**2nd Guardianship Conference of Hong Kong**
**Key-note speech: Trends of legal development of guardianship: a transition or a destination**

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## Introduction

A person's ability to determine their own future and to make choices about their own life and circumstances strikes at the very heart of what it means to be human. So what happens when a person's capacity to make decisions for themselves about important issues affecting their everyday life and the management of their assets is impaired? How are questions like these answered?: "Where should the person live?", "What medical treatment and services should they receive" and "How is their money to be managed?" Who should provide the assistance that a person needs and in what circumstances should that assistance be provided? Whose values or standards or what decision making framework is to be applied in making such decisions? How is the desire to prevent the risk to or the exploitation of vulnerable people balanced against a person's freedom to make their own decisions? And even before that, what tests should be applied to determine the level of capacity required to make these everyday decisions? Should a person be free to make decisions that may not accord with a 'best interests' standard? These are not new questions but have their origins in the time of the Chancery where the common law started to try to find ways to answer these questions through formal legal structures and the formation of administrative law.

In recent times, these questions have received a renewed attention and focus, propelled by the UN Convention on the Rights of Persons with Disabilities ('the Convention'), which came into being in 2008[1].

In Australia, specialist tribunals predominantly exercise the power to answer these questions, using the framework of substitute decision making. Such matters are only dealt with by the courts in small numbers. However, the existing substitute decision making model or 'best interests' model has been criticised for being too paternalistic and for taking away the right to self-determination too easily.

International law and thinking on the rights of persons with disabilities now favours a model that puts the 'will, preferences and rights' of the person concerned at the centre of the decision making process. A ***supported*** decision making model is preferred to the current ***substitute*** decision making model, in keeping with the Convention.

[1] *Convention on the Rights of Persons with Disabilities* opened for signature, 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

In the time I have today I will endeavour to explain the current Australian system for the appointment of substitute decision makers, examine how concepts of supported decision making currently exist (largely informally), and look at some of the reform proposals currently being examined.

## The Australian context

So that my remarks may be better understood, I will provide a brief outline of the context in which my jurisdiction in the state of New South Wales (NSW) operates.


The population of Australia in June 2016 was estimated to be 24,127 million[2]. The population of NSW in 2016 was 7.72 million[3]. NSW is one of eight states and territories which make up the Commonwealth of Australia, that is, we operate under a federal system of government. There is a division of responsibility for discrete areas as set out in the Australian Constitution and the rest is determined by agreement between the Federal government and the individual state and territory governments. The states and territories are broadly responsible for making laws and providing services concerning guardianship so we have 8 separate (but quite similar) systems operating in Australia. To add to the complexity however, the Federal Government is largely responsible for legislation impacting upon those most likely to have recourse to the guardianship jurisdiction, such as the aged care sector and the newly implemented National Disability Insurance Scheme (NDIS).

[2] Australian Bureau of Statistics, available at: http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0 [accessed 3 February 2017]
[3] Australian Bureau of Statistics, available at: http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0 [accessed 3 February 2017]

## Current Guardianship laws

The legislation pertaining to guardianship in NSW is very similar to other Australian jurisdictions. The *Guardianship Act 1987* (NSW) commenced in 1989 and has not been significantly reformed since that time.

The Guardianship Division of the NSW Civil and Administrative Tribunal (the Tribunal or 'NCAT') is the primary body in NSW for making orders relating to people with cognitive disabilities. The Tribunal appoints substitute decision makers for adults with decision making incapacity. That is, it appoints guardians for personal, health and lifestyle decisions, and financial managers for financial and/or legal decisions.

The Tribunal must observe the principles in the *Guardianship Act* . These principles state that everyone exercising functions under the Act with respect to people with a disability has a duty to:

- give the person's welfare and interests paramount consideration;
- restrict the person's freedom of decision and freedom of action as little as possible;
- encourage the person, as far as possible, to live a normal life in the community;
- take the person's views into consideration;
- recognise the importance of preserving family relationships and cultural and linguistic environments;
- encourage the person, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs;
- protect the person from neglect, abuse and exploitation; and
- encourage the community to apply and promote these principles.

