**WITHOUT PREJUDICE**

DATE: January 16, 2014

TO Australian Law Reform Commission

Level 40, MLC Tower

19 Martin Place

SYDNEY NSW 2000

RE: Review of Equal Recognition before the Law and Legal Capacity for People with Disabilities

As my mother is currently a protected person under the NSW Guardianship Act, 2009, I am not permitted to identify my mother or any family members. For this reason, if my submission is published, I request that my name be redacted.

My response to the Inquiry will cover only those questions which relate to the denial of human and legal rights of the disabled whilst under the control of the NSW Guardianship Tribunal and the NSW Public Trustee & Guardian. The disability I am concentrating on in this submission is dementia/Alzheimer's disease affecting the frail and elderly and will refer to disability, in the main, as meaning “cognitively impaired”. I have no doubt that the same complaints will resonate with those who have other disabilities.

**Q1**. Australia does have an understanding and recognition that people with a disability have a right to enjoy legal capacity on an equal basis with others in all aspects of life. However, the CRDP guidelines addressing these issues simply serve as guidelines and General Principles.

For the cognitively impaired and their loved ones, Article 12 of the CRPD has not had any or is likely to have a positive impact on their rights to equal recognition before the law. It has not enforced the provision for supported or substitute-decsion making arrangements nor has it served people with disabilities in their efforts to receive recognition before the law and their ability to exercise legal capacity. Australia has a duty to adopt its own Bill of Rights to protect its citizens, particularly the vulnerable, aged, infirm, disabled and cognitively impaired. We do not have to rely on the United Nations CRDP to think or act for us.

Australia does not have a Bill of Rights or any other mechanism which would make the CRDP guidelines and General Principles legally enforceable. Until they are legally binding, they will not be implemented or adhered to by any Guardianship Tribunal or Public Trustee & Guardian. Instead, its sole purpose will be to serve these government bodies

well by providing them with window dressing and motherhood spin, enhancing their image to the naïve and uninformed, but with no relevance in their day to day operations.

The reality is, that neither of those organisations adhere to anything contained in the CRDP and continually fail to act in the best interests of the protected persons. They do this because they can since there are no useful or effective safeguards in place to ensure that they act in the best interests of those under their control. Guardianship Standards and General Principles are published for all to see. In principle they are very reasonable documents but in practice, their mandates are ignored and violated. Complaints through the usual govt. channels are ineffective and provide predicable outcomes. No Govt. department is going to bite the hand that feeds them hence our efforts in seeking justice or fairness are pointless. In fact they are counterproductive because the only certainty that ensues is retribution and vindictive behaviour against the person/family who had the temerity to make the complaint. Because of the lack of accountability, lack of transparency and no safeguards of any note, The Public Trustees & Guardians are, in essence, untouchable.

Where can the cognitively impaired person and his/her family effectively turn to for help – nowhere! The key carer cannot act on behalf of the cognitively impaired and the cognitively impaired cannot act for themselves – it lose /lose in all counts. They have no voice or legal standing to fight for their basic human rights. Once in the clutches of the Guardianship Tribunal and the Public Trustee, there is no way out. Whilst I accept that not all Public Guardians and Trustee cannot be tarred with the same brush and there are those that try and to do the best within their capabilities, the sad truth is that these people are in the minority.

The cognitively impaired and their carer(s) families etc. should have available to them the services of a completely independent Public Advocate, fully experienced and understanding of the special needs and diversity of the disabled. This Public Advocate would need to be a fully endorsed and recognised body by the Government -

a) and have the full legal authority to investigate any complaint, examine, recommend and enforce decisions to be made for and on behalf of the disabled and cognitively impaired person, in accordance with their wishes;

b) have the power to ensure that the human and legal rights of the disabled and cognitively impaired people are restored and respected;

c) have the role and power to raise important matters and concerns with the Minister;

d) have the authority to attend with police and remove the cognitively impaired person from the place they are detained against their will and which is detrimental to the health and wellbeing of the cognitively impaired person;

e) and would promote, as an issue of public interest, the rights, protections and services available to ensure those rights are respected.

There must be a Bill of Rights in Australia. Without that or the the establishment of a Public Advocate (non government) there is no opportunity for the human and legal rights of the

disabled and cognitively impaired or their carers and families to be respected or enforced.

