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**Presentation delivered by Deputy President Malcolm Schyvens with assistance in preparation received from Ms Nicole D'Souza[1]**

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. HS Theobold takes us through the formation of these structures and principles, starting with delegations from the Crown to the Lord Chancellor. Much of the Lord Chancellor's work was necessarily performed by his delegates or administrative staff.[2] 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[3].

The law (for those from the common law world) has responded with the creation of a *'parens patriae'* or 'parent of the nation' jurisdiction which allows Judges to make decisions in the best interests of a person found to be vulnerable and in need of the law's protection, because of their incapacity. In addition, specialist tribunals have been established in various states and Countries under the creation of statutes, drawing on these legal principles of the protective jurisdiction, with the power and expertise to answer these questions, using the framework of substitute decision-making. This 'best interests' model has been criticised for

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[2] HS Theobald, *The Law Relating to Lunacy* (Stevens & Sons, London, 1924), page 61; Leonard Shelford, *A Practical Treatise on the Law concerning Lunatics, Idiots and Persons of Unsound Mind* (Sweet, and Stevens & Sons, London, 1833), pages 25-27.

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

being too paternalistic and for taking away the fundamental human rights of a person to self-determination.

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.

This paper provides an overview of how the questions I posed at the outset are currently answered in my jurisdiction in NSW Australia, how they have been answered in the past and how it is proposed that they may be answered in the future more generally. As part of this overview, this paper will also consider key questions concerning a person's capacity, how that is assessed, the role of medical practitioners in providing the necessary medical evidence and other evidence that a decision-maker can and should consider in arriving at answers to these questions.

**The Australian context**

So that my remarks may be better understood, I provide a brief outline of the context in which my jurisdiction operates. Australia is the world's sixth largest country, after Russia, Canada, China, the USA, and Brazil and the land area of NSW alone is approximately 800,600 square kilometres. (See map below)[4]


[4] Geoscience Australia, Australian Government, available at http://www.ga.gov.au/scientific-topics/geographic-information/dimensions/areas-of-australia-states-and-territories [accessed 3 September 2015]

The population of Australia in September 2015 was projected to be 23.89 million[5]. The population of NSW in 2014 was 7.57 million[6]. 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 healthcare and consequently there are separate statutes and Tribunals in each state and territory concerning substitute-decision making. This gives you some indication of the challenges of the delivery of health services in the Australian context.

**Guardianship laws and jurisdiction in NSW**

The NSW Civil and Administrative Tribunal (the Tribunal or 'NCAT') commenced operations on 1 January 2014, creating a 'one-stop shop' for specialist tribunal services in the state of New South Wales.

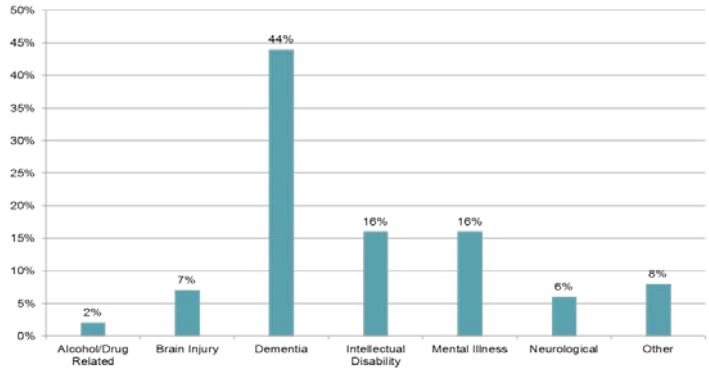
The Tribunal deals with a broad and diverse range of matters, from tenancy issues and building works, to professional discipline, to decisions on guardianship and administrative review of government decisions. Consolidating the work of 22 former tribunals into a single point of access, the Tribunal provides services that are prompt, accessible, economical and effective. One of the former tribunals which now falls under the NCAT umbrella is the former Guardianship Tribunal. That work is now performed by the Guardianship Division of NCAT.

In the first two years of the Tribunal's operation, that is from 1989 – 1991, 47.2% of its clients were people with an intellectual disability, only 33.8% of its clients were people with dementia, most of its clients were under 61 years of age (54.9%) and the Tribunal received 4,988 applications and conducted 2,973 hearings.

In the Financial year 2014/2015, 44% of the Tribunal's clients were people with dementia, only 16% of the Tribunal's clients were people with an intellectual disability, a further 16% were people with a mental illness, over 60% of the Tribunal's clients were over 65 years of age and the Tribunal received 8963 applications and conducted 7,489 hearings. We experience an average growth of 5% per year in the number of applications lodged with the Tribunal, something that is unlikely to abate given the broader aging population in which we operate. According to a study by Deloitte Access Economics, NSW had 91,308 people with dementia in 2011, projected to increase to 303,673 people by 2050[7].

