

12 May 2017

Mr Alan Cameron AO
Chairperson
NSW Law Reform Commission

By email: nsw-lrc@justice.nsw.gov.au

Dear Mr Cameron,

Thank you for the opportunity to provide this submission to the review of the *Guardianship Act 1987 (NSW)*.

If this submission is made public, my only request is that my address at the end of this submission be redacted.

I write to you as a private citizen who is subject to the provisions of the *Guardianship Act 1987 (NSW)*, regarding a family member who has a lifelong profound intellectual disability (or as also discussed, as having a profound decision-making incapacity).

In this submission, I restrict my comments only to the lifelong profoundly intellectually disabled. That is, people who acquired irreversible neurological damage at or near birth, are incommunicate, with an IQ of <20 and with substantive impairment in communication, self-care, social/interpersonal skills, use of community resources, self-direction, functional skills, and health and safety skills. With the lifelong profoundly intellectually disabled, intentionality and the concept of self are minimal to non-existent throughout life. What is cherished though is the relational space of shared community and the ongoing challenge of making sense of a decision-making incapacity, and that when reasonably dealt with affirms a life well lived to whatever extent is possible under the circumstances.

This review of the *Guardianship Act 1987 (NSW)* has been refreshing to see, and the considerable extent of materials presented within the review has been heartening. Having said this, and regarding those with a lifelong profound decision-making incapacity, I would like to recommend a step I have not so far come across within the review. I do recognise that it may be a step that cannot be taken within the *Guardianship Act 1987 (NSW)* or is unwise to contemplate doing. I will put my recommendation as a response to Question Paper 6: question 5.5 (QP 6: 5.5). I will also add in my response to other questions drawn from the Question Papers, as sub-components of QP 6: 5.5. I have chosen to do this in this manner as it makes it easier to present the idea of what amounts to a 'cradle to grave' system for the lifelong profoundly intellectually disabled.

Before I lay out my answer to QP6: 5.5, I wish to highlight this text from Question Paper 6 – sub-section 5.31:

'Parents of children with lifelong profound intellectual disability fall into a special category. A parent cannot be appointed as their child's enduring guardian or power of attorney due to their child's lifelong incapacity. Their children need help making decisions on a daily basis and there is no prospect of them regaining capacity.'

If lifelong profound intellectual disability can be recognised in the *Guardianship Act*, regarding streamlining the method for parents of adult children with profound intellectual disability to become the guardian of their child, then it may be possible to take a further step, and to capture in the *Guardianship Act* a more expansive idea of lifelong support that recognises the consequences of a child never developing capacity.

Finally, I also recognise that the lifelong profoundly intellectually disabled are a minority (of those severely disabled) of a minority (the disabled generally). The total number of people who fall into this category are small indeed, but that does not reduce the need to seek more effective solutions to the challenges of their lives and that of the community of people who love and support them. I've also avoided, due to the difficulty of working the complexities through, trying to add in considerations below regarding any changes to substitute decision making that may stem from this review.

Question Paper 6 - question 5.5: Process for appointing parents as guardians - (2) What other mechanisms could be made available for parents to make decisions for an adult with profound decision-making incapacity?

The answer to this question extends to the end of this submission.

A single unified and lifelong framework could be made available for parents to support decision-making for a person with a lifelong profound decision-making incapacity.

Capturing the idea that persons with a lifelong profoundly intellectual disability fall into a special category, leads to the idea that such a framework and how it would function could be added as a separate part of the *Guardianship Act*.

I make the case for a single unified and lifelong framework as if tragedy strikes a child at or near birth, and they are forever to be cognitively an infant, then the system that supports the family to provide ongoing care should conform to the reality of the situation, and that is that the effects of the disability go from birth to death, and are essentially severe, irreversible and unchangeable.

I make the above statement in hindsight. Even though I resist the thought of a system controlled by the government that substantially impacts on the autonomy of a person, and even though for near 30 years my family managed our disabled family member informally and without any legal orders (being necessary), I find myself recommending a unitary system as defined in a *Guardianship Act*. I am not comfortable with this idea, but as the informal system of old appears to be increasingly replaced with more bureaucratised, legalised and professionalised set of systems, it may be time to go onto the front-foot, so to speak. I recommend a unitary system because the consequences of having to master the everchanging systems relating to the care of our family member and to strive towards achieving stability in care over the long-term, alongside being loving family members attempting to make sense of the journey we were all on, has come with extraordinary consequences many of which have been quite difficult for our family. In looking back, and also forward to the challenges to come, I wish there had been a singular, simple, external supportive system like that I suggest below. It would have been even better to have such a system without the need for any legal order/s, but times have changed. I think if it had been in place, our lives collectively would have benefited significantly.

The benefits of establishing a framework in the *Guardianship Act* are:

- As those with lifelong profound intellectual disability have very little capacity, this lack of capacity (or more adequately, the different kind of capacity they have) does not well sit with the general approach in the *Guardianship Act* towards centering on (and in a certain way evoking) capacity as it is *generally* defined. By providing a separate framework within the *Guardianship Act*, this tension can be resolved.
- This step of defining a framework for those with a profound decision-making incapacity may be seen as overtly fixing the link between disability and incapacity, but with such an incapacity I'd argue that earlier identification of the nature of the issue allows for earlier sensitivity to and support of successful family and community life that benefits all involved.

