
Preliminary Submission by [REDACTED] in regards the Law Reform Commission Review of [REDACTED] Guardianship Act 1987 (Call for Preliminary Submissions)

[REDACTED]

Law Reform Commission
GPO Box 31,
SYDNEY, NSW, 2001

21 March 2016

To whom it may concern,

Thank-you for the opportunity to make a preliminary submission to the Law Reform Commission Review of the *Guardianship Act 1987*.

I was informed of this review five days ago. Time has been tight to meet the deadline for submissions. My remarks below are then, I hope, able to meet the criteria for a preliminary submission. My apologies if not, and I would understand if this submission is rejected.

I write to you as a private citizen who has been subject to the provisions of the *Guardianship Act 1987*. This year I was an applicant for a Financial Management Order and Guardianship Order over a person (subject). Specifically, I applied over a family member who has a life-long profound intellectual disability. Currently my family member is in their fourth decade of life and has been medically assessed as having an approximate age of a two-year old. I applied as a number of State organisations were denying consent to any person (excepting medical specialists) involved in acting on behalf of my family member. To be clear, the various carers surrounding and informing my disabled family members life are all in consensus, and have been in consensus over the long term, in regard decisions supporting my family member. The primary driver for my application is what we, my disabled family members carers, perceive as what was an administrative issue lying with the State and private financial organisations (such as a bank). The following comments are therefore driven by my personal experience of being subject to the provisions of the *Guardianship Act 1987*, and the *NSW Trustee and*

Guardian Act 2009 for reasons that appear to stem from issues that reside within the State and similar large-scale private organisations.

I should define certain elements regarding the context in which I am writing this submission:

- With the word ‘carers’, I am referring to family, friends and the paid people who have day-to-day care and oversight of my disabled family member (including members of the medical fraternity).
- With the word ‘authority’, I am referring to Power of Attorney, Guardianship, person responsible, *etc.*
- I wish to largely restrict my comments to refer only to the place of the profoundly intellectually disabled within the relevant Act/s. That is, people who are incommunicate, who may have an IQ of <20 and have substantive impairment in communication, self-care, social/interpersonal skills, use of community resources, self direction, functional academic skills, and health and safety skills.
- I also recognize that my comments may overlap with the role and practices of the organisations that enact the Act/s, and I will endeavor to largely base my comments below on the material within the Act/s, and not the principles actioned by said organisations.

Broadly speaking, I wish to discuss the:

- A. overly complex nature of the authorities that can be granted under the Act/s, from the perspective of a member of the public having to use these powers;
- B. disbalance between capacities delivered by different authorities within the Act/s; and,
- C. lack of a duty of care or similar admonishment in the Act/s in regards the context in which a profoundly intellectually disabled person lives their life, and which also touches on the definitional aspects around who does what and where in regards a profoundly intellectually disabled person.

A. Complexity of authorities

This section is written in relation to this term of reference: “1. The relationship between the Guardianship Act 1987 (NSW) and [other relevant Acts]”.

At the time a person makes, or has made for them, some kind of authority under or in relation to the above Act/s, there appears to be the following options (within NSW):

1. Person with capacity
 - Person responsible
 - Power of Attorney – General
 - Power of Attorney – Enduring
 - Enduring Guardianship
2. Person with reduced or little capacity
 - Financial Management Order
 - Guardianship (Order)

Under each of the above are differing circumstances in terms of application, differing criteria of operation, differing time-frames for action and dependent on your physical location, different criteria (and namings) dependent on jurisdiction. Although the emergence and functionality of the above items are historically

dependent, I am going to argue that this now shows a systemic failure that is functionally problematic for the very people it is supposed to be operating in favour of, that is, the public.

As an example of the above problem, currently, and over three people, I hold or (in the case of 'person responsible' are subject to) the following authorities:

- Person responsible
- Power of Attorney – General
- Power of Attorney – Enduring
- Enduring Guardianship
- Financial Management Order

From my perspective, the complexity in authorities is a part reflection of the history of the emergence of these authorities but which is also seemingly an organizational (institutional) requirement, and not a reflection of functionality for the person having to use the authorities. In order to make my point, I wish to bring in a further context.

