our voice Australia
Vision Opportunity Identity Choice Equality

The Secretariat
NSW Law Reform Commission
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1 April, 2016

Dear Committee members

We thank the Committee for this opportunity to make a submission to this review of the *Guardianship Act, 1987.*

Our Voice Australia is a parent-led organisation which advocates for people with moderate to profound intellectual disability and complex support needs and their families.

Our mission is to promote and advance the interests of people with moderate to profound intellectual disability and complex needs who often have communication disabilities (our target group). We want to see a way forward to ensure that they are protected and for their families to worry less, not more; and to ease the way a little over the road less travelled, which so many in this situation have traversed, a road full of pot-holes, sometimes small, other times chasmic.

And the chasm exists in relation to the rights of our target group, we call them – The Unremembered Australians, overlooked by the movers and shakers in the human rights circles because The Unremembered must rely on others to be their voice, to champion their rights and to make the running on their behalf. The Unremembered are not noticed because more often than not they literally cannot speak, cannot get in touch with the mainstream media, start a change.org petition or otherwise chant about the infringement of their basic human rights because they don't know they have human rights, they don't understand what they are or how to claim them.

Their plight appears lost on everyone except their parents and families and now we must mobilise because the National Disability Insurance Scheme (NDIS) is coming, and the lack of formal representation for our sons and daughters is endemic. Who will speak for our sons and daughters in this transfer across from state operated services? The current legislation only gives voice to a legal guardian and the NDIS legislation gives power to nominees which is also highly problematic in light of the different authorities decision-makers may have and in light of the appointment, suspension and cancellations powers of the Chief Executive Officer (CEO) of the National Disability Insurance Agency (NDIA) under sections 89, 90, 91and other provisions in the legislation.

Our issue for many years has been the issue of guardianship. There is no denying the fact that in Australia there are tens of thousands of people who are The Unremembered - deemed to be in need of guardianship and financial management who are without either. The majority of those people are living at home with ageing parents who love them, are devoted to them and who have always supported them all of their lives. Why are they The Unremembered? Because the law has simply forgotten them.

On page 4 of the NSW Ageing Disability and Home Care Policy document on Decision-making and Consent it says:

Policy and Principles
The Policy and Principles contained in Part 1 are mandatory for both ADHC operated and funded non-government services

1.1 Purpose
The policy is to inform service providers and care workers who need to obtain consent either directly from a client or from a legally appointed guardian.

Then on page 7 in relation to Decision-making and Consent it says:

If there is no legally appointed guardian, staff should contact the Guardianship Tribunal on 1800 463 928 or 9556 7600 for advice about applying for the appointment of a guardian.

If staff are concerned that decisions being made by the family or a guardian are not in the best interests of the client, they should refer the matter to the line manager who will assess the need for a review by the Guardianship Tribunal.

This applies in all situations where the person with disability who has decision-making incapacity is over the age of 16 years.

Furthermore a large number of applications for Guardianship are made by Service Providers and this will escalate over the coming years as providers are looking for control of the far more lucrative funding under NDIS, without families making decisions that may remove them from being the service provider. With the NDIS being implemented in the next year or so the matter of Guardianship must be resolved.

Under the Australian Constitution guardianship is a state issue and legislation must be passed by the States. However if the States decide that that power can be vested in the Commonwealth then the States can agree to surrender that power to the Commonwealth which is what they did with income tax back in 1942 and disability services which they did in 2012/2013 with the National Disability Insurance Scheme.

We urge the Committee to look at the statistics in relation to applications for Guardianship with respect to our target group to ascertain the number of applications made by service providers (including ADHC) compared to the number of applications made by any other type of applicant.

We also believe the Committee would find it valuable to compare the Australian experience to that of other countries which have a similar system of Guardianship. We refer you to a presentation by Deputy President Malcolm Schyvens to the 2nd International Conference of Pyscho-geriatricians in Berlin on 13 October, 2015 (copy attached).

With respect to people with moderate to profound intellectual and communication disability guardianship can be applied for either through the Guardianship Tribunal or through the Supreme Court.