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

[5] Australian Bureau of Statistics, available at: http://www.abs.gov.au/websitedbs/D3310114.nsf/home/home?opendocument [accessed 3 September 2015]
[6] Australian Bureau of Statistics, available at: http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0 [accessed 3 September 2015]
[7] Deloitte Access Economics, "Dementia Across Australia: 2011-2050", 9 September 2011, p16, available at https://fightdementia.org.au/sites/default/files/20111014_Nat_Access_DemAcrossAust.pdf [accessed 4 September 2015]




**Functions and Guiding Principles of the *Guardianship Act 1987 (NSW)***

The Division appoints substitute decision makers for adults with a decision-making incapacity. That is, it appoints guardians for personal, health and lifestyle decisions, financial managers for financial and/or legal decisions, it reviews guardianship and financial management orders, it also reviews enduring guardianship appointments and enduring powers of attorneys and provides consent to medical treatment and special medical treatment (a special category of treatment defined in the law that affect a person's fertility e.g. sterilisation) and it approves clinical trials.

The Guardianship Division of the Tribunal must observe the principles in the *Guardianship Act 1987*. 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.

Where there is a suitable person available and willing to be appointed as the substitute decision-maker for the person who is the subject of the application 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 who is the subject of the application 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.

As at 30 June 2015, there were 10,999 people whose finances were being managed by the NSW Trustee & Guardian and a further 3,771 people whose finances were being managed by a private financial manager and there were 2096 people under responsibility of the Public Guardian.

**Australia (NSW) in context**

In the financial year ending June 2015, the Guardianship Division received 8963 applications and experienced 22.6% growth in the number of applications received in the preceding five year period. This is a consistent workload with that experienced across other Australian jurisdictions.

By comparison, the Court of Protection in London, which has responsibility for guardianship matters in England and Wales, received approximately 1,500 applications a month in 2011[8] and heard approximately 23,000 cases a year[9].

One jurisdiction for which a detailed comparison may be offered, is Hong Kong. In the late 1980s, about a decade prior to the introduction of Hong Kong's new guardianship legislation, parent groups and the Hong Kong Social Welfare Department started to study the possibility of a new guardianship system for Hong Kong. They concluded that the NSW model was preferable and so the guardianship Hong Kong legislation[10] was drafted based on the NSW *Guardianship Act 1987*. Study visits to the NSW Tribunal were conducted by Social Welfare Department and following amendments to the laws passed in 1997 and before the Board was fully functional, a 3-day in-depth training session was conducted with the Hong Kong Social Welfare Department social workers, 3 panels of Board members and Hong Kong's first Chairperson conducted by Mr Nick O'Neill, the then President of NSW Guardianship Tribunal, in Hong Kong in April 1999.

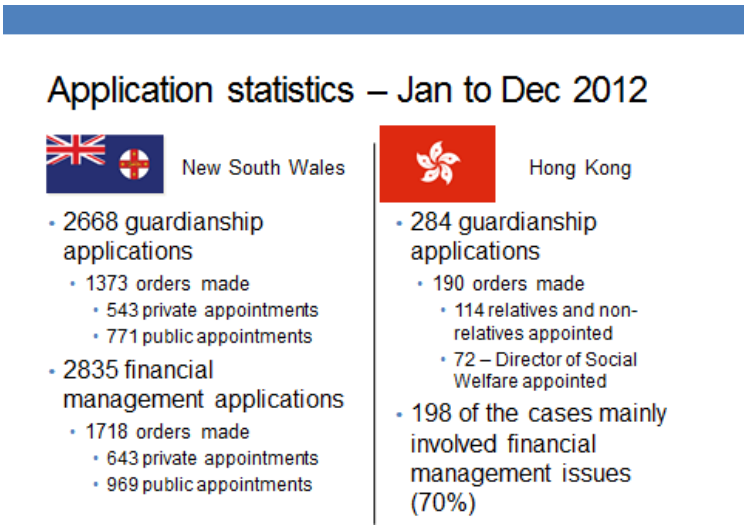
In 2014, the Chairman of the Hong Kong Guardianship Board Mr Charles Chu, and I gave a joint presentation to the 3rd World Congress on Adult Guardianship, providing a comparison of the work done by our two organisations. Hong Kong has a similar population to NSW, at 7.24 million in 2014, yet the Board in Hong Kong received approximately one-tenth, or fewer, of the applications received by the Tribunal in NSW for the appointment of substitute decisions makers, as illustrated by the graphics below.