**Q2.** If an independent audit were to be undertaken of all the families and protected persons who had the misfortune to become involved with the NSW Guardian Tribunal and the NSW Public Trustee & Guardian, the evidence and general consensus would clearly identify the level to which the disabled and cognitively impaired are consistently denied their basic and legal human rights. The glowing Annual Reports and Audits published by the Guardianship Tribunal and the Public Trustee & Guardian waxing lyrical about their operations and performance is nothing short of a slap in the face to those under their control. One does not have to look far to see where the truth actually lies – past or present.

The Guardianship Tribunal should be totally reformed, hearing matters which deal only with the most vulnerable persons “at risk” who have no family, friends or support network available or willing to assist with their care needs. As it stands, the Guardianship Tribunal is nothing better than a Kangaroo Court and a “clearing house” providing a steady stream of “victims” for the Public Trustee & Guardian. That is why the term “guardian of last resort” is known as “guardian of the first port”.

An independent and Specialist Court, which relies on rule of evidence, should be established to hear other matters of more complexity and which would be dealt with by Judges who are experienced in the needs and special considerations of the disabled, vulnerable, elderly and cognitively impaired.

Neither the NSW Guardianship Tribunal nor the NSW Public Trustee & Guardian have suitable personnel who have the capabilities, expertise or understanding required to deal with the special needs of the disabled and cognitively impaired.

Without the establishment of a Bill of Rights and a Public Advocate (non government) there is no opportunity for the cognitively impaired and their carers/families etc. to have their human and legal rights to be enforced. In addition, carers and their families must have a greater input and legal recognition of the value of their opinions, knowledge and close understanding of the cognitively impaired person over the views and opinion of strangers

**Q3** Yes. In addition to the framing principles of the ALRC there must be some uniform directives given to solicitors when a client may appear to have a decsion making impairment

which may affect their legal capacity to execute documentation.

This is particularly important when revoking long standing Powers of Attorney and Wills. Evidence should be held on file by the solicitors confirming that they have complied with all the directives and a signed copy given to the cognitively impaired, the carers and family members who were in attendance. If the solicitors have not followed this procedure, then the new documentation should be nullified and the solicitor legally required to make good any resultant damages claimed as a result of their failure to do so.

These directives or safeguards should be uniform and a national requirement. For example -

(a) check for any signs of lack of full comprehension of the import of the revised document (s) by asking the client to repeat his/her understanding of what the

documents mean;

(b) ask for the imput of key carers, family or friends as to whether there is another

way that clarification of the situation can be made in order for the client to satisfy

the solicitor that the cognitively impaired person has full comprehension of the import of the revised document(s);

(c) be aware of any coersion or manipulation of the cognitively impaired person by

persons in the room and look for any warning signs;

(d) if in doubt in making an assessment, refer the client to a psychologist or

specialist who has expertise in assessing cognitive capacity before revoking

a Power of Attorney or drawing a new Will;

(e) ask a question in different ways to see if the client provides the same answer, for

example -

“I know that you would like all of your children to look after you. Do

you mean that you would like them all to visit you? Who would you

like to take care of you most of the time?

Now what about your financial matters, like taking care of your finances, banking and so on and looking after the house – Who do you want

to take care of that?

Who do you think would be the best person to do this – which of your

children? Can I ask you why you prefer that person(s)?

By asking questions along those lines, there is a greater chance that the client will

tell you what they really want rather than give answers that they think they should

give such as Yes/No answers or answers that they think will please you or put them

in a good light.

**Q4.** Yes, this is an absolute necessity. The issue of “capacity” is an extremely contentious issue when dealing with the Guardianship Tribunal and the Public Trustee & Guardian particularly in the case of people suffering from the various forms of dementia and Alzheimer's disease. Neither of these two entities are appropriate or competent bodies to decide whether a person lacks capacity. They do not have the appropriate training, knowledge, understanding or expertise to make such an assessment nor, more importantly, do they view capacity as a fluid concept. Their concept of capacity is a “one size fits all” and a “one-time only” classification which is not corrrect and is absolutely discriminatory with far reaching consequences. To do so is a clear indication of their lack of knowledge and expertise in the

field.

The best people to assess the capacity of the cognitively impaired person and whoes opinons and views should carry more weight are the key family carers, family, supporters, paid carers, friends and advocates – all of whom have a longer and more intimate knowledge and understanding of the cognitively impaired person.

Relying on a report from GP or specialist who has had only a limited contact with the disabled person should not be considered the sole determinant of whether a person has capacity or not. Nor indeed, should the odd one or two banal questions posed to the cognitively impaired person during a tribunal hearing form part of the assessment by the presiding members of the tribunal. Any questioning of the cognitively impaired person should not take place before a Tribunal. This is confronting, confusing and a totally inappropriate avenue for competently assessing any level of cognitive impairment the person may have.