The tragedy of my disabled family members' profound intellectual disability is also in part the tragedy of my family. The easy way of saying this is that over the long term, now four decades (with more to come by all appearances), the family space of resilience and capacity to offer support has become wafer thin. We make do, and continue to operate, but crises (stemming from and connected to my disabled family member) are a part of family life. It has become such that a primary operational approach for the family is to make things simple and to avoid stresses. To return to the main point I wish to make, the *complexity of entry to access the authorities* involved in managing and in their operation are at odds to reducing stress and providing clarity for ongoing action. In other words, the very authorities that are supposed to expedite coping in crisis and struggle are in and of themselves implicated in creating crisis and struggle, as there is a fundamental lack of clarity across what is needed, where it is needed, and moreover with the understanding organisations have when they respond to such authorities. I appreciate this is not just a problem for NSW, as it is a lack of clarity across jurisdictions and in regards to the complexity facing the Commonwealth in engaging with the other jurisdictions.

No doubt, historically, legally and organizationally there are grounds for the current number of authorities used to exercise control over another's affairs and person. Personally, I would argue for one single authority. There would only ever be one pathway to application (albeit split between the practical aspect of say a solicitor crafting for someone with capacity, or a Guardianship Tribunal ordering one for someone with limited capacity). Within that authority should be the contractual obligations around the overseeing organisation (for the authority), jurisdiction, time-frame, and capacity to act (or not as the case may be). Organisations should also then be obliged to engage with the contractual description *within* the authority and not just the category of authority.

At the core of my argument here is simplicity in understanding the conjunction of all the various capacities embodied in the various authorities currently available. Reducing to one authority then shifts understanding from all the authorities as a whole down to where the focus should be, the specifics of why the authority was required in the first place and what it can or cannot do in practice within some defined time-frame. This then takes me to my next point, and in specific reference to a Financial Management Order and Guardianship Order as obtained through a Guardianship Tribunal.

B. Disbalance of capacity between authorities

This section is written in relation to these terms of reference: “1. The relationship between the Guardianship Act 1987 (NSW) and The NSW Trustee and Guardian Act 2009 (NSW)”.

In regards the profoundly intellectually disabled it seems problematic that in order to overcome consent issues around finances there is either (what amounts to) no formally proscribed power to act, or the need to obtain a Financial Management Order. Whilst with guardianship, which involve what seem to me to be far more invasive decisions (*eg.*, around sedation, administration of medications of potentially significant affect (*eg.*, psychotropic drugs) or decisions around surgery), there is no formal assessment of the carers ability to act, but there is a formal prescription that one can just be designated person responsible by dint of the relationship one holds. I do note that person responsible requires a collaborating medical official, but one might muse that a financial decision, by and large, also requires a collaborating financial official. Guardianship under the Act is more nuanced and sophisticated than control over finances, yet it leads to a disjunct in terms of the apparent capacity to act in regards finances that is at variance with what the *overall* aims of (caring) management, which include both control over body and finances (from a carers perspective). Another way of saying this is that as a carer under ‘person responsible’, if the system accepts major decisions can be made over a profoundly intellectually disabled persons body with no formal application for extra powers then why is this not the case for financial capacity? From the perspective of someone who has to respond to the actual blunt end of the operation of the Acts, this does not appear to be logical.

No doubt, yet again, there is a logic at work historically, legally and organizationally, but I circle back to my earlier comments that *our family space of resilience and capacity to offer support is thin*. It would appear systemically that the construct we face is not structured to reduce carer stressors, which in turn reduce resilience and erode support capacity. This in turn leads me to my next point.

C. Lack of duty of care and adequate definitional framework in regards the context in which a profoundly disabled person subject to the Act sits

This section is written *roughly* in relation to these terms of reference - although I recognize that what follows may not fit the terms of reference at all: “Whether the language of 'disability' is the appropriate conceptual language for the guardianship and financial management regime and to what extent 'decision making capacity' is more appropriate”; and “The model or models of decision making that should be employed for persons who cannot make decisions for themselves.”

