NSW Law Reform Commission
GPO Box 31
SYDNEY NSW 2001

Preliminary Submission
Review of the NSW Guardianship Act 1987

Dear Commissioners

I welcome the opportunity to make a preliminary submission to the NSW Law Reform Commission regarding a review of the Guardianship Act 1987 (NSW).

Thank you for the opportunity to look to the interest of people who are in need of not just decision-making support, but the support of a legally recognised decision maker. It is a complex area of law that has been given far too little thought.

The NSW Law Reform Commission should consult with and actively involve families of people with decision-making incapacity as experts on the needs of this cohort, in the development and implementation of a new decision-making framework. It should include a working group of families whose lived experience come from differing knowledge of differing vulnerable groups who are in need of a decision-maker. These areas of experience will vary from families with the lived experience of supporting people with moderate/severe intellectual disability with complex needs, treatment resistant psycho-social disability, age-related loss of cognitive function, people who understand criminal justice or health systems supporting people who may have cognitive decision-making ability disrupted by a lack of insight. The voices are vast, the needs and answers are varying. Both families and health professionals can inform the review from their areas of lived or medical expertise.

My submission to this inquiry is only about lifelong moderate/severe intellectual disability and complex needs as this is the background of my personal lived experience. I cannot comment on the time or place as to when capacity becomes reduced through age related decline in cognitive function and the slow process of loss of capacity and how this is measured or when lack of insight can place an individual or others around them at risk. Others have far greater experience of this than I.

The group of individuals I am speaking of can be supported within the law easily and automatically, as their legal decision making capacity is not in doubt.

The Commonwealth Law Reform Commission review refused to allow families a voice in that review, even though this was mandated in the guidelines from the Commonwealth Attorney General. Instead they looked to people with little to no lived experience of legal incapacity. That review looked at disability as a homogenised concept and gave great voice to the disability activist lobby. To me, it appears that the disability activist lobby are not understanding the decision-making incapacity context of people that come before a Guardianship Tribunal in legitimate need of guardianship.

This review not a 'generalist' disability review, it is not about people with disability per se, as a generalised group, it is about a small group of people who actually lack legal decision making capacity and/or personal insight.

We do though, need to ensure that those with legal decision-making capacity are not caught up in a framework where less arduous supports will be enough to ensure that their human rights are protected from overly intrusive systems. As such, this review should be defined by *legal decision-making incapacity and lack of personal insight* rather than simply target persons with cognitive disability or disability as a generalised concept. The issues are very disparate.

The Guardianship Act is in desperate need of review. As it currently stands a person with moderate/severe intellectual disability along with other complex disability needs actually have no safety valve. They are at the mercy of a system that all too often fails them. They have no automatic protections. Guardianship is not encouraged, *person responsible* appears to have little meaning and is easily manipulated in order to gain control. The most vulnerable of our citizens are simply cast adrift in a world which advocates the same thing for all, no matter what your disability type. It appears that many are of the belief that having a disability, albeit one with full decision-making capacity and ability, somehow makes one an expert on all things to do with disability - including legal decision-making incapacity.

Unless you  have a lived experience of supporting someone who does not have legal decision-making capacity, you cannot fully comprehend the many barriers and civil/legal death that the person faces. We are experts through our own lived experiences. We are not experts on the lived experiences of others by having a very different life experience. We can become experts by sharing the lives of that person, by loving, nurturing and caring for that person because generally this provides us with a window of knowledge. It supports our understanding of the person and provides insight into supporting better choices, choices borne out of love, nurture and knowledge of that person.

Representative or legal decision-making power is not something one simply wants. One would prefer that the person you support was not in need of such intrusion.

Our current Guardianship laws, which often look to plenary guardianship by a stranger are without safeguards and therefore encourages neglect and abuse of power by service providers who, more often than not, are given free reign over a supported person’s life, answerable to no-one as the family are cut out and often willfully ignored. It is not designed to have an individual’s needs met in the least obtrusive way. It cannot respond with agility. It is a cumbersome, antiquated law that does not always consider the changing needs of an individual in a timely fashion. It is a messy system where one can find oneself cut adrift, without the input of anyone who really has your wellbeing as their priority.

If people needing decision-making support are not viewed as having decision-making incapacity, the subject is mute for them. Legal incapacity is a reality for some. You either have the intellectual capacity to make legal and financial decisions, or you cannot be supported to make legal and financial decisions because of incapacity. There is a very large difference in capacity to make legal and life altering decisions and being able to make minor decisions with support. All people should be supported to make day-to-day decisions with regard to their life to the extent that they are able.