As with any long-standing legislation its underlying purpose and intent is at times undermined because people just make stuff up. Our Voice Australia is concerned that misinformation is rife. We have direct and anecdotal evidence that parents and family members are told that where there is no dispute there is no need to apply for guardianship and that the title 'person responsible' is sufficient; while on the other hand, as shown above, we have policy documents that only give weight to a legal guardian as the only decision-maker that has any standing; other anecdotal evidence exists where a sibling has wanted to apply for guardianship only to be told that guardianship is not given to siblings. This kind of misinformation is disadvantageous and wrong. There is nothing in the Guardianship Act, 1987 that supports those assertions and it is wrong for staff and officers of the Tribunal to provide misleading/false information. Perhaps the intention is not to flood the Tribunal with applications. If that is the case then that is all the more reason to have a simpler system in place which can deal with simple applications on an ex-parte basis through a Registrar of the Supreme Court. (This point will be expanded below)

Members of the Committee of Our Voice Australia have borne witness to several very distressing guardianship matters which have coloured our view of the Guardianship Tribunal process and that is why we believe the process should be undertaken by the operation of a law passed to make application for guardianship and financial management simpler, easier and more timely and less emotionally and psychologically draining.

Members of Our Voice Australia are concerned that service providers seeking to impose their will, attempt to use the Guardianship Tribunal as either a threat to families terrified of losing their informal guardianship or as a rubber stamp to impose their will on the person without decision-making capacity.

We are concerned that disputes are confected in order to bring a matter before the Guardianship Tribunal. This has occurred in a number of matters in which Our Voice Australia members have acted as support persons/advocates.

We have seen a pattern of what we believe is unconscionable behavior in the bringing of applications for guardianship. The situation is this – a divorced 'person responsible'/informal guardian decides that a proposed course of action by a service provider is not in the best interest of their person with disability – the service provider then brings into the equation the ex-partner of the 'person responsible'/informal guardian and seeks to leverage any residual animosity to confect a dispute and thereby justify a recourse to the Guardianship Tribunal.

We have seen this ploy used on a number of occasions. We believe this is unconscionable conduct particularly when the 'person responsible'/informal guardian has provided the long-term care and support of the person with decision-making incapacity and in all likelihood had been awarded custody/residence of the then child with disabilities by a Family Court Order.

In other circumstances a divorced couple may have been granted 'shared' custody/residence, with one of the parents never taking up this shared parental responsibility, leaving it to one party to bring up their vulnerable child unsupported and oftentimes in impoverished circumstance. When that child with decision-making incapacity becomes an adult and is subsequently in receipt of accommodation services and needs no real financial or physical supports from the long-term primary carer/informal guardian/person responsible, the other parent family member can simply come in and claim their 'responsibility for decision making', frequently as a means to undermine the position of lifelong parent-carer. We also have direct knowledge of such circumstances where the service provider has precipitated a dispute by the introduction into the mix of an ex-partner who has not previously made decisions in relation to services and supports for the person with decision-making incapacity.

We request either a face-to-face meeting with the Committee to expand upon this point or a teleconference. We also recommend the Committee seek out and hear first hand of these instances where service providers (including ADHC) have behaved in a manner which creates disputes in order to wrest guardianship from loving devoted family members. And given that the Guardianship Tribunal not bound by the rules of evidence perhaps injustices are done and people with disabilities put at risk by service providers hell-bent on getting their way. The Guardianship Tribunal should not be feared and yet it is feared by parents who are afraid of the fact that decisions are made without the application of the rules of evidence; nor should the Guardianship Tribunal be used as a threat to compel compliance with the service providers dictates, nor should Guardianship Tribunal be a rubber stamp to sanction the will of service providers.

Our Voice Australian can provide to the Committee examples of this kind of behaviour and the people who were subjected to this are more than willing to speak to the Committee in relation to their experience.

We refer you to the evidence provided to the NSW Upper House Inquiry into *Services provided or funded by the Department of Ageing Disability and Home Care* in Submission No 14 by Ms Carolyn Mason which articulates fulsomely an example of such behaviour as set out above. (Link is here)

In order to give certainty to families we believe a simpler and better system must be designed and implemented. We believe legislation is required as an adjunct to the current law as it stands and we believe such legislation should be applied and administered by the Supreme Court for one very important reason - the rules of evidence apply in the Supreme Court; whereas, in the Guardianship Tribunal **the rules of evidence do not apply. Within a Guardianship Tribunal hearing, one party can denigrate and tell untruths that are not challenged. These untruths and/or distortions are often accepted as fact. It frequently comes down to how articulate the parties are, whether they have a service provider assisting their application, and whether it is a provider determined to wrest control. The tribunal panel members are have extraordinary powers in a situation when evidence and truth are not always the key components to arriving at a just decision.**