Whilst these principles were formulated well before the introduction of the UN Convention, they have guided the Tribunal for many years to make decisions which, in my view, are substantially in compliance with the Convention. In NSW, like most Australian jurisdictions, an order appointing a substitute decision maker is a last resort. An order will only be made if there is no other option, and if so made, will be limited to that aspect of the person's life where the order is required. For example, the Tribunal would frequently make orders appointing a guardian to decide a person's accommodation needs, but otherwise all other decision making authority would remain with the person, meaning they would make the decisions themselves or through informal support mechanisms. In most Australian jurisdictions, orders must be reviewed every 1- 3 years.

Where there is a suitable person, such as a family member or a friend, able and willing to be appointed as the substitute decision maker for the person, the Tribunal must consider that person for appointment. Where there is no such person available or it would not be in the best interests of the person to appoint a private person, then the Tribunal must appoint the

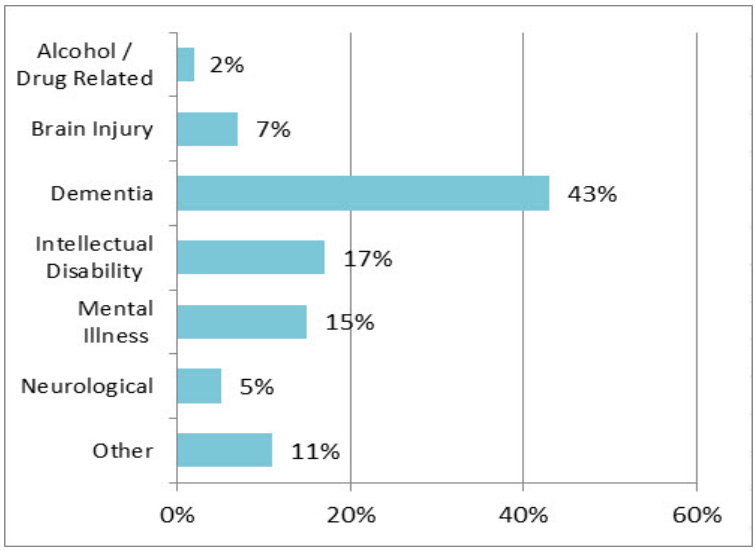
Public Guardian for guardianship matters and the NSW Trustee and Guardian for financial matters, both statutory office holders. Australia does not currently have a system of appointing volunteers or professionals who are unknown to the person as substitute decision makers.

The focus on the interests of the person with a disability is reflected in the work that the Tribunal's staff undertake before an application or review of an order is heard by the Tribunal[4]. Tribunal officers strive to involve the person with a disability in the pre-hearing case preparation process as much as possible. Tribunal staff use their experience and expertise in a range of disability fields to engage with the person with a disability to explain the Tribunal's role, seek the person's view about the case before the Tribunal and assist with any questions or concerns the person may have.

In NSW, for a guardianship or financial management order to be made, the Tribunal must be constituted by 3 members, one being a barrister or solicitor who presides at the hearing, one being a healthcare professional (eg. a psychologist or a geriatrician), and one being a community member, usually a person who identifies as a person with a disability, or is a carer or advocate for a person with a disability. This structure brings a wealth of knowledge and expertise to the Tribunal process and is designed to assist in the involvement of the person in the hearing. The Tribunal does not follow an adversarial approach and uses more inquisitorial methods.

In the Financial year 2015/2016, 43% of the Tribunal's clients were people with dementia, only 17% of the Tribunal's clients were people with an intellectual disability, and a further 15% were people with a mental illness. Over 60% of the Tribunal's clients were over 65 years of age. The Tribunal attended to 11,455 applications or reviews of orders and conducted 7,792 hearings.

The following graph depicts the distribution of applications received by the Tribunal in the last financial year, by disability:




[4] Guardianship Tribunal, "24 years – empowering and protecting" Annual Report 2012/2013, p 21

Interestingly, the Tribunal's statistics above are distinctly different to the statistics in Hong Kong. I was very privileged back in 2012 to work with Chairperson Charles Chiu on the paper "*How does Culture Impact Upon Best Practices in Guardianship?: A Comparative Study of the Achievements and Challenges in Hong Kong and New South Wales, Australia*", which we presented at the 3rd International Congress on Guardianship in Washington DC. The comparisons between the two jurisdictions demonstrated that while the statistics from Hong Kong may be similar to NSW in terms of population, median age and life expectancy, the workload in our two jurisdictions were vastly different.