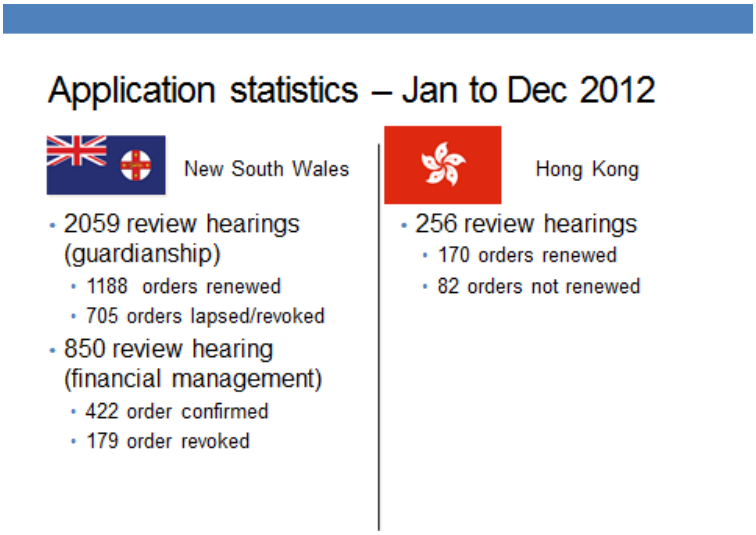
This stark difference might be attributable to a number of factors including the cultural differences between Australian society where there is a greater focus on individual autonomy and Hong Kong society where there is a greater dependence and interconnectedness with extended family, the geographic differences and the ethnic make-up of the two populations, in terms of access to local familial support.

[8] Martin Terrell, 'Court of protection must balance needs of vulnerable with rights of family', *The Guardian,* 8 November 2011, available at http://www.theguardian.com/law/2011/nov/07/court-of-protection-family-rights [access 9 September 2015]

[9] Martin Terrell, 'The court of protection: defender of the vulnerable or shadowy and unjust?' *The Guardian*, 7 November 2011, available at http://www.theguardian.com/law/2011/nov/06/court-protection-defender-vulnerable-unjust [access 9 September 2015]

[10] Mental Health Ordinance, Cap 136 and associated rules and regulations, available at http://www.legislation.gov.hk/eng/home.htm [accessed 9 September 2015]




**Access to justice in a protective jurisdiction**

Anyone with a genuine concern for the welfare of a person who is incapable of making his or her own decisions may apply to the Guardianship Division of the Tribunal. To facilitate access to its protective jurisdiction no fees are required for lodging an application in the Guardianship Division. The protective framework within which the Tribunal operates underpins the work of both the Tribunal's members and staff.

**Preparing applications for hearing**

The focus on the interests of the person with a disability is reflected in the work that the Division's staff undertake before an application or review of an order is heard by the Tribunal.

In every case before the Guardianship Division, the Tribunal officers of the Application Management Team 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 communicate 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.

Tribunal officers also contact the applicant and the parties to provide them with information about the Tribunal hearing and clarify what evidence is required.

**Hearings in the Guardianship Division of the Tribunal[11]**

The Tribunal will schedule hearings to allow sufficient time for appropriate exploration of the person's circumstances and his or her need for orders to be made. However, the Tribunal can convene an urgent hearing within hours of receipt of an application. These hearings are often conducted by telephone. The Tribunal operates an after-hours service where urgent applications are made and need to be heard outside normal business hours. The hearing rooms at the Tribunal's premises are less formal than a court room and are designed to assist the person with a disability to feel at ease, if such a thing is possible in the context of a hearing. Hearings may also be conducted by video conferencing and parties may participate by telephone.

The Guardianship Tribunal does not follow an adversarial approach in the conduct of its hearings and in its decision making. It uses more inquisitorial methods and the Tribunal may inform itself on any matter in such manner as it sees fit. The Tribunal is not bound by the rules of evidence however it must act in accordance with the rules of procedural fairness.

During a hearing the Tribunal focuses on the issues concerning the person with a disability and will try, where possible, to facilitate the person's participation and to seek his or her view.

The Tribunal is able to make arrangements for parties with particular needs. Where appropriate, the Tribunal arranges the attendance of accredited interpreters to assist parties participating in hearings. Interpreters were used on 524 occasions during the 2012/2013 financial year and provided services across 51 different languages including Arabic, Cantonese, Croatian, Greek, Italian, Macedonian, Mandarin, Serbian, Spanish, Vietnamese and Auslan.

Although the Tribunal premises and staff are located in Sydney CBD, the Tribunal conducts hearings in a number of metropolitan, regional and rural locations across New South Wales. This facilitates access to the Tribunal and participation in proceedings by people with disabilities for whom applications are made, their family, friends and professionals and service providers.