Our Voice Australia believes that where there is no dispute there should be the operation of a law that permits an ex-parte application by summons (this is an application which does not need to have the parties present) supported by affidavit evidence meeting criteria set out in legislation, along the lines of when applying for probate for example for such an application as we envisage: evidence from medical and allied health and disability professionals, lawyers and others who can attest to the situation and the need for guardianship financial management etc…; at the end of the process and provided the Court is satisified that all criteria are met, a Grant is ordered by the Registrar of the Equity Division using the court's *parens patriae* protective power, a power which is not available to the CEO of the NDIA which again makes the intersection of the various state guardianship laws and the NDIS legislation, problematic.

In our view that a situation persists in 21st century Australia where tens of thousands of Australian citizens are simply left without the guardianship, financial management and decision-making and legal agency we believe is a matter of discrimination against our sons and daughters with moderate to profound intellectual and communication disability, based solely on their severe disability and incapacity.

Those of us who do not have a disability are whole persons with physical and intellectual capacity, we have legal agency by virtue of our capacities and we have it every day of our lives, it is not intermittent nor is it bestowed or withdrawn by fiat, nor is it episodic.

Until a child of our target group turns 18 that child is a whole person, because the deficits in the child's intellectual capacity are covered by the parents, this is the case for all children under the law.

However, when the child with disabilities turns 18 we maintain that in the transition from child to adult our target group suffers a civil death. The child-now-adult cannot make decisions about the how, when, where, by whom and whys of their life, they need assistance with every aspect of their life, parents/families continue to provide that assistance in every regard but parents/families/significant others currently have absolutely no legal standing. Furthermore, in the eyes of the law the child-now-adult is civilly dead until someone does something to become the legal guardian and/or financial manager, nominee and so forth. Only by pro-active action on the part of someone else can their civil life and civil rights be restored/claimed.

Civil death is the loss of all or almost all civil rights by a person due to the conviction for a felony or due to the action or the inaction by the government of a country that results in the loss of civil rights. So in effect far from our target group being equal before the law, their disability renders them non-persons in the law because no means exists in law for their civil rights to survive the attainment of majority.

To explain what we mean a little clearer we will use the following analogy: Say a young person is born with a physical disability but otherwise intellectually competent, let's call her Sarah. Sarah is provided with the physical aid which best enables her to have mobility and to be included in all activities to the greatest extent possible. She grows up into a wonderful young person intelligent, well-educated, confident, eminently employable, then she turns 18 and .... well for Sarah life just goes on.

However, what do you think would happen if, upon Sarah attaining her majority, the law says Sarah is not longer permitted to have that physical aid which makes her a whole person to the greatest extent possible? She is to never have that physical assistance unless she goes to a special court hearing to allow that aid to be restored/provided?

There'd be a societal Krakatoa --- society would not stand for it. Yet, basically that is what happens to our sons and daughters who have severe to profound intellectual and communication disability.

For all intents and purposes the powers-that-be have condoned this state of affairs, and have done so certainly for the last 30 years by all accounts. Well we believe that is an unacceptable abrogation of responsibility to our citizens with decision-making incapacity. In fact on behalf of our target group we are incensed by it.

Essentially our target group are victims of chronology. While chronologically they may be 18, 21, 25, 45 years old, developmentally and intellectually they may not have attained the capacity for decision-making or financial management because of their disability. Where is the reasonable adjustments and accommodations at law for them which the UN Convention on the Rights of Persons with Disabilities calls for, and to which Australia is a signatory?

Yet the law and society justifies its inaction on this point by equivocating, lest the United Nations Convention on the Rights of Persons with Disabilities be infringed; inaction is justified by claiming the human rights of our target group are infringed by making decisions for them; when, in reality it infringes their human rights for society NOT to intervene to provide those decision-makers and financial managers who will make them complete in the eyes of the law and in the eyes of society; where they themselves are represented and their rights affirmed, validated and championed through the agency of their guardians; usually their parents, family members and/or significant others.

