Approximately 2 months later, however, Bella discovered that her possessions had been destroyed. When Bella and the appointed guardian queried this, they were informed that the date in the initial email was an error, but that the Department could not be held liable. The relevant legislation provides that the lessor or provider only need to store an individual's goods for at least one month.

Bella was very distressed by what had taken place, and her advocate put to the Department that it was reasonable to expect that its staff would be experts regarding the relevant provisions and that Bella and the appointed guardian were therefore entitled to rely on the Department's communication in good faith.

Bella's advocate conveyed Bella's distress to the Department and to the Office of the Adult Guardian about the way that events had transpired. While Bella's belongings could obviously not be recovered, given that Bella had an outstanding debt with the Department – including, ironically, the expense of removing and storing her belongings - the advocate was able to have this debt waived as a form of redress for the loss of her belongings.

As simple as this compromise may seem, it is an important example of how advocates can build pragmatic bridges for those who they advocate for. This audience knows how the accumulation of debts, however small, can be one of the disabling forces that trap people in disadvantage, one piling on top of another and preventing people from retaining, or regaining, control of their affairs.

Another, and perhaps more acute, reminder of the value of advocacy can be found in the story of Rose.

Rose was living in a shared housing arrangement, receiving 24 hour support from a non-government service. When her mother visited, she was horrified to see that Rose had an infected eye; that her shoulder bone was protruding and was obviously broken; and that there was bruising on her left shoulder, arm, stomach and leg. When Rose's mother asked what had happened, nobody knew how Rose had received her injuries, despite the fact that Rose was supposedly under 24 hour care. Meanwhile, Rose's limited verbal skills meant that she was unable to relate what had occurred.

An advocate became involved in Rose's case and found that, not only had Rose been seriously injured, but that she had been videoed without her permission and the video shown to various parties. In

addition, she had been unlawfully chemically restrained, while her money had also been misused by the service.

Following the advocate's intervention, Rose was moved from the service in question and placed in respite while the various concerns were being investigated. Police became involved but were unable to obtain sufficient evidence. A complaint was then ultimately referred to the Department's Compliance Unit due to the potential criminal nature of the matter.

A complaint was also made regarding the breaches to Rose's privacy and illegal use of chemical restraint – both of which were substantiated, with the service now committing to develop strategies to ensure that such failures are not repeated. In addition, the advocate also requested that the Public Trustee undertake a full financial audit of Rose's finances and, as a result, the service has been ordered to pay several thousand dollars back into Rose's account.

It defies belief that this kind of scenario can arise in the land of the purported fair go. Yet, as this audience will know, myriad stories like this exist - stories of recurrent failure by agencies; of people falling through the service delivery cracks; of marginalisation compounded, rather than alleviated by the wider health and justice systems; of individuals hand balled from one agency to another, with few of these agencies equipped or prepared to respond to any complexity.

The fact that these stories *do* occur must therefore be a reminder to policy makers that service provision is not always enough; and that, as Rose's story illustrates, the consequences of service failure are very, very real.

This means that advocacy is not just about individual cases, but about keeping these consequences firmly in the public eye, with the outcomes achieved in both cases I've described hopefully to have flow-on effects for other vulnerable people with disability who are reliant on the services in question. By drawing attention to mistreatment or injustice for specific clients, *systemic* injustice is also exposed, meaning that unacceptable practices are hopefully minimised or discontinued, with risks for service providers also negated.

In other words, advocacy is about mutual benefits. Certainly, no-one heading up a service agency, whether government or non-government, wants abuse or neglect to occur on their watch. Yet too

often the various parties involved – from policy makers to advocates to front line service - work as if in opposition to each other. We must remind ourselves, then, that we *all* share an interest in minimising incidences of vulnerable people being abused, neglected and degraded of their humanity. Until we tackle the disabling effects of structural and systemic disadvantage, however, stories like Rose's will continue to occur.

Disabling structures and the insurmountable hill

In particular, we all know that Australians with disability experience disproportionate rates of physical violence and abuse. To compound this, when this violence occurs, often victims are disbelieved or discredited; denied appropriate support; perhaps unable to convey their version of events, like Rose; or are dependent upon their offender for material or financial assistance.

In a disturbing example, staff members of a Queensland Independent Living facility were found guilty in 2009 of assaulting and depriving children and adults with disability of their liberty. Common practices included tying children to the toilet; rubbing chilli in their mouths; beating them with fly swatters; removing prosthetic limbs; washing out resident's mouths with soap; hitting, humiliating and pulling hair. Upon sentencing one of the former staff, the judge noted that a culture of abuse flourished in the facility and 'permeated from the top down'.

The assumption behind this culture could arguably be that experiencing abuse is inherent to the condition of disability.²

In this way, behaviours considered a violation of rights in an able bodied person - enforced isolation, widespread chemical restraint, or the neglect of personal hygiene - are seen as almost inevitable in association with disability; the usual equation inverted, with the human being becoming aberration and the violence becoming 'normal'.