At the time of the report in 2012, the Tribunal in NSW received 2668 guardianship applications in that year while the Guardianship Board of Hong Kong received 284 guardianship applications. We hypothesized that this may have been the result of the impact of key cultural differences between the two populations, such as differing views on reliance on Government services versus reliance on family, an individual rights-based perspective versus deeply rooted familial obligations, and the willingness to engage in formal legal dispute resolution versus a preference towards resolving disputes internally.

## What does the future hold for the guardianship jurisdiction?

### *Supported decision making*

Since 2010, the debate for reform in Australia has largely centred on the need for the implementation of supported decision making over substitute decision making, effectively requiring a paradigm shift from a 'best interests' model towards 'will and preferences' and 'human rights' models of decision making.

By some views, mechanisms for supported decision making have been available in all Australian jurisdictions for many years – however these mechanisms are generally only available to those assessed as having the requisite capacity to understand and otherwise execute the instruments of appointment.

Whilst terminology differs across the country, in NSW, a person with the requisite capacity can sign an instrument appointing an enduring power of attorney which will allow the person appointed to manage their financial and legal affairs if they become unable to do so at some future point, and similarly, can sign an instrument appointing an enduring guardian to make lifestyle and medical decisions if they become able to do so. Whilst these appointments are regulated by legislation, and can be challenged or reviewed in tribunals and courts, there is no systemic oversight of those who perform these roles as attorneys or enduring guardians. These instruments, particularly instruments appointing a Power of Attorney, have become an important focal point for recent inquiries in Australia regarding elder abuse[5].

[5] Parliament of NSW, *Elder Abuse in New South Wales,* Report 44 (2016), available at https://www.parliament.nsw.gov.au/committees/inquiries/Pages/inquiry-details.aspx?pk=2387#tab-reports, [accessed 16 August 2016]; Australian Law Reform Commission, *Protecting the Rights of Older Australians from Abuse*, (2016).

The majority of Australians with a cognitive disability do not have a court or tribunal appointed decision maker. By default, most are supported informally by family, friends or carers. Many would define this as supported decision making. However, this form of support is unregulated, lacks any of the safeguards contemplated by Art 12.4 of the UN Convention, and leaves those who perform the support role without any guiding principles.

To date, the UN Convention has largely not been implemented into Australian domestic law as it pertains to Article 12. Having said this, it is clearly the driving force behind much policy reform. The most significant reform in this space is the implementation of the National Disability Insurance Scheme (NDIS) by the Federal Government. The NDIS is a major policy change in Australia concerning the way support and services are provided for eligible people with permanent and significant disability. The scheme is a lifetime disability insurance scheme funded by a 0.5% levy on all tax payers which shifts the model of service delivery from being government funded by service provision to one of individualised support. Individuals can formulate their own support plans, to determine what form of support and services they receive and from whom. After trials in some pilot sites, the major roll out of the scheme across Australia commenced on 1 July 2016.

This move towards individual funding packages means eligible participants have more choice and therefore more decision to make. For those who may have a cognitive impairment, the NDIS promotes supported decision making over substitute decision making whenever possible. There is however much ambiguity as to what this support entails, who provides and funds it, and safeguards are yet to be implemented[6]. In those circumstances, there is likely to be, at least in the short term, an increase in the applications for the appointment of formal substitute decision makers.

In Australia, while the debate has focused on the implementation of supported decision making over substitute decision making and the various methodologies that could be legislated to allow this,, there has been little discourse about how supported decision making would be practically implemented "on the ground". There are several research projects currently underway designed to evaluate the quality and effectiveness of different models of supported decision making. One such study, led by Professor Terry Carney of the University of Sydney and other investigators from across the country, is designed to test the hypotheses that supporters who are provided extensive training on how to perform a support role to a person with a cognitive disability together with structured principles will show significantly superior outcomes in measures of decision making support[7]. As noted in the background paper to this research project:

> *"Over 1 million Australian (5% of the population) have some form of cognitive impairment due to intellectual disability or acquired brain injury (AIHW 2013) and require significant levels of support for decision-making. To date, however, the range and quality of support available has been poor, often tending toward undue paternalism, with deleterious consequences for the individual's sense of identity and quality of life. Efforts to rectify this situation have recently been championed by law reform commission, which have focused on establishing new legal structures for support with decision-making. These structures are very*

[6] For example, see decision of NCAT in KCG [2014] NSWCATGD 7 at [64] to [73].
[7] Australian Research Council Funded Linkage Project, *Effective Decision-Making Support for People with Cognitive Disability*, (2016).