So, what might the framework presented below may look like in action? It is likely that a child with a profound (irreversible) intellectual disability will be identified as having such an outcome through the medical system sometime in the first handful of years of life. At this point, a single unified and lifelong framework for decision making could be activated. It could be activated through the medical system, but it should be run by the government (perhaps with the NSW Civil and Administrative Tribunal as the overseeing body). The main aim is that all necessary legal powers, identity issues, supervision processes and periodic review systems, plus possible training requirements, and a line of succession (to siblings or other identified close relatives or friends of the family) is put in place from the very start of a life arc, rather than in a haphazard, ad-hoc and likely stressful manner as the years go by. It could be incorporated into one single document, so being simple to manage. If such a framework existed it could remove ambiguity about what needs to be done when, thereby assisting in making sure that any oncoming management issues are resolved in a timely manner; it could be updated over time when necessary; it could take into account the caring capacity of the family and work to support that; it could be subject to periodic review by the government; and, most critically, it can serve to help conserve family energies for the most important task of all, providing an environment of loving care to the person with the profound decision making incapacity.

Suggested changes to the *Guardianship Act 1987 (NSW)*:

1. Establishing within the *Guardianship Act* a separate part that defines:
 1. What constitutes the framework
 2. What defines a lifelong profound intellectual disability
 3. Assessment and ongoing review
 4. Principles statement
 5. Legal powers granted and how they are managed
 6. State monitoring and oversight requirements
 7. Parental (familial) and other carer training requirements
 8. Recognition of the community of carers
 9. Line of succession

I will expand on some of the points above, to follow (and several of these points incorporate questions from the latest round of open review papers).

1. What constitutes a framework
 - Defined by a set of responsibilities and principles.
 - Created as a single document conforming to a defined structure.
 - Held and reviewed by a government organisation (eg., the (NSW Civil and Administrative) Tribunal).
 - Available to those defined as having a lifelong profound intellectual disability.
2. What defines a lifelong profound intellectual disability
 - Having acquired irreversible neurological damage at or near birth, are incommunicate, with an IQ of <20 and with substantive impairment in communication, self-care, social/interpersonal skills, use of community resources, self-direction, functional skills, and health and safety skills.
 - Defined by medical professionals as oversights by the government.
3. Assessment and ongoing review
 - Both assessment and review by the Tribunal (not NSW Trustee and Guardian, unless under circumstances of having a substantive estate).
 - Tribunal hearing at the point a legal order is to be granted.

- Periodic review of the framework and of the legal order at 18 years of age and then every 10 years thereafter. Done by written assessment of medical professionals and social workers.
 - Keep the management space as informal and simple as possible in regards assessment and review.
4. Principles statement
- **Question paper 6 - Question 2.2: General principles: (2) Should there be multiple statements of principles that are tailored to particular decision-making situations? What are those situations and what principles should be included?**
 - If principles are to be put into the *Guardianship Act*, then there should be a requirement for a separate list of principles for the profoundly intellectually disabled, as numerous principles discussed in the Question Paper report cannot apply to the profoundly intellectually disabled. For instance, “People with disability have the right to access information in a way that is appropriate for their disability and cultural background, and enables them to make informed choices”.
 - Principles could be provided as tailored to the particular decision-making situation of the lifelong profoundly intellectually disabled (*eg.*, such as the affirming the challenges of dealing with the incommunicate).
5. Legal powers granted and how they are managed:
- **Question paper 6 - Question 7.1: A single order for guardianship and financial management - (1) Should there continue to be separate orders for guardianship and financial management?**
 - In the case of lifelong profoundly intellectually disabled there is no reason to separate financial and guardianship orders, due to the extent of the lifelong neurological disorder, so this would mean the provision of a single legal order (whatever it is called) that covers all aspects relating to lifelong support. As the disability is profound across all life measures and lifelong, it stands to reason that all required powers should be put in place at the time the legal order is given.
 - **Question paper 6 - Question 7.1: A single order for guardianship and financial management - (2) What arrangements would be required if a single order were to cover both personal and financial decisions?**
 - The granting of single legal order should happen at the time at which a person is conclusively identified as having a profound intellectual disability (*eg.*, although the disability will have well manifested by several years of age, realistically around 8-10 years old is likely conclusive). This would match the reality of such a person’s ongoing life, in that there is no real transitional cognitive stage within childhood nor between childhood and adulthood (this issue overlaps with **QP 6 - Question 5.1: Age threshold for guardianship orders - What should the age threshold for guardianship orders in the Guardianship Act 1987 (NSW) be?** It also overlaps with **Question Paper 5 - question 5.5: Process for appointing parents as guardians - (1) Should NSW introduce a streamlined method for parents of adult children with profound intellectual disability to become their guardian when they turn 18 without the need for a NSW Civil and Administrative Tribunal hearing?**).
 - The granting of single legal order early in life would also deal with another issue, which is the nebulous nature of parental responsibility for a profoundly intellectual disability child who is under 18. A person with a lifelong profound intellectual disability will largely have the same challenging guardianship context no matter what chronological age they are, therefore it seems problematic to have a parental responsibility capacity up to 18 years of age and then an informal decision making system thereon after, yet there is no difference in cognitive state either side of 18 years old no matter how many years back

or forward you go. Rather, the limits to parental responsibility over a disabled child should be defined from an early age and done so in a way that considers the circumstances of the disability. The single order can define what is and what is not allowable (under the order), the not allowable part indicating aspects of what might have to be planned for as a child's body develops into an adult body (eg., in terms of controlling fertility, which would require a tribunal hearing).