This is reflected in the fact that women with disability are subjected to physical violence at higher rates, more frequently, for longer, by more perpetrators, and in more ways than their able bodied peers. In addition, women with disability are less likely to report violence, to

² Extracts from *Violence Against People with Disabilities: Seminar Proceedings*, 29 November 2004. Available at <http://www.nda.ie/cntmgmtnew.nsf/0/BE967D49F3E2CD488025707B004C4016?OpenDocument>

access support, to have their cases prosecuted, or to see any prosecution be successful.³

In short, the policy and service environment fail children, women and men with disability because violation of their rights is deemed unavoidable – and insurmountable, perhaps, when relative to other, more achievable, reform.

Accordingly, the lived experience of disability becomes less about actual impairment and more about the obstacles that stand in its way. As Graeme Innes, Federal Disability Discrimination Commissioner, told a Federal Parliament Joint Standing Committee on migration treatment of disability: ‘...[in many cases] it is not the disability which is the cause of the problem, but rather the way that society has constructed itself...’⁴

With violence and other forms of disadvantage normalised by the system, the implicit message to vulnerable people with disability, their families and advocates alike is that asking for anything *less* than violence is simply asking too much. We need to remember instead that what we are asking for in these cases is, in fact, the bottom line – the essentials, rather than an added bonus; and the fundamental standard upon which the international community has agreed.

The international bottom line and the economic argument

For as practical and local as Bella’s and Rose’s stories may seem, their entitlements to due process, to privacy, to dignity and to justice are founded in international law. Certainly, treaties such as the International Covenant on Civil and Political Rights, and the International Covenant on Economic and Social Rights spell out these entitlements as they apply to every human being. We must remember that economic rights are just as imperative as are political civil, social and cultural rights. I believe it is critical to use economic arguments and as advocates you should not shy away from the use of economic arguments.

³ Women with Disabilities Australia, Submission to the Preparation Phase of the UN Analytical Study on Violence against Women and Girls with Disabilities, December 2011. See <http://www.wwda.org.au/subs2011.htm>

⁴ Dismantling the deficit model’ House of Representatives Committee. Joint Standing Committee on Migration, 12 November 2009.

The ultimate goal of public policy should be the well-being and fulfilment of the rights of all citizens, this includes people with disability. The economic argument seeks to highlight the complementary links between social and economic policy, and the positive implications of social investment for economic development and productivity. This was the framework the productivity commission utilised in coming to its conclusion that a National Disability Insurance Scheme (NDIS) was not only in the best interests of people with disability and their families it would contribute positively towards Australia's economic future.

The productivity commission reported that the current disability support system is "underfunded, unfair fragmented and inefficient..." People with disabilities are recognised as one of the most disadvantaged group, with substandard outcomes on most indicators of community participation and well-being.⁵

When the Universal Declaration of Human Rights was pronounced it effectively meant that human rights were indivisible. Unfortunately in light of the Cold War human rights were prioritised. Political and Civil Rights were seen as higher order rights and social, economic and cultural rights were seen as soft rights.

However, the Convention on the Rights of People with Disabilities (or the CRPD) brings all international human rights obligations relevant to disability together under one umbrella. In doing so, it recognises disability not as static, but as an 'evolving concept', one that results 'from the interaction between persons with impairments and attitudinal and environmental barriers...'. It also emphasises the obligation of the state to take a positive approach to rights – to protect people, rather than just refrain from discriminating against them.⁶

For example, Article 16 of the CRPD requires state parties to take' *...all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.*'

Further, it requires that states do so by providing: *...appropriate forms of gender- and age-sensitive assistance and support [on] ... how to avoid, recognize and report instances of exploitation, violence and abuse...* and by ensuring effective monitoring by independent authorities. The Article goes on to determine that: *States Parties shall*

⁵ <http://www.pwc.com.au/industry/government/publications/disability-in-australia.htm>

⁶ CRPD preamble (e).

put in place effective legislation and policies ...to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Clearly, these provisions set solid benchmarks, requiring governments to do more than merely abstain from discrimination and signalling that exploitation, violence and abuse against people with disabilities is unacceptable. Like our commitment to so many rights obligations, however, they do not always translate into reality.

As a prime example, there is no national legislation to enact the substance of the CRPD, while human rights instruments are not enforceable at the local or state court level either. More specifically, no actions in the National Disability Strategy address the particular discrimination that women with disability face.⁷

Despite this, instruments such as the CRPD do offer a glimpse of how we might frame an argument - helping us reconfigure, or lend further weight, to our approach; explaining that we are not asking for an exception, but for the rule to be applied; and confirming that, often, the most disabling force in many individual's lives is not their impairment but the structures that surround and respond to it.