**Q5**. Key carers play a very important role in the life of the disabled and cognitively impaired. Currently, there is no legal recognition of the status of a key carer. This is a totally unacceptable and unfair situation for the key carer who is best placed to advocate on the cognitively impaired person's behalf. This must change.

The status of a key carer MUST be given definition and legally acknowleged as significantly important whenever decisions are to be made concerning the disabled or cognitively impaired.

By creating a legal framework and definition regarding Carer Status, the views and

opinions of carers will be legally acknowledge as -

* significantly important whenever decisions are to be made which affect the disabled and cognitively impaired by government bodies and medical professionals;
* provides for full evaluation and consideration of those opinions and views to be

included and addressed in the decision making process

* provides safeguards against predatory individuals or organisations that are not acting in the best interests of the disabled and cognitively impaired;
* prevents the abuse of power by government and other bodies by legally obliging

them to include carers in the decision making process, and

* provides a safeguard for financial and emotional exploitation by others;
* prevents the almost automatic “substitute decision making” orders by the Guardianship Tribunal on the cognitively impaired when there is no valid reason for them to be made in the first place.

Relevant members of the public, health care providers and others working with carers should be informed, educated and respectful of the status of carers and acknowledge their important role in society in maintaining equality of the disabled and cognitively impaired.

Financial, legal and representative assistance and any other relevant support should be available to carers in maintaining their role as carers. Such information and advice should also be available and be a source of encouragement to others who are willing but uncertain as to whether they should assume that role. This assistance is particularly relevant when protecting or advancing the interest of equality of the disabled and cognitively impaired is concerned.

Without any effective safeguards in place, or formal recognition of the status of carers as an important element in the decision making process, none of the human rights of either the cognitively impaired or the carers and their families will be taken into account by the Guardianship Tribunal or Public Trustee and Guardian. The following breaches of their human rights will continue:

* + abuse of power and a sense of “ownership” of the disabled and cognitively impaired person;
  + dictatorial as opposed to an inclusive and consultative process with the disabled or cognitively impaired, their carers or their families;
  + disregard of the significant importance of the opinions and understanding of

carers and their families, supporters etc. who have intimate and close knowledge and understanding of the cognitively impaired person's needs and wishes;

* + proliferation of the arrogant “them and us” culture which is systemic within the Public Trustee & Guardian;
  + decisions made contrary to the best interests of the cognitively impaired person;
  + complaints made to the usual channels are met with lip service and rarely

serve any purpose – the Public Trustee & Guardian is always right!

* + rudeness and disrespect towards the opinions and views of the carers and families of the cognitively impaired person;
  + disregard of the opinion and recommendations of treating doctors;
  + inappropriate decisions regarding accommodation and lifestyle of the cognitively impaired person;
  + inappropriate decisions and mishandling of the cognitively impaired person's estate and funds;
  + failure to understand or try to understand the special needs and requirements of the cultural values of the cognitively impaired and their carers and family;
  + continued stress, frustration, anger and despair because of the counter productive behaviour and mindset of the Public Trustee & Guardian towards the cognitively impaired person and the carer, family, support persons etc.

Q9. There are a number of issues which do and may arise in relation to review of government decisions affecting the equal recognition before the law of people with cognitive disabilities and their abili,ty to exercise legal capacity. Regretfully, the following are just a small sample of common place situations that have and continue to occur, in particular ,with the