We need a new law which will provide for the guardian and financial manager to be appointed by a legal process which is simple, timely, seamless and can be prepared for while the young person is still under the age of 16 so that it comes into effect at the age of 16. It can be a simple law that extends the current approach in NSW regarding 'person responsible'. The person who last provided, or currently provides meaningful accommodation support, prior to residing in a funded care situation, becomes the Guardian by application. Only if there is evidence that this person is unfit for the role or unwilling to transfer their informal role into a legal one, should it go to a Tribunal hearing.

No longer can our target group be expected to live by the legal fiction ***everyone is deemed to have capacity***, because for them it is just that, a fiction; their lives should not be based by a fiction, they need and deserve to be a whole person; not a civilly dead non-person.

Our Voice Australia knows what we need, we need a new law, we also know that will need a miracle, so that's as good a starting point as any. Expect a miracle and let's get started.

We thank the Committee for the opportunity to make a submission and hope we can assist the Committee further in the future

Yours faithfully

Buckwalter

Maree Buckwalter
Secretary
Our Voice Australia

2nd International Conference on Capacity
International Congress of Psycho-geriatricians
Berlin, Germany, 13 October 2015

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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[1] Mr Schyvens is Deputy President of the New South Wales Civil and Administrative Tribunal (NCAT) and Division Head of the Guardianship Division of NCAT. He is based in Sydney, NSW, Australia. Mr Schyvens was the President of the former Guardianship Tribunal of NSW for its last 8 years, prior to its incorporation into NCAT. Ms D'Souza is an Australian-qualified solicitor who is the legal officer for the Guardianship Division of NCAT.

[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]

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[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:

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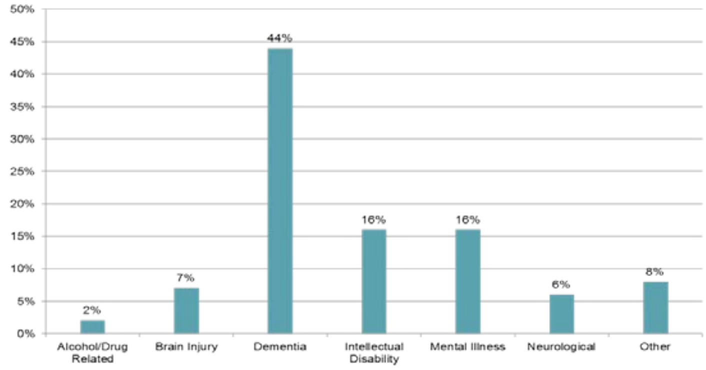
[5] Australian Bureau of Statistics, available at: http://www.abs.gov.au/websitedbs/D3310114.nsf/home/home?opendocument [accessed 3 September 2015]

[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.

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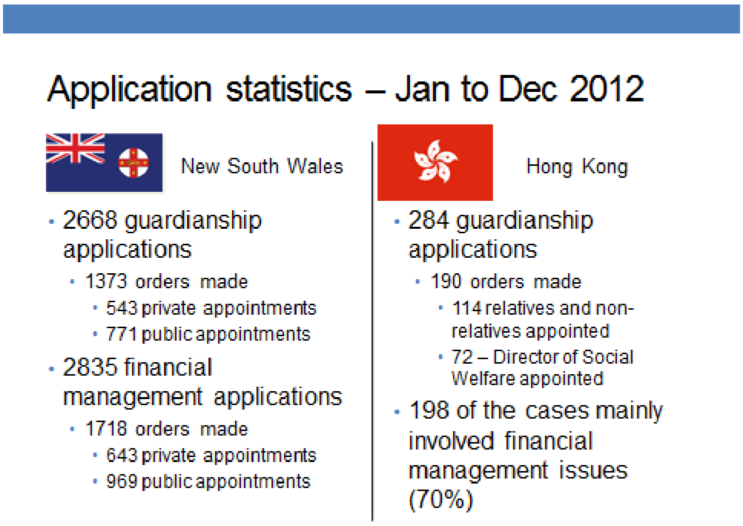
[8] Martin Terrell, 'Court of protection must balance needs of vulnerable with rights of family', *The Guardian,* 8 November 2011, available at http://www.theguardian.com/law/2011/nov/07/court-of-protection-family-rights [access 9 September 2015]

[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]