In 2012/2013 the Tribunal conducted approximately 26% of its hearings outside the Sydney CBD at locations including Albury, Armidale, Ballina, Blue Mountains, Bowral, Central Coast, Coffs Harbour, Dubbo, Goulburn, Lismore, Mittagong, Moruya, Newcastle, Nowra, Orange, Port Macquarie, Queanbeyan, Shoal Bay, Stockton, Tamworth, Taree, Tweed Heads, Wagga Wagga, Wollongong and other locations in the Sydney metropolitan area.

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

**Medical evidence relied upon in Guardianship matters**

One of the key aspects of the preparation of matters for hearing by Registry staff is the effort made to ensure at least two reports have been provided by medical or allied health professionals concerning the application before the Tribunal. As applications to the Tribunal can be made 'by any person who, in the opinion of the Tribunal, has a genuine concern for the welfare of the person'[12], it is possible that the applicant may not have access to relevant medical information that may assist the Tribunal. Accordingly these reports are sought from health professionals by the Tribunal as a matter of course in guardianship and financial management matters and provided by a range of health professionals without the provision of a fee. The Tribunal to this end relies heavily on the good will of health professionals in assisting the Tribunal to carry out its role in a protective jurisdiction to protect and promote the welfare and best interests of people with disabilities. Very often, general practitioners working in country towns or regional areas where there may be little access to specialist services will be called upon to provide their professional opinion as to whether a 'person's disability affect their capacity to make informed decisions' about their 'accommodation, care and services, health and medical care and their financial affairs and any other area'.

In June 2015 there were 7,496 specialist general practitioners in NSW, a further 11,109 medical practitioners with general registration, 1034 psychiatrists and 204 geriatric medicine specialists[13]. Most of these practitioners are concentrated in urban and metropolitan areas and it is not unheard of for smaller regional towns in NSW to have only one or two medical practitioners and in some instances, no medical practitioner.

I am very mindful of the challenges facing general practitioners, more so a solo practitioner working in a country town in so far as the volume of their work is concerned and the weight of the assessment that the Tribunal calls upon them to make. Has the practitioner had an adequate opportunity to assess the patient? Has the patient been a long-term patient or is this a visit brought upon by a concerned family member of the patient? Has the practitioner been able to obtain all the necessary information for a proper evaluation such as family history and the reported history of the illness or presentation? Does the practitioner feel in any way constrained by considerations associated with the treating relationship and concerns about continuity of care? To what extent is a general practitioner expected to be familiar with current best practice in capacity assessment, including different types of cognitive and capacity assessment tools as the diagnosis dictates, such as those used for Alzheimer's or brain injury assessment?

There are two issues in particular that I would like to discuss in relation to the role of a medical practitioner in assessing capacity for the purposes of evidence for the Tribunal's consideration in Guardianship proceedings. The first is that there are different definitions of and levels of capacity relative to the nature of the decision-making in question. The second is that a definitive diagnosis of the nature of a person's disability, although helpful and

[12] Guardianship Act 1987 (NSW), s9(1)(d) concerning guardianship orders, s25I(1)(b) concerning financial management orders

[13] Medical Board of Australia, Australian Health Practitioner Regulation Agency, "Medical practitioner registrant data: June 2015", August 2015, available at http://www.medicalboard.gov.au/News/Statistics.aspx [accessed 4 September 2015]

persuasive, may not be necessary where there is powerful evidence of the extent of a person's capacity in one or more areas.

This is an area where some level of Foucaudian discourse analysis would not go astray. The Medical discipline is driven by scientific proofs and assessments, the use of diagnostic tools to arrive at a diagnosis of the patient's ailment and the formulation of a treatment plan. The legal discipline also has its own legal tests and definitions, categorisations and hierarchy of relevant and credible evidence that assist in determining the legal outcome. In this field of endeavour we can add a third discipline, that of the disability rights and advocacy sector, which advocates for a focus on a person's abilities, rather than their disabilities, the focus on the person as a whole, rather than one discrete area of difference and the empowerment of the person so as to be able to make decisions for themselves, with informal support as the situation demands. Which discourse is to take precedence in determining the framework in which decisions about a person are made?