I wish to make reference to the *Guardianship Act 1987* in regards the way that carers (family, friends, carers with remuneration) are discussed. Again I am particularly interested in focusing on this in regards the subject, in this case someone who is profoundly intellectually disabled. The relevant sections and sub-sections from the Act are as follows:

- 3E (1)
- 4 (e)
- 4 (h)
- 14 (2b)
- 28 (b)
- 33A (c)
- 33A (d)

In the *definitions* (3E(1) and 33(A4c and A4d)); *principles* (4e and 4h); *taking into account the views of* (14 (2b)); and *in the giving directions to* (28b) the wording of the Act fails to give due consideration to the complexity of the relationship in terms of the profoundly intellectually disabled and the people who provide day-to-day and oversight care for them.

I have split the following into two parts, one on the wording, the other is on *who* is acknowledged *where* in the various statements within the Act.

The wording establishes a hierarchy that in part lacks relevance to the life of someone who is profoundly intellectually disabled. For example:

- “the views of such persons in relation to the exercise of those functions should be taken into consideration” (4d)
- “such persons should be encouraged, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs” (4f)
- the Tribunal shall have regard to: the views (if any) of the person (14 (2i))
- the Tribunal shall have regard to: the views (if any) of the person’s spouse, if any... (14 (2ii))

I do recognize the use of the words ‘if any’ in the above, but this seems to still set up an ineluctable tension that weighs towards capacity. Also, this is not to say that the profoundly intellectually disabled don’t actually have some degree of capacity to communicate in some way, in many cases (even though highly variable) there is some remnant capacity, just that it is likely that the Tribunal will have no access to this (during the only primary contact point of the Hearing), and neither will any persons sitting further removed than from day-to-day contact. In other words, I believe that the language used in the Act should be altered and extended in terms of the profoundly intellectually disabled. It should be done so as to recognize and empower the disabled person themselves as part of an immediate collection of people who are involved with and overseeing the day-to-day life of that person. Such a statement or set of statements might look like this (dependent on how the language itself was structured; *eg.*, disabled as a pejorative word, or focus on decision making capacity) (I use the word *collective* below to include the profoundly intellectually disabled person and the people who have day-to-day interaction with or oversight of the disabled person):

- the views of the collective in relation to the exercise of those functions should be taken into consideration
- the Tribunal shall have regard to: operating in support of the collective in such a way as to reduce the stresses on this collective in meeting the requirements set by the Tribunal

In terms of who is acknowledged where in the various statements within the Act, I would argue that the definitions, principles, and indicated capacities to act be re-written and expanded to incorporate, for the profoundly intellectually disabled:

- a) the carers context (as the collective) as being inseparable from the person under care;
- b) that (however it is designated in language) the profoundly intellectually disabled are acknowledged as requiring a differing set of rules regarding who makes decisions and how they are made.

To expand on this, and in the case of our family member who has no capacity for all intents and purposes, supported consent for instance is not workable. What is required is substitute consent, but substitute consent that is placed within a more effective framework as defined within the Act. This framework should recognize that separateness (of profound disability) and have it flow through into the practical application of the Act. My

following comments potentially go outside the purvey of the Act/s involved and reside more with the organisation administering the Act/s, but my recent experience was such that I came to the conclusion that the system we were engaged with was almost entirely unable to provide any sensitivity to our context whatsoever (I should be clear that the people we dealt with were good and supporting, they were just working inside parameters that align to the Act and organizational context and not our context). As an example:

- the application forms were at variance to my understanding of the person I was applying for legal powers cover (eg., questions like what language did the subject speak, with no option to indicate the subject did not speak);
- I was required to deliver a notice of hearing to the subject and sign a document to attest to the delivery, knowing full-well that my family member had *no capacity* to understand any of the process that was unfolding;
- the subject was required to attend the hearing, when those around my family member knew all too well that to do this might mean a substantively difficult to manage reaction from my disabled family member – it appeared that assessment of my family member’s capacity was to occur in the Hearing whilst from our perspective this assessment should have occurred separate to the Hearing, which would have lowered substantially the extraordinary stressors this whole process placed on our family.

All in all, there appear no understanding that, as I said earlier, *our family space of resilience and capacity to offer support is thin*. The Act and practices that flow from it, are shaped towards capacity.