**The CRPD (Article 12) 2(c) states that 'a person's decision-making capacity must be considered in the context of available supports'.** The harsh reality is that the more pronounced your decision-making incapacity, the less likely you are to understand this very fact and the less likely a satisfactory amount of funded informal support is provided or would, if it was, have much meaning. Minor decisions can, of course, be guided with supported decision-making, even for those with highly complex needs, but if you have no understanding of what 'decision-making capacity' actually is, or the ramifications of your decisions, how are you able to be guided to make legal decisions or complex decisions by someone with no inherent knowledge of you as a complete, yet complex person?

Life-altering decisions with long-term ramifications cannot be made even with supported decision-making if the supported person fails to understand context, to understand outcomes, to understand permanency or even to understand timelines.

The CRDP was not written for people who have no capacity to make important decisions. It was written as a generalist, global document covering the entire spectrum of disability from the most mild forms of disability to the most severe forms of disability across all spectrums and focussing on the natural capacity of that vast cohort. Within the CRDP, people with intellectual disability were given very short shrift with little mention. **I believe that the CRDP, if looking at this particular meaning regarding legal incapacity would consider that available supports first and foremost would more often than not refer to the family or responsible person who has shown continued and long-term care, commitment and support for the individual.**

Disability is highly diverse, it is not a homogenised concept as the current thinking appears to believe. People with complex cognitive/intellectual disability support needs have just that - complex needs that have to be considered. For some, calling in a supported decision-maker is a solution, for others, it will result in paralysis of decision-making, poor decision-making and outright dangerous decision-making coming from an area of lack of individual knowledge of the person. There is no dignity in the well-worn expression that there is dignity in risk if you have legal decision-making incapacity. How can there be 'dignity in risk' if you do not know what dignity is or for that matter what risk is? At what point is risk actually a loss of human dignity? I would say at the point of overtly intrusive practices unless there is no other available option to allow you legal rights.

If we, the family had have waited for a supported decision-maker or for that matter an advocate for our sons and daughters, very few services would exist today. Service provision was built upon the work, the championing and advocacy of the family. The family has always been at the heart of the funding and development of the service system. It is the family who fought for the right for population-based funding models for disability services, which we have now in the shape of the National Disability Insurance Scheme (NDIS). The service providers of today were built upon the sweat equity of the family. At the heart of service provision are individuals' rights to have their needs met in the most unobtrusive way possible. It was the family that was always there, always seeking other ways, new ways, the third way, seeking knowledge and seeking justice for their family members with disability.

We understand better than most exactly how adrift a person with legal decision-making incapacity is. Our systems from government agencies covering housing, medicare, health and welfare, right through to our financial institutions, are simply not geared to meet the challenges of people who do not have the capacity to make legal decisions and offers little support for the person that the NSW Guardianship Act deems ‘person responsible’ because person responsible is not a legal term and can simply be rode roughshod over, particularly by service providers who seek total financial control. If you have moderate/ severe intellectual disability with complex needs, decision-making incapacity simply does not fluctuate and you need to be protected.

**Legal incapacity for those born within the moderate/severe/complex intellectual disability, is legal incapacity for life, it is a case where you either develop to the point of having legal capacity at the attainment of majority or you do not.**

Some people will never be able to exercise their legal agency. It is fanciful. It is dangerous and places persons at great risk of unscrupulous institutions or individuals.

The state is obligated to ensure smooth transition of decision-making for those with legal decision-making incapacity. It is obvious who these people are. They do not simply have borderline or physical disability, they are unable to be independent and to care for themselves. They very often have complex care needs, behavioural needs and often cannot be left alone or supported to manage their own legal needs. It is very simple and the State must offer the protection through the agency of those who know them best.

Currently, the State offers nothing much at all unless a person needs a decision-maker appointed because of risk. This ensures that most highly vulnerable people are in limbo unless crisis comes banging on the door. This often becomes too little, provided too late.

Crisis can also be manufactured, a deliberate act to create a dispute by some unscrupulous service providers intent on controlling an individual’s funding. It can be as simple as placing a clause into a mental health care plan or a service agreement that means that the *person responsible* must sign away their *person responsible* autonomy because the provider champions the cause of another party with an axe to grind. If in this instance if the *person responsible* refuses sign away their *person responsible* status it will become a trigger for a Guardianship challenge because the plan cannot be funded or implemented without the *person responsible*’*s* signature. This type of thing is not a rare event, and I can see how coming into an NDIS-funded world, more and more unscrupulous providers will manufacture a ‘trigger’ for a Guardianship review of a parent who remains the natural ‘*person responsible*’ as set down within the NSW Guardianship Act. Some service providers fear the move towards voice, choice and control and where this might leave them if a person decides that their service is no longer in their best interest or where families might decide to self-manage or use a broker, leaving the provider without a guaranteed form of income or reduced income.