*welcome, but the crucial issue of how decision-making support is delivered in practice – in terms of quality and effectiveness – remains severely neglected."*[8]

### *From 'best interests' to 'will and preferences'*

Several inquiries or reform initiatives have occurred, or are currently ongoing in Australia, in relation to the disability sector. Reform inquiries that have been completed have all concluded that there is a need for greater empowerment of the person with the disability in the decision making process. This would involve a shift away from a 'best interests' model of substitute decision making towards one that 'promotes and safeguards the adult's rights, interests and opportunities'[9] or acknowledges that 'people with impaired decision making disabilities have wishes and preferences that should inform decisions made in their lives'[10] and 'act in consultation with the person, giving effect to their wishes'[11]. This confirms the appropriateness of the theme of our Conference today – "Respecting Will and Wishes".

### *Commonwealth – National Decision Making Principles*

One of the reform most notable reform initiatives was the Australian Law Reform Commission's enquiry into '*Equality, Capacity and Disability in Commonwealth Laws'* (ALRC report)[12].

The ALRC report recommends that reform of Commonwealth, state and territory laws and legal frameworks concerning individual decision making should be guided by the four National Decision Making Principles (and associated Guidelines), namely:

1. Everyone has an equal right to make decisions and to have their decisions respected

2. Persons who need support should be given access to the support they need in decision-making

3. A person's will, preferences and rights must direct decisions that affect their lives

4. There must be appropriate and effective safeguards in relation to interventions for persons who may require decision-making support.

A person's 'will, preferences and rights' is explained by the ALRC as follows:

*Article 12(4) of the CRPD uses the formulation 'rights, will and preferences'. The ALRC formulation follows the spectrum of decision-making based on the will and preferences of a person, through to a human rights focus in circumstances where the will and preferences of a*

[8] Ibid at [1].
[9] Queensland Law Reform Commission, *A review of Queensland's Guardianship Laws*, Chapter 4, 2010 available at http://www.qlrc.qld.gov.au/publications [Accessed 9 September 2015].
[10] Victorian Law Reform Commission, *Guardianship* Final Report 24, January 2012, at xxxv.
[11] Victorian Law Reform Commission, *Guardianship* Final Report 24, January 2012, at xviii.
[12] Australian Law Reform Commission, 'Equality, Capacity and Disability in Commonwealth Laws', ALRC Report 124, available at http://www.alrc.gov.au/publications/equality-capacity-disability-report-124 [accessed 9 September 2015]

*person cannot be determined. The inclusion of 'rights' is the crucial safeguard. In cases where it is not possible to determine the will and preferences of the person, the default position must be to consider the human rights relevant to the situation as the guide for the decision to be made.*

*The emphasis should be shifted from 'best interests' to 'will and preferences' approaches. Even in those examples of approaches where 'best interests' are defined by giving priority to 'will and preferences',[46] the standard of 'best interests' is still anchored conceptually in regimes from which the ALRC is seeking to depart.*

It remains to be seen whether these recommendations will be taken up by the Federal or state governments. However, we are already seeing a contest of ideas occurring within civil society. The NSW Council for Intellectual Disability (CID), a peak advocacy group for people with Intellectual Disabilities, has expressed concern about the move towards a human rights based model of substitute decision making where a substitute decision maker is still required[13]. CID questions whether the particular linguistic and cultural background of the person will be appropriately reflected in the decision making process and expresses concerns that a sophisticated understanding of human rights will be necessary in order to make a substitute decision which is in keeping with a person's human rights. CID puts forward the view that such a standard could exclude family members from the substitute decision making role, as there may not be the sophisticated level of understanding of human rights amongst the family of a person in need of a substitute decision maker.

### *Victoria*

In addition to the ALRC report, published in August 2014, the Victorian[14] Law Reform Commission also conducted their own inquiry. Some of the recommendations included: improving the processes of the Victorian Tribunal[15], integrating the different statutory decision making regimes into a single Act, introducing supported decision making arrangements, changing the modern capacity standard to accommodate fluctuations in decision making ability and the development of community education programs.