- The single legal order should be grantable to two or more people, but would require clear instructions about shared decision making.
 - Finally, a single order granted earlier in the disabled persons life means that as the power to act stems from a framework separate to the implicit parental role seen with a child who is healthy, then from an early stage the parents are explicitly aware of the legal situation in which they make decisions, which can stand them in good stead for the fullness of a life.
 - **Question paper 4 - Question 3.2: Time limits for orders - (1) Are the time limits that apply to guardianship orders appropriate? If not, what should change?**
 - For the those with a lifelong profound decision-making incapacity, time limit for renewal every 10 years and incorporate into a regular (written) review process.
 - Grant legal power to at least two people (likely at first both parents), due to the time frames involved in caring for the lifelong profoundly intellectually disabled. As siblings of the disabled child come of age, they could also be granted decision making capacity within aspects of the framework, all the way up to the legal order itself.
 - Recognising other laws:
 - **Question Paper 6 - Question 3.1: Relationship between Commonwealth and NSW laws - What should be done to ensure an effective interrelationship between Commonwealth nominee or representative provisions and state-based arrangements for managing a person's financial and personal affairs?**
 - Commonwealth nominee arrangements can be listed in the framework document and clear assessment made (with the assistance of the skills available through the Tribunal) if they need to be activated or not dependent on the capacities granted in the legal order.
6. State monitoring and oversight requirements
- Central registration: **Question Paper 4 - Question 4.1: Benefits and disadvantages of a registration system (1) What are the potential benefits and disadvantages of a registration system? Do the benefits outweigh the disadvantages? (2) Should NSW introduce a registration system?**
 - As much as I have trouble asking for this, and to answer point (2) above first, a central registration system for those with a lifelong profound decision-making incapacity, linked to the granted legal power/s and systemic supports, would simplify and unify the framework. In regards point (1) above, it would allow the government to contact family and to regulate the framework document. It would allow family and carers a single point of reference for support regarding any legal or allied concerns and to promote the updating of materials into the framework document over time. It would also mean the government can be somewhat proactive, rather than reactive.
 - **Question Paper 4 - Question 5.2: The supervision of private managers: What, if anything, should change about the NSW Trustee and Guardian's supervisory role under the NSW Trustee and Guardian Act 2009 (NSW)?"**
 - NSW Trustee and Guardian should not be involved in the oversighting of the lifelong profoundly intellectually disabled as long as the Tribunal is satisfied that the relationship

space and other safeguards are effective or unless said disabled person comes into a large estate at some time.

- Review: Assuming the Tribunal oversights, then first hearing at point of conclusive diagnosis of profound intellectual disability. Second hearing at 18 as a re-check. Then written reviews at 10 yearly periods.
7. Parental (familial) and other carer training requirements:
- Those within the framework (at first this is likely to be family of the profoundly intellectually disabled person and later carers who are in close ongoing contact to the person), could be required to undertake training to cover respect for and use of legal powers, sensitisation to administrative systems likely required over a lifetime, the substantive challenges in care that are required, how to interpret the wishes of someone who is incommunicate, plus how to update and manage the framework.
8. Recognition of community of carers:
- Formal recognition of the community of carers that cluster around the lifelong profoundly intellectually disabled person and a system to identify and update who they are.
 - Codify the informal powers that carers have and use in supporting the disabled person, and define the boundaries where decision making overlaps with family, and where decision making can only be by those with a legal order or through the Tribunal/court system.
9. Line of succession:
- Succession can deal with passing on of the legal order as well as developing other elements in the framework, and generally succession would involve parents and siblings of the person with a profound decision-making incapacity. The capacity to identify family members further removed from the disabled person and people within a friendship (of the family) network could also be crafted.
 - There should be no general impediment to succession of legal powers and of general support systems, outside of the periodic assessment process mentioned above under government supervision or where prior failure has been identified so creating greater and more invasive oversight (*eg.*, a parent or carer with a conviction for fraud, *etc*). Succession could trigger a review of the person who is going to succeed another, but this could be by written application or a Tribunal hearing centered only on the person involved. Succession should be written into the framework in terms of who is succeeded by whom, under what circumstances succession occurs and when succession occurs.
 - The question of succession should be triggered at a specified age, *eg.*, when a parent reaches 70 years of age this could raise the question to those in succession about the timeliness of transferring power and practices.

Submitted for your consideration,

Yours Sincerely,

Peter

Peter Deane