This lack of legal decision-making status is currently a train wreck waiting to happen as we waltz towards this brave new world with our eyes closed.

The answer to this dilemma for the cohort of which I speak is a simple one because their lack of legal decision making capacity is not in doubt. It is as simple as adopting the ‘*person responsible*’ as laid out under section 33a of the NSW Guardianship Act - the natural **legal** agency for the person needing decision-making, expanded to become the Natural Legal Guardian or Natural Legal Representative or ‘Natural Legal Person Responsible’ as it is currently defined given true legal standing - not just for medical and dental but for legal decision making within the care continuum. Adopting this easy method will ensure that this group are not left in limbo. An application should be possible with longstanding continuing care prior to a funded accommodation placement or still living with the person in need of decision-making as the precursor. Not a hearing, just a formalised legal application with proof of continuing care.

Not all people of course should have this responsibility, some make poor or adverse decisions, some families are negligent. The reality is that those are thankfully small in number and the majority should not be penalised, or should the person without legal capacity, by having the person in legal limbo for the few. If that decision maker for whatever reason proves to be a poor decision maker, or negligent, the Legal Guardian or Legal Representative can then be challenged. The Guardianship Tribunal can offer due process to make a decision regarding a possible need for other forms of Guardianship as it can currently do.

I ask that this review does not place too much importance on the CRDP without careful consideration of the document, who it speaks for and what considerations and whose input was considered during its development. I ask this because as I read it, the CRDP is a global document, it overridingly considers the needs of those with physical, sensory and psychiatric disability, which is of course the largest cohort of disability. Others with more complex needs appear to be simply an afterthought.

One would not deny an entitlement to have legal capacity. It should be a natural right to all who actually have legal capacity. To place all people, no matter what their disability type in one basket is sadly the common thread of current thinking. One thing is certain - those advocating for people with disability certainly have capacity and some have very little understanding of true legal incapacity and the legal issues and barriers that can arise with incapacity with decision-making.

It is with this understanding that I do not believe that the CRDP can be used as the template for acknowledging capacity for all.

It has never provided meaningful or total understanding of the diversity of need amongst differing disability types. The NDIS legislation paid too much heed to the CRDP in so far as it presumes capacity and allows the CEO or agent to appoint a substitute decision-maker when the knowledge of the background of the ‘participant’ and the understanding of the individual’s complexities are irrelevant or unknown.

This is dangerous and will be damaging to those who are most vulnerable to this approach. This review is vital and it is also vital that the State opens dialogue with the Commonwealth Attorney General regarding repeal of the decision-making clauses of the NDIS Legislation before it becomes a damaging, catastrophic mistake when viewed in hindsight. Hindsight is far too little, far too late. We need a homogenising of national and state based laws so that whoever you are and wherever you live in our great nation, you are afforded the same rights and protections.

I understand that universal consensus is a political minefield.

Because of this, in the interim, to protect our most vulnerable citizens, State laws should be overhauled to ensure that every person who is in need of legal decision-making agency is granted this in the easiest way possible, in a process that is simply a part of the care continuum.

I hope this review considers those whose legal capacity is in need of the continuing advocacy and support of their often lifelong support persons - most often family members and provides a simplified legal agency to support this process.

Furthermore, I believe that guardianship law in NSW should explicitly address the circumstances in which the use of restrictive practices will be lawful in relation to people with a decision making incapacity. All people have a right to live with as few restrictions as possible. Restrictions should only ever be used to keep the individual and others safe from serious harm or to deliver a better quality of life to the person being supported. Currently far too many people are subject to restrictive practices to assist the service provider/facility rather than the person being supported.

I believe there should be a state registry of any form of restrictive practice that outlines the practice, the reasons for the practice and the age of the person under restricted practices as well as the service/facility that uses these practices. This register should also include permissions and be held by the NSW Ombudsman or the Attorney Generals Department for annual review and for public reporting. Any service/facility that appears to use this as a common practice should be placed under investigation.

I was recently made aware of a situation where people living in a group home were recommended to be placed under restrictive practices (medication and curtailed community access) to make it easier for the service provider to cope with the behaviours of another client.

I hope that the Law Reform Commission agrees to set up an panel of experts that includes family members and health professionals.

Thank you for your time. I look forward to something substantial and responsive to the needs of the cohort of which I speak to come from this review. A response  that affords simple protections to those who need it, but also allows greater flexibility for those who can, with support, make their own legal and financial decisions.

With regards

Nell Brown

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