Guardianship Tribunal and Public Trustee & Guardian nationally:-

* + Inadequately trained, qualified or experienced staff in administrative positions or Government bodies, in health care or civil rights;
  + Inadequately qualified or experienced staff, in health care or civil rights, and who make decisions for Government bodies;
  + Lack of maturity, perception and grasp of life skills and family values by employees at Public Service level such as the Office of Public Trustee & Guardian when making final or long term decisions on behalf of the cognitively impaired;
  + Lack of transparency and a counterproductive obsession with secrecy by Government bodies which does little to assist those in need, but does a lot to destroy accountability and confidence in the administration and implementation of the law;
  + Lack of communication skills, perception and empathy;
  + The abuse of power, arrogance and dictatorial stance when dealing with the cognitively impaired, carers and their families who are viewed as “persona non grata” with little human value;
  + Failure to develop, encourage and foster a common objective to protect and maintain independence, dignity and welfare of the disabled and cognitively impaired in order that equality of human rights is preserved rather than diminished;
  + Inability of and neglect by Government and Administrative Bodies to acquire and update their understanding and awareness of the individual desires and wishes of the disabled and the cognitively impaired, prior to and in the course of consideration of, what action or decision should be made in their best interests
  + Failure by Government bodies to act on or act contrary to independent professional advice when given or received, on behalf of affected persons. Reasons for non-compliance are rarely, unpredictably or inconsistently given.
  + Inconsistent and unpredictable attitudes of Government and Administrative bodies when reasons for decisions are requested from them or alternatively when reasons must be provided as of right
  + Inconsistent and unpredictable delays at all levels. Non-existent affirmative action. Apathy, inability and failure by Government employees to recognise major issues when undertaking administrative duties and functions;
  + Inconsistent, unpredictable and dysfunctional views between government department staff of their respective roles and legal responsibilities when purportedly having the common purpose to protect those in their care, e.g. Public Guardian/Trustee in NSW;
  + Failure to implement processes for the removal of a decision maker or reallocation of their work when bias or apathy exists or when there is a very real or probable basis for its perception, when a decision is being made at administrative or Public Service level;
  + Lack of understanding or ability to understand the mandates under which they operate even at the most basic level;
  + Lack of understanding or ability to understand the issues at hand which result in

the failure to act in the best interests of the disabled or cognitively impaired person;

* + There is no enforceable, universal or mandatory requirement that Government and Administrative bodies and their employees must ascertain the facts on the evidence, act fairly on those facts or on other clear and reasonable grounds, prior to making a decision which ultimately adversely impacts on the health, wellbeing, freedom and

human rights of the disabled and cognitively impaired person;

* + Lack of accountability encourages the widespread culture of ignorance, bigotry and prejudice within the ranks of Administrative and Government bodies and their employees and staff which reinforces the “them and us” attitude towards the disabled and cognitively impaired, their carers, families and support persons.
  + Procedural duplication, arrogance and round-robin methodology which promotes dysfunction, inordinate delays and inefficiencies detrimental to the disabled and cognitively impaired, their carers and families.
  + Government bodies are not readily and efficiently held to account for delays, mistakes and neglect which cause financial loss or wastage of funds or assets held on Trust or which leads to detriment to the quality of life, health and welfare of those under care and unable to present their views, e.g. NSW Public Trustee & Guardian;
  + Damages should be paid by Government bodies in all cases of departmental incompetence, negligence, delay, bias and lack of fairness which results in financial loss. In this way robust standards may be enhanced and quality of service encouraged to be delivered more openly, efficiently and thus earn Public confidence.
  + Unsatisfactory internal or external review bodies and appeal procedures which are not truly independent but often self serving. Such avenues of redress are often illusory and cause delay, and hardship to the disabled and cognitively impaired, carers and their family.
  + Automatic right of appeal to a Court of Law whenever a grievance needs to be addressed or sufficient grounds exist. Such rights of appeal must not to be limited to matters of law alone .
  + A dedicated and fully independent Public Advocacy Office should be created to provide advice, mediation and legal representation on behalf of the disabled and the cognitively impaired when disputes arise between government bodies such as Public Trustee & Guardian and their or their Carers, and Government bodies, e.g. Public Guardian/Trustee. In this way human rights, values and standards may be protected and enhanced through better understanding and communication. Similarly, this Office would encourage a higher quality of service to be delivered by Government and Administrative bodies. Greater efficiency and consistency with the delivery of legislative goals would be achieved more readily.

**Q23 & Q24**

* Cost of legal representation to Carers and their family in dispute with Government bodies which have access to and expend a protected persons funds in order to engage in a war of attrition, in order to maintain their position;
* Limited experience in and exposure to this area of justice by legal practitioners due to their exclusion, ie no right of appearance before some Tribunals and the deprivation of the right of the Incapacitated and Aged to representation by independent legal practitioners. The Aged and Incapacitated are the very people who need and would benefit the most from equality, inclusion and participation before the Law;
* Arbitrary and protected nature of Government and Administrative bodies and Tribunals. Such bodies are not truly independent of Government Department or Public Service culture, methodology and subjectivity when evaluating what is in the best interests of individuals and the means used to protect their rights of equality and autonomy as human beings, whether Aged or Incapacitated
* No Government or Administrative body or Public Servant dealing with the Aged and Incapacitated should regard themselves as unaccountable, beyond scrutiny or above the Law in the course of their work. All dealings must accord with accepted notions of openness, fairness, Justice and Human Rights values. To continue otherwise would support the growth of a culture tainted with ignorance, bigotry and prejudice within the ranks of Administrative and Government bodies and their employees and staff.
* A need to create a specialist Court as mentioned in Question 2, with true and perceived independence, which applies the law and acts on proven evidence and has extensive jurisdiction over all relevant Administrative and Government Bodies.
* Decisions of Government and Administrative bodies should be based on the proven facts and full and proper weight given to evidence from relevant Doctors, health care providers and other professionals having the relevant skills and knowledge. All arbitrary and untested statements of fact or opinions from Government and Administrative bodies and their staff to be tested or excluded, and not treated inherently as being proof or evidence of facts relied on.
* Lack of information given to and poor education of Health Care professionals of their role in legal matters or considerations which are relevant to their field of operation, eg Hospital professional staff and which may impact on the quality, ambit and nature of their services, reports, and recommendations, made on behalf of the Aged and Incapacitated