**Various legal definitions of capacity – an overview**

The definition and test (in a legal sense) for 'capacity' varies depending on the nature of the task for which one's capacity is being assessed. Legal practitioners are asked to ensure that their clients are competent to give instructions in legal matters. This becomes particularly relevant where a person goes to a solicitor to make or amend a will and to draw up substitute decision making documents, known in NSW as enduring guardianship and enduring powers of attorney instruments. The validity of these instruments can be challenged in the Tribunal, both on the basis that they were not validly made and also on the basis that they are not operating in the best interests of the principal, that is, the appointer. There is no specific case law which gives us a neat answer as to the validity of the making of such instruments. Instead, we rely on the general test at law for a person's capacity to make a legal instrument. The High Court in the case of *Gibbons v Wright*[14] stated

> [T]he mental capacity required by the law in respect of any instrument is relative to the particular transaction which is being effected by means of the instrument and may be described as the capacity to understand the nature of that transaction when it is explained.

Another way that this has been explained is,

> "Despite the many different legal tests for capacity, the fundamental issue is whether the client is able to:
>
> - understand the facts involved in the decision-making and the main choices;
> - weigh up the consequences of those choices and understand how the consequences affect them;
> - and communicate their decision."[15]

[14] Gibbons v Wright (1954) 91 CLR 423 at 438

[15] Jenna MacNab, "Capacity: A practical guide for lawyers" (2008),46 No.5 *LSJ* 68 at 71. Available at http://www.lawsociety.com.au/cs/groups/public/documents/internetcontent/023880.pdf [accessed 4 September 2015]

The recent Supreme Court of New South Wales case of *P v NSW Trustee and Guardian* [2015] NSWSC 579 (*'P'*) warrants some discussion. It is fair to say that over time, there have been different interpretations by the Supreme Court in the approach to be taken in assessing a person's capacity to manage their own financial affairs. In *P*, there was a reconsideration of how to interpret s25G of the *Guardianship Act 1987*, which states that the Tribunal may make a financial management order "only if the Tribunal has considered the person's capability to manage his or her own affairs and is satisfied that "the person is not capable of managing those affairs".[16]

Previously the Court tended towards an objective assessment of a person's ability to deal competently with "the ordinary routine affairs of man."[17], however, the extent of the financial management required was considered to be relevant to the determination of the issue. "Whilst one does not have to be a person who is capable of managing complex financial affairs, one has to go beyond just managing household bills." (*H v H*, unreported, NSW Supreme Court, Young J, 20 March 2000).

In *P*, a consideration of the subjective circumstances of the individual was considered to be preferable. However, Justice Lindsay still considered the question of capacity within the context of a protective jurisdiction and cautioned that a holistic approach should be taken with regard to the governing legislation, that is in light of the protective jurisdiction that has been set up by the legislation[18]. Justice Lindsay states that the purpose of the protective jurisdiction is "To protect a person incapable of managing his or her own affairs in a proper and provident manner, because he or she is liable to be robbed by anyone, giving rise to a necessity of taking care of him or her."[19]

The test for capacity in terms of Guardianship is set out in the *Guardianship Act 1987* (NSW) as follows:

> The Tribunal may make a guardianship order for a person who is in need of a guardian (s 14(1)). A person in need of a guardian is defined as "a person who, because of a disability, is totally or partially incapable of managing his or her person" (s 3).
>
> A reference to a person who has a disability is a reference to a person:
>
> (a) who is intellectually, physically, psychologically or sensorily disabled;
> (b) who is of advanced age;
> (c) who is a mentally ill person within the meaning of the *Mental Health Act 2007* (NSW); or
> (d) who is otherwise disabled;
>
> and who, by virtue of that fact, is restricted in one or more major life activities to such an extent that he or she requires supervision or social habilitation (s 3(2)).

[16] *Guardianship Act* 1987 (NSW), s25G(a)
[17] *PY v RJS & Ors* [1982] 2 NSWLR 700 per Powell J at 702
[18] *P v NSW Trustee and Guardian* [2015] NSWSC 579 at paras 304-314.
[19] *P v NSW Trustee and Guardian* [2015] NSWSC 579, Lindsay J [241].

It is not enough for the Tribunal to be satisfied that the person has a disability. The law also requires that, by virtue of that disability, the person is restricted in one or more major life activities to such an extent that he or she requires supervision or social habilitation.

We turn then to the question of special medical treatments, general medical and dental treatment and the question of informed consent and whether or not a person has the capability to communicate their consent or lack thereof. In NSW, a 'person responsible' can consent to major and minor medical treatment. Only the Tribunal can consent to special medical treatment which is treatment which may have the effect of rendering a person infertile. Section 33(2) of the *Guardianship Act 1987* provides that a person is incapable of giving consent to the carrying out of medical or dental consent if he or she is:

a) incapable of understanding the general nature and effect of the proposed treatment; or
b) incapable of indicating whether or not he or she consents, or does not consent, to the proposed treatment.