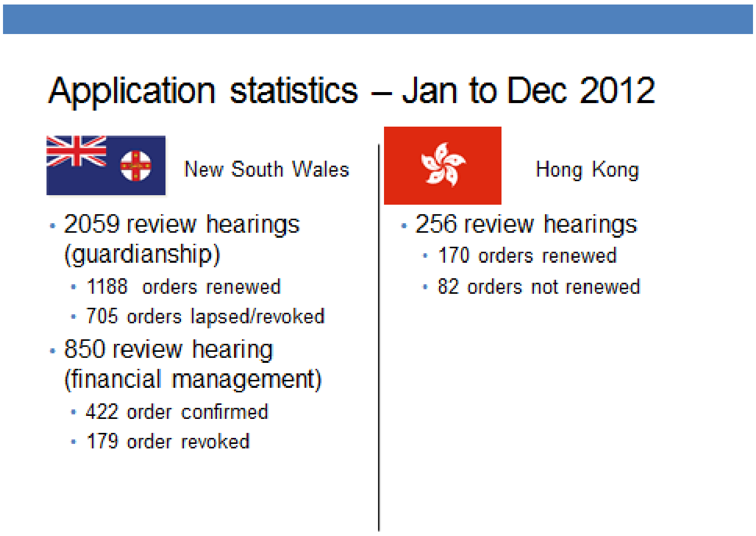
Application statistics – Jan to Dec 2012

New South Wales

- 2668 guardianship applications
  - 1373 orders made
    - 543 private appointments
    - 771 public appointments
- 2835 financial management applications
  - 1718 orders made
    - 643 private appointments
    - 969 public appointments

Hong Kong

- 284 guardianship applications
  - 190 orders made
    - 114 relatives and non-relatives appointed
    - 72 – Director of Social Welfare appointed
- 198 of the cases mainly involved financial management issues (70%)



Application statistics – Jan to Dec 2012

New South Wales

- 2059 review hearings (guardianship)
  - 1188 orders renewed
  - 705 orders lapsed/revoked
- 850 review hearing (financial management)
  - 422 order confirmed
  - 179 order revoked

Hong Kong

- 256 review hearings
  - 170 orders renewed
  - 82 orders not renewed

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.

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[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

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[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]

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[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)).

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[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/Equalrecognitionbeforethelawarticle12.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

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[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.

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[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

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[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.

Submission
No 14

INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

Name: Ms Carolyn Mason

Date received: 30/07/2010

Parliamentary StandindingCommittee on Social Issues .

Submission prepared by
Ms Carolyn Mason

Date: 27 July 2010

The Hon Ian West
Committee Chair
Standing Committee on Social Issues
Parliament House
Macquarie Street
Sydney NSW 2000

Dear Mr West

1 refer your letter dated 6 July 2010 in which you invited me to forward a written submission in regards to the inquiry into the quality, effectiveness and delivery of services provided or funded by the Department of Ageing, Disability and Home Care, (DADHC) which it currently being conducted by the NSW Legislative Council's Standing Committee on Social Issues. I thank you for the opportunity in this regard to submit the following details concerning the personal circumstances surrounding my daughter Amy Mason who has an intellectual Disability.

Background

My name is Carolyn Mason. I am a divorced mother of two children. My children are Amy 20yrs of age and Riley aged 16yrs. Amy has a moderate intellectual disability, autism and a severe anxiety disorder. Amy was first diagnosed with a Global Developmental Delay when she was two years of age.

My daughter Amy is' currently residing back home with myself and her younger brother. I am Amy's primary carer on a full time basis.

Submission

This submission will provide clear evidence of breaches of the policies and procedures. and guidelines with respect to 'restrictive and prohibited practices, physical and emotional neglect, confinement, systemic abuse and lack of an adequate duty of care . for Amy whilst she was in the care of both (supported accommodation) and their auspice authority ADHC (Ageing, Disability and Home Care) from 2007 till 2009 inclusive. It also mentions the 'unauthorised release of confidential information' about Amy by a senior member of ADHC management.

This report also includes the Role of (PWD) People with Disability Australia Incorporated and their role in providing a lack of advocacy services to my. daughter and family. Their actions include breaches of the Draft National Disability Advocacy Standards and unprofessional and inadequate service provision, including total disregard for the service authorisation and constants agreed upon when first commencing with their Advocacy services.