**Q34 & Q35**

Firstly, I do not support substituted decision making in health care. This should be the

the right of the disabled or cognitively impaired or their carers/family/support people to

make informed decsions and choices in this regard, particular regarding medical treatment.

Secondly, the Aged Care Act should be amended to ensure that older people, particularly cognitively impaired with dementia, are not forced to live in nursing facilities when they are able, willing and wish to live in their own home with their key carer and the support of family/friends/advocates.

Thirdly, the following issues are prevalent throughout the aged care industry and are

relevant concerns affecting the disabled, infirm, aged, vulnerable and cognitively impaired:-

* Lack of understanding on the meaning of and consequences of mental incapacity, whenever it exists, in legal or medical terms by Government and Administrative staff and employees
* Lack of experience and education of medical and non-medical people when faced with occasions of doubt or uncertainty as to the existence of incapacity of a person, or when dealing with Carers on behalf of the disabled, aged and cognitively impaired, eg police, hospital staff
* Insufficient recognition of the role and contribution of Carers and family members who possess intimate knowledge of and who are exposed daily and witness the needs, wishes and welfare of an Aged or Incapacitated person and therefore are in a unique position to represent a balanced view on their behalf, as individuals with equal rights in society
* Failure by Government bodies and their staff to enquire, recognise and act upon the wishes and needs of Aged and Incapacitated people, when moments of lucidity and comprehension exist. Carers and family members can contribute to such understanding. Government bodies and their staff are remote and unable or unwilling to acknowledge or act in such circumstances, unless it suits their own convenience to do so.
* Lack of accountability for the receipt and use of Government funds, eg aged care facilities/homes. In these circumstances, Aged or Incapacitated persons lose their rights to participate and express the nature of their needs, and the allocation and use of funds. As a consequence they do not benefit to the maximum potential, as intended, by the availability

of Government funds.

**S U M M A R Y**

The above issues raised are not new. At least twenty years have passed during which time the same complaints have been made by numerous organisations and individuals. Reports, Inquiries, Reviews, Submissions, editorials, documentaries et al have been prepared yet nothing of any note has occurred to address those issues.

The only difference now is that the complaints are increasing and the cries for reform are getting louder and maybe, this time, change will come.

Nobody should be denied their basic human rights, least of all the most vulnerable who are already marginalised because of their disabilities. The Guardianship Tribunals and the Public Trustees & Guardians who are supposed to be their protectors are, in fact, their tormentors. How can any Government justify this state of affairs and not act expeditiously to bring about the much needed reforms.

Australia must develop its own Bill of Rights and not simply pay lip service to the CRDP. The

Australian Government can no longer sweep this public interest issue under the carpet and hope that it will go away - it will not. People are getting older, living longer and our demands for equality and fairness are getting louder.

The current system is broken and it cannot be fixed. The Guardianship Tribunal in its present form must be disbanded and replaced by a new Specialist Court. The operations and conduct of the Public Trustee & Guardian must no longer be afforded the current largess of unaccountability and lack of transparency. Those under their control are human beings and not just a number to be toyed with. Life must be respected and afforded the dignity and freedom at any age or level of health.

Australia is not a dictatorship but the Guardianship Tribunals and Public Trustee & Guardians are. This must stop now and law reforms ensuring that the legal and human rights of all its Australian citizens are legally binding and upheld is the only way forward.

I thank the Disability Discrimination Commissioner, Mr. Graeme Innes and the Australian Law Reform Commission for the opporunity to make this submission. My sincere hope is that this Inquiry will be distinguished by a positive outcome as opposed to the many failed initiatives that have occurred in the past when seeking much needed law reforms in the above areas.

**To quote an old Principle “Justice delayed is Justice denied”.**

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