However, despite the final report of that inquiry being released in 2012, very few of the major forms proposed have yet to be introduced in Victoria. One recommendation that has been recently introduced is a scheme for the appointment of "supportive attorneys". The scheme permits a person who has the requisite capacity to enter into the instrument to appoint a supportive attorney who then has the power to access or provide information about them to organisations (such as hospitals, banks and utility providers), communicate with organisations, communicate their decisions, and give effect to their decisions. The goal is that the supportive attorney supports the person to make and act on their own decisions thereby increasing their independence and self-reliance. The scheme does not apply to "significant financial transactions" such as transactions relating to real property or investments of greater than $10,000 and the appointment does not have effect for any

[13] Council for Intellectual Disability, Blog, 'Supported decision making YES! But what role for substitute decision-making?', Blog, 25 June 2015, available at http://nswcid.blogspot.com.au/2015/06/supported-decision-making-yes-but-what.html [accessed 9 September 2015]
[14] Victorian Law Reform Commission, *Guardianship*, Final Report 24, January 2012.
[15] The Victorian Civil and Administrative Tribunal ("VCAT")

period during which the person does not have decision making capacity for the matters to which the supportive attorney appointment applies[16].

### *New South Wales – Review of the Guardianship Act*

In November 2015 the then Attorney General of NSW requested that the Law Reform Commission of NSW ("the Commission") conduct a review into the *Guardianship Act*, the legislation which underpins the jurisdiction of the Guardianship Division of the Tribunal in NSW. The Commission has been asked to have regard to a number of matters in conducting the review, including the UN Convention, the desirability of introducing a supported decision making scheme, and whether the language of "disability" remains appropriate to the guardianship jurisdiction or is a focus on "decision making capacity" more appropriate?

The Commission's review remains in the consultation phase with three discussion papers having been released in 2016. The next discussion paper is due to be released this month and will focus on the Tribunal and how we operate.

Some of the questions that the Commission has sought views on so far include:

- Should formal supported decision making or co-decision making schemes be introduced?
- Should substitute decision making, that is the current jurisdiction of the Tribunal, be retained?
- If substitute decision making is to be retained, should the current obligation on appointed guardians and financial managers to make decisions in the "best interests" of a person be replaced with a requirement to give effect to the person's "will and preferences"?

We await with anticipation the final report of the Commission which is due to be released before the end of the year.

## Conclusion

I have attempted to provide a brief overview of how questions of impaired decision making capacity and decision making arrangements are currently determined and how it is proposed that they may be answered in the future in Australia.

Whilst all Australian jurisdictions continue to operate legal frameworks entrenched in the appointment of a substitute decision maker, there has been a significant policy shift encouraging those appointed to these roles to engage in supported decision making whenever possible. This policy shift is not unique to Australia and is occurring in many countries throughout the world. In my view, this is a transition more than a destination. It is a transition that reflects society's ever developing views as to the capability and the rights of persons of disabilities.

[16] See Part 7 of the *Powers of Attorney Act 2014* (Vic)

Should the momentum that the disability sector is presently experiencing eventually lead to a change in the legal framework from one that emphasises substitute decision making, to one of supported decision making in accordance with a person's will, preferences and rights, it will be important for the issues that have been raised in this presentation to be properly addressed. There will need to be a proper assessment of any risks associated with a move away from formalised substitute decision making to ensure that what it is replaced with is a supported decision making model that genuinely enables the person to make their own decisions, with support, rather than a *de facto* substitute decision maker making decisions whilst standing in the shoes of a support person, without any oversight.

Like many things, if and when new models of supported decision making are implemented, the "devil will be in the detail". The assessment of a person's capacity, and by whom, must be front and centre in the development of any new legislated model. The reform process must endeavour to provide a framework which provides practical answers to the following questions which will need to be addressed daily by relatives, friends and carers of people with decision making disabilities:

- if a person's decision making capacity to make a particular decision is called into question, what is the test for assessing capacity to ensure that a person can be supported to make that decision?

- who makes this assessment and then determines what level of support is required?

- how do models of supported decision making work for people with fluctuating cognitive capacity?

- what safeguards are required to ensure that:

    - supports provided are suitably independent and free from conflict of interest?;

    - if a person's capacity diminishes, that substitute decision-making does not take place under the nomenclature of supported decision-making, that is how and when are steps taken to appoint a substitute decision maker for someone who can no longer be supported to make their own decisions?

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