

Disability is part of our human diversity

Mary Lou Carter

Page 1 of 4

The Committee of the
NSW Law Reform Commission
Reviewing the *Guardianship Act, 1987*

1 April, 2016

I thank the Committee for extending the time for submitting my personal views in relation to the review of Guardianship Act, 1987.

I would just like to say that it's not before time that a review of this piece of legislation is had; given that the Act is almost 30 years old and given that its provisions impinge on the quality of life of human beings who lack the capacity to literally give voice to any complaint that vexes them. I note the only amendments made to the legislation have been administrative niceties which tells us something of the priorities involved.

I am the mother of a [REDACTED] who is now [REDACTED] years old. [REDACTED] is diagnosed with a rare Syndrome – Angelman Syndrome. Suffice to say [REDACTED] is severely intellectually disabled with multiple attendant complex needs. [REDACTED] does not have decision-making capacity, cannot speak, use the telephone, use email or social media, cannot travel independently and requires assistance and guidance with all daily activities and will require that assistance more or less for all of his life. There is currently no cure for Angelman Syndrome though hope springs eternal for future therapies which may mitigate the severity of the manifest disabilities of the Syndrome.

I have 25 years lived experience of my [REDACTED] disability and believe I have gained considerable insight and expertise through that experience. Over the last decade and a half I have engaged actively and ardently to promote and advance the rights of **all** people with disabilities. However given the number of absolutely amazing people with physical disabilities who are eminently intellectually capable and who can self-advocate, agitate and variously give voice to their vexing issues I have concentrated on the group I know best people with moderate to profound intellectual disabilities and complex needs, the focus group of this review.

In July 2013 the Australian Law Reform Commission undertook its *Equality, Capacity and Disability in Commonwealth Laws* Inquiry and released its report in November, 2014. Its findings and recommendations have triggered much

Every day we must run the risk of hope

welcome discussion and debate on the issue of capacity and decision-making. I believe the Inquiry was prompted by the Committee which oversees the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) coming to the view that there should be no substituted decision-makers for people with decision-making incapacity. The conventional wisdom now espoused by that august body is that people with decision-making incapacity should be supported sufficiently to make a decision. I am all for that but is that going to be the case for EVERYONE?; because no matter how much you support my [REDACTED], he's not going to comprehend the provisions of the Health Insurance Act nor the Guardianship Act or any other statute, or even that he has civil rights of any kind.

No doubt this Committee is well aware that there are tens of thousands of our Australian citizens who do not have decision-making capacity because of the severity of their intellectual and complex disabilities. They are also people who, once they attain the age of 18 years, the magic majority, no longer have the legal agency, guardianship and financial management hitherto provided by their parents/families/significant others. For them there is no such thing as equality before the law because the law has forgotten them and abandoned them to their fate.

Just like everyone else, people with moderate to profound intellectual and complex disabilities **are treated as equal** irrespective of the severity of the intellectual disabilities. However, in my view being **treated** as equal does not endow you with the intellectual capacity to even know what that means and it sure as hell doesn't therefore **make you equal**. And of course the natural authority of the family has all but been eroded to nothingness by the incursion into families by bureaucracies and the we-know-best brigade. I recall writing to Robert McClelland in 2008 when he was Commonwealth Attorney General and asking whether parents had any legal standing whatsoever once their sons/daughters with decision-making incapacity attained the age of 18 years – the simple answer was no; parents/families/significant others have absolutely no legal standing whatsoever to in the eyes of the law once the age of 18 years has been attained.

Under the Australian constitution the matter of guardianship and legal agency is a state responsibility and states make the laws which of course means 8 sets of laws for the state and territory jurisdictions and now an overarching National Disability Insurance Scheme which refers to decision-makers as correspondence nominees and plan nominees. This heightens the propensity for confusion and inevitably there will need to be tests in which the bus-rider on the 373 might be called on to adjudicate.

The advent of the National Disability Insurance Scheme will expose the flaws in the system and exacerbate the chaos that exists only because for decades the law has totally forgotten those citizens who, because of the nature of their disability, cannot make decisions for themselves and rely totally on others to do so.

Every day we must run the risk of hope

No doubt the Committee would have heard directly the grave concerns held by the head of the Guardianship Division of NCAT. Those concerns relate directly to the inadequacy of legislation, the disparate and various authorities that exist which have been accepted over time; such as nominees (Centrelink and Medicare), persons responsible, formal and informal guardianship, limited guardianship and in the mix is the natural authority of the family bestowed by that quaint document the Universal Declaration on Human Rights .

Dispute resolution mechanisms are virtually non-existent and what exists is variously arbitrary, cumbersome and unsatisfactory.

The matters relating to guardianship have been raised directly by me with the Minister for Social Services whose portfolio responsibility includes the implementation of the National Disability Insurance Scheme; the Minister has undertaken to raise the matter of guardianship with the Council of Australian Governments and I am hoping there will be some decisions made in this regard which will go some way to solving a problem which needs to be solved sooner rather than later.

In the meantime, however, the *status quo* remains, and as far as I am concerned that kind of *quo* has no *status*.

I believe what is needed is a new law that will provide a simple and easy means to have guardianship granted to the people who know best the needs, likes, will and preferences of the person with decision-making incapacity, while maintaining structures which safeguard the person in need of guardianship and decision-making agency and their interests.

There has been a grave injustice done to the focus group of this review who don't know about their rights, they don't even know they have rights, and yet no-one gives a tinker's cuss about this monstrous wrong. All the while you have families who are willing, wanting and able to be their guardians yet we are fobbed off in the most disrespectful and egregiously insulting manner while our adult children are denied their civil rights.

This is fundamentally a matter of equality, how can you be equal before the law when you are essentially rendered civilly dead for want of the law.

I am a member of an advocacy group called Our Voice Australia which is making a submission to this Review. I unreservedly support and endorse their submission.

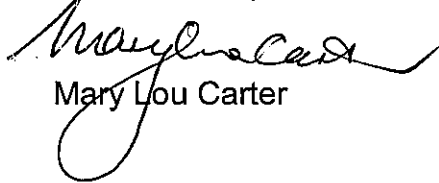
I wish the Committee every good wish in its endeavours and am very grateful that this review is underway.

Every day we must run the risk of hope

My hope is that the civil rights of people with moderate to profound intellectual and complex disabilities will be actualised through legislative instruments that honour them by recognising that they must be given the guardianship of which they are deemed to be in need and that their legal and decision-making capacity through the agency of those who know best their needs, likes, will and preferences.

What needs to be accepted by the Committee is the reality that there are some people whose disabilities are such that they require a substituted decision-maker; that the extent of their disabilities are such that they cannot be supported to do what their disability renders impossible for them to do. It is nonsensical to pretend otherwise and that nonsense demeans and devalues them and their inherent humanity.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Mary Lou Carter', with a large, sweeping flourish at the end.

Mary Lou Carter