KEY ISSUES: (INCLUDING A CHRONOLOGY OF EVENTS)

This report will include matters of significant instances of breaches of not only human rights issues, but breaches of relevant legislation, polices and procedures together with breaches of NSW Disability Service standards. which include the following, amongst other things:

a) Constraint/Seclusion and unauthorised use of Restrictive Practices/Prohibited Practices-assault

b) Systemic Abuse

c) Wilful Deprivation

d) Physical Neglect

e) Psychological/Emotional Abuse and Neglect

f) Abuse of Human Rights

g) Failure of duty of care

h) Defamation

Additional failures to meet NSW Disability Service Standards such as the following:

(1) Meeting the individual needs,

(ii) Decision making and choice,

(iii) Service management,

(iv) Family relationships,

(v) Complaints and disputes,

(vi) Protection of freedom from abuse,

(vii) The rights to privacy, dignity and confidentiality,

See in attached folder Independent Report compiled by Disability Programmes Manager at outlines some of her major concerns surrounding my daughters care and the poor management and unprofessional, inappropriate behaviours of both ADHC and staff and management. Annexure 1

LIST OF ISSUES during the period of 2007 to 2009 surrounding the care of Amy Mason whilst living in supported accommodation run and managed by and funded by the Department of Ageing Disability and Home Care (DADHC).

(i) A complete failure of to adequately manage the care needs of Amy, including but not limited to lack of staff training and competence. Incidents reports show a lack of understanding and training of staff in how to work with Amy. See Ombudsman's report 29.6.09 See Annexure 3.

(ii) Staff were not trained in line with and did not consistently follow her Behaviour Support Plan (BIS) that was consented to by the person responsible dated Nov 2007. It did not include restrictive practices and involved both reactive strategies and positive programs. Staff Training records were examined and found to be blank and contained no information. did not follow their policies and procedures. Ombudsman report 29/6/09 Annexure 3

(iii) did not follow their policies in reviewing Amy's Behavioural Support Plan on a three monthly basis. Ombudsman report 29/6/09

(iv) *Use of psychotropic medication including (Valium six times daily) on PRN without consent of the person responsible or authorisation from the restricted practices panel as (behaviour support policy requirement) in 2007 and 2009. See copy of prescriptions and note of concern (statement) of the pharmacist, who queries the large quantities of medication being sought by to be administered to Amy. Amy's life could have been put at risk by untrained persons acting negligently in administering Amy potentially lethal dosages of medication. See copies of scripts and notes of pharmacist. Also copy of document presented to me, note the incorrect medication and dosage written by staff not signed by a doctor (these actions contrary to all policies and procedures.)* See Annexure 4.

(v) failure to obtain written consent from the person responsible when using prescription medications (See Ombudsmen report 28/1 0/09) See Annexure 4.

(vi) Policies clearly state, PRN and psychotropic medication when used must form part of a documented support plan. They were not a documented part of Amy's Behavioural Support Plan (BIS plan) (breach of behaviour support policy and procedures DADHC). See Annexure 5.

(vii) Restrictive practices - including containment/seclusion, response cost and restricted assess of Amy into the community including Amy not being allowed to use a telephone to contact her parents, were implemented by staff using a new Behavioural Support Plan (BIS) plan dated March/April 2009. (See Annexure 6A and Annexure 15 (updated BIS plan page 51 restrictive practice) see Annexure 29 email 13/3/09 control standards to eliminate, reduce or contain i.e.: large males to work alone with Amy etc.

(viii) Furthermore, in the Ombudsman's report dated 29/6/09 it is stated that staff became confused and started to implement the new (BIS) plan containing restrictive practices which· did not have signed consent from me, the person 'responsible. I had never be shown the or even allowed any input or consultation into its development. No person involved with its development ever met with or consulted with my daughter in anyway wit~ its development. They had no consent or authorisation from the Restricted Practices Panel (RPP).

(ix) Only after obtaining both my daughters ADHC files and files under the Freedom of Information (FOI) Act was it then revealed to me that there where two different behaviour support plans in existence. Both contained restricted practices to use on Amy, but the BIS plan contained in her ADHC file, which was the one presented to the NSW OMBUDSMAN WAS ONLY 28 PAGES IN CONTENT and contained considerably less restricted practices than the behavioural support plan found in my daughters files which is 68 PAGES AND LISTS CONSIDERABLY MORE RESTRICTIVE PRACTICES.

(x) Neither plan had ever been shown to me nor did they contain consent or input from me (THE PERSON RESPONSIBLE) nor any consultation with other professionals involved with Amy. They had no consent from the Restrictive Practices Panel and complete disregard for proper implementation of policy and procedures: See Ombudsman report 29/6/09 pages 2, 3. See BIS Plans at Annexure 14 page 18 and 19 page.