The irony in all of this from my perspective, is that as the primary (and in certain places, only) functional member in this context, the system established to protect and support the person with the disability, was providing enough stress into the care space to render the primary carer, myself, ineffectual. Further, as noted at the start of this submission, for reasons that had nothing to do with the collaborative care environment around my disabled family member, and everything to do with the State and private organisations incapacity to make consent a viable and straightforward proposition. To say this in other words, we as a family, have been forced to bear the costs (stress) of administrative and legal failure on behalf of entities that hold us to a higher level of accountability than they in turn seem to hold themselves to us (as a collective). The incoherence in the overarching system is evidence of systemic failures embedded in the instructional structure informed by the related Acts and organisations that control and enable these Acts.

To return to an earlier point about language used in the Act, the ultimate human right here then becomes the connectivity and network, the *collective* if you like and as I used it earlier, of all the people involved in and through and including my disabled family member. From my perspective it is this collective that should be at the heart of the Act/s (in regards the profoundly intellectually disabled) and which is enabled by the Act and supporting organisations. The shift over time onto a focus of the human rights of the disabled is to be applauded, but leaving behind the challenges and errors of the past requires that the conceptualisation of who acts, who benefits and who controls be defined in the first sense via the group and not the individual or sub-group (eg., paid carers, family, friends, medical practitioners, etc). Furthermore, it should then be defined by the *lack of power* of those involved – in which case my disabled family member is the first amongst equals, these equals being the carers who are directly looking after and oversighting the space my disabled family member lives in and through. As noted at the beginning of this submission, in regards the profoundly intellectually disabled, we are forced to speak on their behalf but as part of their and our own lived-reality as a *shared experience*. Centre this in the Act/s, and then place the various authorities in a widening circle around that, and which of course should include a further layer of oversight and potential restrictive legal capacity (if

circumstances require). Anything short of some system like this leaves us back where my submission started, the carers continue to be the delegitimised and downgraded people in the efforts to redress old failures around supporting the profoundly intellectually disabled.

This would mean in terms of the *Guardianship Act 1987* additional language in certain sections. For instance, 3E (Meaning of “close friend or relative”) would get an addition that would explain what the collective is in regards the profoundly intellectually disabled.

The general principles in 4e and 4h would get another category in regards the importance of preserving and when required supporting the decision making of the collective. Same goes for 14a and 14b, and 28 (2a) and (2b).

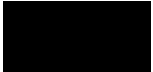
Finally, I’d suggest the person responsible section (33A) be re-written to incorporate the responsibility of such a person for someone who is incommunicate in a way that is different to a person with some degree of capacity. In this, the person responsible must be supported and shown how to *talk for* the incommunicate person by being kin, in having kinship (in the broad meaning of the word, not just as family), and in weaving together a degree of justice and advocacy in the multitude of ways that the profoundly intellectually disabled are different, yet in essence the same as we are. In this sense too, person responsible becomes a legally identified category, which makes it a formal identity that is owned and handed on when required.

All in all, I am arguing here for a more nuanced and active duty of care as defined and detailed within the Act and as supported by the Tribunal in regards the context in which the profoundly disabled person sits and which also includes the people who cluster close to them.

As a final point, I do want to actually applaud the work of the many people, in the legal, political and bureaucratic systems, who have tried to make the ongoing care and oversight of all people with capacity problems and issues work more effectively and to be supported in a more caring manner. My submission reads like a set of complaints, but I do wish this to be taken as a kind of loving care in and of itself, as unless we all find a way to conciliate these issues, the deeper problems in helping those less fortunate than us, or who have had more complex lives than ourselves, are likely to continue.

If this preliminary submission is valid, I note that the Law Reform Commission may publish it on its website or in related materials, as detailed under the Law Reform Commission Privacy and Information Management Policy at: http://www.lawreform.justice.nsw.gov.au/Pages/lrc/lrc_policytableddoc/LRC_policydoc/lrc_impp.aspx). I would request that additional to the above care that the Commission takes over address details and similar, that *my name be redacted from this document* thanks, as there is no doubt that my identity would tumble other identities to a reader who may know (or simply run a search engine over) me.

Yours Sincerely



21 March 2016