Taking the rights approach

What's more, a rights based approach can increasingly be spotted in the Australian legal and policy landscape. It is certainly the basis of Queensland Anti-discrimination act 1991 and the Commonwealth's *Disability Discrimination Act 1992* which, over 20 years, both acts have had a particular impact in areas such as public transport and accessible building, with positive obligations placed on service providers to meet certain basic standards.⁸

More recently, the Victorian *Charter of Rights and Responsibilities*, offers a state-based model – placing positive obligations on government agencies and decision makers to consider human rights; and on the Parliament to contemplate and account for human rights in the development of any legislation. In the first six years of its operation, it has already been used in a range of ways to achieve meaningful improvement in the lives of Victorians with disability.ⁱ

⁷ *Disability Rights Now*, Civil Society Report to the United Nations Committee on the Rights of Persons with Disabilities, August 2012, p 45-47 at http://doc.afdo.org.au/CRPD_Civil_Society_Report_PDF

⁸ See *Don't judge what I can do by what you think I can't: Ten Years of Achievements using the Disability Discrimination Act*, Australian Human Rights Commission, at <http://www.humanrights.gov.au/publications/dont-judge>

Meanwhile, the NDIS is the most significant disability reform in generations, and offers the potential to dramatically restructure service provision. For the first time, the manner in which a person receives disability services will not vary depending on where they live; or on the effectiveness of particular agencies, with people with disability instead positioned as rights holders - autonomous participants in the marketplace, rather than as passive recipients. In doing so, the NDIS frames impairment as a normal part of the human condition.⁹

Such is the promise of the NDIS that suggestions have been made that, as a result, people with disabilities will no longer need the support of advocates. No matter how effective the scheme may be, however, this could not be further from the truth. Though the NDIS was designed to increase individual autonomy, a bridge will often still be needed between service provision and users – in short, between the marketplace and the consumer.

It is arguable, perhaps, that devolving to an individualised system in this way will make the need for advocacy even greater. After all, most Australians find it hard enough to negotiate marketplaces of any kind, but the stories of Bella and Rose reveal how much more vulnerable people with disabilities can be in terms of negotiating how to meet their needs or resolve problems that arise.

What's more, stories circulating earlier this week that the current Federal Government may consider asking Medibank to operate the scheme – a body which it has, in turn, expressed an intention to privatise – makes the argument that advocacy will no longer be needed even less credible.

As much as the NDIS may change the landscape, then, advocates will still need to be on the scene. For we cannot assume that choice alone is enough, nor that there won't be situations in which choice has very little to do with it.

In fact, before I end today, I would like to show you a reminder of such a situation – a story with which you may already be familiar and in which the disabling effects of the justice system, in this case, are made all too clear.

⁹ See, for example, the Human Rights Law Centre's submissions to the Review of the Victorian Charter of Rights and Responsibilities at <http://www.hrlc.org.au/files/HRLC-Submission-to-the-Review-of-the-Victorian-Charter.pdf> and <http://www.hrlc.org.au/files/Further-HRLC-Submission-to-the-Review-of-the-Victorian-Charter.pdf>

Marlon's story

<http://www.humanrights.gov.au/twentystories/video-presumed-guilty.html>

Marlon's case speaks of ongoing and structural failure on multiple levels – abandoned by the system because of his impairment, yet deemed ineligible for support. No doubt many people spoke up for Marlon at the time. For the purposes of today, however, it is reasonable to wonder whether more formal advocacy could have made a difference to Marlon's circumstances at the outset. As it is, Ida's informal advocacy – the simple act of talking to people, of asking questions – led, at least, to Marlon's release, if not to his freedom. As many of you know informal advocacy carried out by people such as Ida is by far the most commonly experienced advocacy by people with disability and I suggest that at times informal advocacy potentially is the most powerful form of advocacy.

Conclusion

Marlon's case is another reminder that the difference between the absence and presence of advocacy can be profound. Sometimes it can involve seemingly small acts, such as phone calls or letters. Sometimes it simply involves drawing a line in the sand – someone to say 'this situation isn't good enough', to point out that service providers and justice systems alike have fundamental obligations, and that individuals have corresponding rights.

Always, however, the role of advocates is not just to draw attention to these rights and obligations but to build a bridge in terms of how they might be realised – illustrating that these seemingly distant principles can manifest in very real terms.

Too often policy makers, service providers, lawyers and advocates alike can forget to fashion this bridge, speaking about rights in theory without highlighting their practical applications, or forgetting that our very practical claims are based on a fundamental bottom line.

This bottom line, however, is the very thing that can unite us. It provides a framework in which individuals with disabilities can measure their entitlements; in which agencies - from the Department of Housing, to non-government support services and the wider legal system - must conduct their work; and in which advocates of every kind can hold them to account.

In short, it provides a foundation on which all of us can stand – confident in our claims and expectations, lending greater strength to that valuable bridge that advocacy can build. I commend you all for the work that you continue to do every day and urge you to keep building that bridge, one rights based brick at a time.

Thank you.