(xi) After obtaining my daughters ADHC files it was then revealed to me in an email stating have their own ((RPP) restricted practice panel where this plan was to be presented. I find this extremely alarming that a service provider be is given this type of power of the very people they are funded to care for without any consultation with parents ·or guardians. Annexure 45

(xii) See Ombudsman report dated 26/6/09 the lack of understanding of how to work with Amy. staff started using restrictive practices on Amy both before and after she was housed at 28/3/09 to 11/4/09. The facts where distorted when reported by Regional Manager) in his reply to the Ombudsman.

(xiii) did not follow their own Behaviour Intervention and support polices. See Annexure 6B (Behaviour Intervention and Service policy and Procedure Manual version 3.0 page 2, POINT 4,5,6,7.

(xiv) See Annexure 41: Email 30/3/09 from house manager to PWD (People with Disability) advocate, stating 'I would not agree to sign consent for medication or restrictive practices'. How could I sign a document if I had never seen or had any knowledge of or input into it's development? Neither Amy nor I had ever met or been introduced to the persons responsible for its development.

(xv) It is alleged also that Amy on occasions had been left alone, exposed and unsupervised in the company of one male employee of and that this male employee inappropriately touched, i.e.: 'indecently assaulted' her, whilst she was alone in his care. These departmental actions in themselves amount to a breach of policy/procedure/ in not providing a safe and secure living environment for her gender. This resulted in the alleged indecent assault being committed upon her, by this employee of . (Amy has reported this to , Amy's treating psychiatrist.) "Report to be obtained from Doctor but is contained in her clinical notes.

(xvi) house manager, engaged in unprofessional and inappropriate behaviours and subsequent abuse, both emotionally and sexual abuse) of residents, and engaged in inappropriate behaviour including bullying, intimidation and harassment of staff and alleged misappropriation of funds. House Manager also made false statements to investigators regarding her abuse. (Management from the resident's day programme and employed staff from the group home made up to four (4) reports of their concerns about Amy's treatment to Regional Manager who again failed to take any action. Unfortunately for Amy the staff member that came forward to expose her was not employed in the house whilst Amy was residing there. (Confirmation from the parent of victim) This staff member had to take stress leave because of House Managers abuse and has now left the organisation.

(xvi) House Manager was given total control by to employ whoever she wished at the house, i.e.: her mother i.e.: Favouritism, conflict of interest etc., and mostly very young in experienced staff effectively aiding and assisting her control and manipulation of the system and staff.

(xvii) It was reported to both and DADHC that at meetings conducted at the Group Home, which were attended by management and staff of that the House Manager would openly boast about the fact 'she knew what to tell DADHC as to get what she wanted'. In fact she also told both I and the father of another resident, the same thing and that this was how she would help us get the right funding and services from DADHC and for our daughters.

(xviii) The House Manager had her services terminated by in December 2009, eight (8) months after I removed Amy from her care. This was only after a report of further "abuse of another resident was made to the Ombudsman by , a day programme service provider of both Amy and another resident. and DADHC were then finally forced to act. were allowed to undertake their own internal investigation.

(xix) Reports were made about (The House Manager also mown as The Team Leader) and staffs inexperience, inappropriate and unprofessional behaviours etc, and mismanagement of Amy were made back in March, April and June 2009 from management. Staff at the programme had also made reports of their concerns for Amy's mistreatment to their manager, . These reports were passed on the management and also many DADHC staff. ADHC DID FOLLOW ITS OWN PRINCIPLES AND GUIDELINES FOR FEEDBACK AND COMPLAINT HANDLING. Two examples I quote from the above guidelines:

1. *You can make a complaint to any DADHC staff member, such as your case manager, the person delivering your service or" regional or central office service manager. You are encouraged to discuss your complaint with the DADHC staff you know or you may prefer to speak with that person's supervisor or manager.*

2. *General complaints may be received in and any format - written and verbal, via correspondence, email, over the phone or in person, the manner by which the complaint is received should in no· way influence the priority afforded to, or quality of, the response provided.*

(xx) See email 30/3/09 from college regarding serious concerns and complaints sent to my daughter's ADHC CASEWORKER which was THEN COPIED AND emailed TO NO LESS THAN THREE OTHER ADHC SENIOR MANAGEMENT STAFF AND AGAIN NOT ACTED UPON. Also see copies of reports at Annexure 7.