So what does all this mean for medical practitioners assessing capacity for legal purposes? Well, firstly, it highlights the complexity of the task, not only for lawyers but for medical practitioners who need to have an understanding of the legal tests together with relevant medical models of assessment. It is of great assistance to decision-making bodies such as the Tribunal to have available before it, evidence of assessments from medical practitioners that has been conducted in the light of the task that the Tribunal has to perform.

**How has the UN Convention on the Rights of Persons with Disabilities challenged traditional legal concepts of capacity?**

The UN Convention represents a paradigm shift in thinking about the ability of people with disabilities to make decisions for themselves.

Article 12 of the Convention which concerns equal recognition before the law states:

> 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
>
> 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
>
> 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
>
> 4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

> 5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

There is now a concerted push towards supported decision making, as opposed to substitute decision making. Indeed, the concluding observations on the initial report of Australia adopted by the UN Committee on the RPWD at its tenth session in September 2013 concerning article 12 are clear – Australia's system of substitute decision-making is seen to be at odds with the rights of persons with disabilities to self-determination. The Committee recommended that "Australia take immediate steps to replace substitute decision making with supported decision making and provide a wide range of measures which respect the person's autonomy, will and preferences and is in full conformity with article 12 of the Convention."[20]

However, there are divergent views as to the need for a system of substitute decision making and the Australian government has lodged an interpretative Declaration regarding Article 12, stating that it allows for substituted decision making arrangements, where they are necessary, as a last resort and subject to safeguards[21].

**The future?**

A number of law and policy reforms and initiatives have now taken place in Australia in the Disability sector. The most notable two amongst these are the establishment of the National Disability Insurance Scheme (NDIS) and the Australian Law Reform Commission's major enquiry into 'Equality, Capacity and Disability in Commonwealth Laws' (ALRC report)[22].

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, their families and carers. 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 provisions to one of individualised support. The NDIS aims to provide to eligible people a flexible, whole-of-life approach to the support needed to pursue their goals and aspirations and participate in daily life. Individuals will be able to formulate their own support plans, to determine what form of support and services they receive and from whom. The scheme is presently at the pilot and early roll-out stage, with a national roll-out date expected to be announced shortly.

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[20] UN Committee on the Rights of Persons with Disabilities Concluding Observations on the initial report of Australia, 4 October 2013.

[21] Attorney General's Department, 'Australia's initial report under the Convention on the rights of persons with disabilities' , 3 December 2010, available at http://www.ag.gov.au/RightsAndProtections/HumanRights/ReportCRPD/Pages/Equalrecognitionbeforethelaw article12.aspx [accessed 3 September 2015].

[22] 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]

Whilst in its early days, the NDIS has faced challenges with regard to the issue of substitute or supported decision making. This issue came before the Tribunal in early 2014 in the decision of *KCG*[23]. That decision provides as follows:

> The Tribunal's view is that where important lifestyle and financial decisions are required to be made on behalf of a person who lacks the requisite decision making capacity (and cannot be supported to make decisions for themselves), such as Miss KCG, it is appropriate that an independent substitute decision maker such as guardian or financial manager (depending on the nature of the decision) is appointed to undertake that responsibility. The NDIS nominee scheme is a substitute decision making scheme designed for people with disability like Miss KCG. As the Hon. Julia Gillard, then Prime Minister, stated in the second reading speech for the NDIS Bill on 29 November 2012:
>
> > ...a nominee can be appointed to make decisions on behalf of a participant, while ensuring that the rights of participants are maintained and that nominees must consider the participant's wishes.
>
> The Tribunal considers that any substitute decision making regime must include appropriate safeguards to ensure that the rights of the person with the disability are not infringed and that the arrangements are regularly reviewed to ensure that, firstly, the appointed decision maker is acting in the person's best interests and, secondly, to vary or revoke the arrangements where they are no longer needed. The Guardianship Act contains provisions to ensure that a guardian's authority is limited to the specific functions or areas of decision making where there is a current need for substitute decision making, orders are only in place for the shortest time possible and that they are subject to regular review by the Tribunal.
>
> Comparatively, it is arguable that, where the NDIA is making decisions on behalf of a participant and the participant has diminished or no capacity to express a view or be supported to participate in the process, in addition to having no private support network to advocate on their behalf or any person to initiate a review of a decision by the NDIA, then there may be a lack of appropriate safeguards in place. Accordingly, there may be limitations to Miss KCG's NDIS plan being managed by the NDIA without independent scrutiny. The irony in reaching this conclusion is that a state based appointment is required for a person in Miss KCG's circumstances to ensure that her interests in relation to a Commonwealth scheme are protected, as it seems there is no Commonwealth equivalent of a Public Guardian, a Public Advocate or other independent body who could be appointed as a nominee on her behalf.

In addition to the ALRC report, published in August 2014, the Victorian[24] and Queensland[25] state governments have also conducted their own enquiries. All conclude that there is a need for greater empowerment of the person with the disability in the decision-making process and a shift away from a 'best interests' model of substitute decision making towards

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[23] KCG [2014] NSWCATGD 7

[24] Victorian Law Reform Commission, *Guardianship*, Final Report 24, January 2012.

[25] Queensland Law Reform Commission, A review of Queensland's Guardianship Laws, 2010, available at http://www.qlrc.qld.gov.au/publications [Accessed 9 September 2015]

one that 'promotes and safeguards the adult's rights, interests and opportunities'[26] or acknowledges that 'people with impaired decision-making disability… have wishes and preferences that should inform decisions made in their lives'[27] and 'act in consultation with the person, giving effect to their wishes'[28].

The Victorian Law Reform Commission proposes the creation of a Co-decision making framework, in addition to the existing substitute decision-making framework, for which separate recommendations are made to enhance the rights of the person at the centre of the decision-making arrangements. A co-decision maker would be a formal appointment made by the Tribunal (the Victorian Civil and Administrative Tribunal or 'VCAT' in this case) with the same powers as a substitute-decision maker, except for the requirement that all decisions are made jointly with the person concerned and that the person concerned consents to the appointment of the co-decision maker[29]. The VLRC Report also calls for a more flexible approach to capacity assessment and 'the creation of a modern capacity standard and new capacity assessment principles that reflect a more realistic understanding of capacity', that is one which considers the fluctuating nature of capacity and the varying nature of cognitive impairment depending on the nature of the underlying disability which is the cause of the impaired capacity[30]. The VLRC report also considers the supported-decision making model and recommends the creation of the appointment of supporters by VCAT, who are nominated by the person who relies on their support[31]. The VLRC report also acknowledges the potential for exploitation inherent within a supported-decision making model and notes the importance of building safeguards into the framework[32].

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.

The ALRC report recommends a review of state and territory laws and legal frameworks including but not limited to laws with respect to guardianship and administration, consent to medical treatment, mental health and disability services.

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[26] 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].
[27] Victorian Law Reform Commission, *Guardianship*, Final Report 24, January 2012, at xxxv.
[28] Victorian Law Reform Commission, *Guardianship*, Final Report 24, January 2012, at lxviii.
[29] Victorian Law Reform Commission, *Guardianship*, Final Report 24, January 2012, Chapter 9.
[30] Victorian Law Reform Commission, *Guardianship*, Final Report 24, January 2012, at xxiii and Chapter 7 more generally.
[31] Victorian Law Reform Commission, *Guardianship*, Final Report 24, January 2012, Chapter 8.
[32] Victorian Law Reform Commission, *Guardianship*, Final Report 24, January 2012, at p136.

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 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.

The ALRC Report further provides

> The kinds of human rights encompassed by the Guideline include the various matters set out in the CRPD [UN Convention on the Rights of Persons with Disabilities], including:
>
> - respect for inherent dignity—preamble and art 3;
> - non-discrimination—art 5;
> - liberty and security—art 14;
> - freedom from torture or cruel, inhuman or degrading treatment or punishment—art 15;
> - physical and mental integrity—art 17;
> - liberty of movement—art 18;
> - independent living—art 19;
> - respect for privacy—art 22;
> - respect for home and family—art 23; and
> - participation in political and public life—art 29.

It remains to be seen whether these recommendations will be taken up by the Commonwealth 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 expresses concerns about the move towards a human rights based model of substitute decision making where a substitute decision maker is still required[33]. CID questions whether the particular linguistic and cultural background of the person will be appropriately reflected in the decision-making process and expresses concern 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

[33] 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]

understanding of human rights amongst the family of a person in need of a substitute decision maker.

Whilst it is possible that such concerns could be alleviated with appropriate training and support for family members, it is of note that this concern has been expressed by those from within the disability advocacy sector.

CID's views on this issue were also referenced in the ALRC report as follows:

> The NSW Council for Intellectual Disability (NSWCID) questioned whether human rights provide an adequate basis for decisions where a person's will and preferences cannot be ascertained. The NSWCID noted that there is limited understanding of human rights and there are many international instruments. Different rights may point to different outcomes 'so that quite complex balancing exercises are required to make a decision'.
>
> > The result of all this might be that only highly educated people were qualified to make representative decisions. We are concerned about the prospect of removing from eligibility as representatives down to earth practical family members who have a lifetime's knowledge of a person with disability.[78]
>
> 3.81 The NSWCID preferred the standard recommended by the VLRC—that representatives be required to exercise their powers 'in a manner that promotes the personal and social wellbeing of the person', with guidance from a list of relevant factors.[34]

**Case study on behavioural changes that are suggestive of cognitive decline**

I would like to offer a very brief case study to illustrate how the questions of the assessment of capacity and need may vary depending on the nature and assessment of the disability in question, and how the different models of substitute or supported decision-making might respond to the same fact scenario.

The Tribunal has previously heard a matter concerning a man aged in his nineties, Mr A, a retired professional who resides in a retirement village. Mr A has adult children with whom he has a good relationship. Mr A is facing criminal charges relating to the importation of narcotics, after allegedly becoming involved in a scam where he travelled overseas at the cost of third parties and brought back to Australia what he was told and reportedly thought were non-contraband items for gifts, but instead were illicit drugs. Mr A is believed to be vulnerable to financial exploitation by internet scams and has already lost significant funds in this way. The applicants noted that, while he is highly functional in many aspects of life, Mr A demonstrates no insight into these scams and has an irrational belief in their veracity.He has reportedly indicated his intention to continue to forward his funds, including income from his superannuation and pension, to unknown people.

[34] NSW Council for Intellectual Disability, *Submission 131* quoted in Chapter 3 of the ALRC Report, 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]

A financial management order was sought to safeguard his remaining funds and ensure provision for his daily needs. It was noted that Mr A is not paying his bills and may be at risk of losing his accommodation due to non-payment of fees and given his requests of other residents for money. The Tribunal had a functional capacity assessment report and a report of GP available, which provided limited medical evidence of assistance to the Tribunal. The Tribunal largely relied on the evidence of family and Mr A's own evidence as to Mr A's lack of insight and his vulnerability. Mr A's view was that the application and its claims were unfounded, that he is not incapable of managing his affairs and that his family simply do not like how he is managing his finances. With regard to the money he has sent overseas, Mr A submitted that this was for worthwhile matters with some funds going to a family in need, and that others relate to securing an inheritance, which he expects to be finalised very shortly. Mr A noted that the funds have all been sent to banks, not to individuals, and that he is not sending money overseas irresponsibly.

In the current legislative framework, the Tribunal would have no difficulty in making an order for financial management and for guardianship for Mr A given his extreme vulnerability. But what if a will, preferences and rights model were to apply to this scenario? How significant is consideration of the dignity of risk?

The ALRC report explains that the human rights approach reflected in the Will, Preferences and Rights Guidelines 'provides that a representative may override the will and preferences of a person only where necessary to prevent harm.'[35] The consideration would then become what is meant by harm and whether preventing harm by the person to themselves is a legitimate object in depriving a person of their autonomy.

Mr A presents very well and is able to articulate his views and his rationale for his decision-making, despite being in opposition to his children and their concerns. His GP opined that he "could not see any disability" when he last saw Mr A some months prior. Mr A was last assessed by an aged care assessment team prior to moving to his retirement home several years ago and there was no evidence of Alzheimer's or Dementia at that stage. He is presently refusing to be further assessed. Would the end result be that Mr A is free to involve himself in potential scams and therefore expose himself to possible criminal sanction and impoverishment? Would he be free to make 'bad' decisions for himself? What sort of functional capacity assessments would health professionals be able to provide in this regard?

**Reflections**

Through the lens of the operations of the Guardianship Division of NCAT, other Australian jurisdictions and the common law as it is in NSW, Australia, this paper has attempted to provide an overview of how questions of impaired decision-making capacity and decision-making arrangements are currently determined, how they have been answered in the past and how it is proposed that they may be answered in the future more generally. There is no

[35] Chapter 3 of the ALRC Report, 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]

doubt that the determination of a person's capacity is a complex task, both legally and medically and we look to you as the specialists at the pointy end of this medical area for guidance to general practitioners as to the tools at their disposal and to legal decision-makers as to the more nuanced assessments of where a person might sit on the spectrum of capacity.

Should the momentum that the disability sector is presently experiencing eventually lead to a change in the legal framework from one of 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 paper to be properly addressed. That is, there should be a mindfulness of the potentially changing capacity of a person to make decisions for themselves, the nature of the underlying disability and whether or not that is relevant to the questions being asked and how a person's capacity or need for support is assessed, the role of medical practitioners in providing the necessary medical evidence and other evidence that a decision-maker can and should consider in arriving at answers to these questions. It is likely that should this paradigm shift occur, the questions that are asked of you and your health professional colleagues will change and you may be asked for your assessment of a person's capacity to participate in supported or co-decision-making arrangements.

There will also 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. It may be that there should be some Ombudsman-like body responsible for receiving complaints or applications for review in such matters where there is a concern about harm or exploitation or perhaps we will see the development of a whole new body of law within the *parens patriae* jurisdiction of the Courts.