(xxi) DADHC staff and managements complete failure to investigate reports, nor act upon these reports regarding the above abuse and concerns for our daughter's welfare (failure of Duty of Care.)

(xxii) To this day these reports of abuse, neglect and inappropriate behaviours inflicted upon our daughter have never been acted upon or responded too.

(xxiii) The lack of investigative action by both DADHC and also resulted in ongoing abuse of other residents that where left residing at the group home after I removed by daughter, including sexual abuse of another resident.

(xxiv) DADHC took the arbitrary action of taking our family to the Guardianship Tribunal to have our daughter placed under public guardianship, mostly on the hearsay, unsubstantiated evidence, untruths and false documentation of -incidents provided by Manager. *A NOW PROVEN LIAR AND ABUSER.* The house manager wanted me out the picture); because I became aware of her abuse and lies and DADHC and viewed me as a hindrance and an interfering person. I have evidence (Email) to confirm that DADHC did not want Amy to return to care until I was out of the picture and a Public Guardian was appointed, effectively giving the house manager the mandate to continue her abuse without question and a rubber stamp of approval for and ADHC to continue appalling treatment and mismanagement for our daughter. Annexure 9

(xxv) sent a report to the Guardianship Tribunal to support DADHC application. I was not given a copy of the document from the tribunal and it was not contained in my daughters documents obtained by FOI from

(xxvi) PWD Senior Advocate was listed as a person who would support DADHC application and Financial Management Order. The Advocate never revealed this to either my daughter or her parents.

(xxvii) PWD advocate, ie: had the knowledge of the development of the new BIS plan and of the restricted practices it contained and of the guardianship application by DADHC but deliberately and intentionally chose not to inform Amy's family or arrange any meeting or discussions with Amy or either of her parents. WHY??

(xxviii) The PWD advocate had attended a meeting at DAHC offices on the day the application was applied for, i.e.: 25th MARCH 2009 but we had no contact from her until an e-mail some months later discussing our concerns and as to what future planning for our daughter was in place. She replied on the 28th of May 2009, two months later with still no mention of the guardianship hearing or as to what advocacy assistance we would provide to our daughter. Annexure 49.

(xxix) There was never any consultation or discussion from the Advocate with either Amy or her family as to Amy's views, wishes or concerns about the pending Guardianship hearing. On the 26th March the day after the DADHC application was lodged she requested the manager of my daughter's day programme service not to inform me of the guardianship application. We did not hear from her regarding the guardianship tribunal hearing until two days prior to the hearing, to then inform us of her intention to attend.

(xxx) Re: false incidents report 22/3/09. I have evidence in the form of written confirmation from a staff witness contradicting the false and serious allegations made in this report by the House Manager against me. She then passed the report to her Regional Manager, which he then passed on to DADHC senior management. See e-mail from house staff member and associated documents at Annexure 8 Another example of false information given by House Manager, read page 5 DADHC guardianship application referring to week 29th Nov 2008 this allegation has been now checked with daily notes from Amy's file obtained under FOI, its paints a different picture to what she reported in the DADHC guardianship application. Annexure 8

(xxxi) The house Manager made recommendations and further actions based on her false incident and I quote, "I believe guardianship should be investigated with the intention of providing Amy with a" healthier less threatening role model'

See emails and false incidents reports prior to 25/3/09. (DADHC application). See **Annexure 8.**

(xxxii) The house manager also requested that a parent of another resident give her guardianship of his daughter. A resident whom she also went on to abuse.

(xxiii) DADHC caseworker acting upon and in turn spreading hearsay and false and unsubstantiated information about me, from (House Manager)

(xxiv) , Senior management DADHC defamed me to a senior investigator at the Guardianship Tribunal using totally false verbal allegations of house Manager to an effort to discredit my fitness as a responsible person. I will quote him "she's made death threats to staff" See email 11/5/09 at Annexure 9.

(xxv) Both DADHC and received copies of my report to the. Guardianship Tribunal and also a report from the Manager of my daughters day programme, . These reports were sent to the Guardianship Tribunal about genuine fears and concerns about the inappropriate and unprofessional behaviours of the house Manger and house staff and other concerns of the poor Management of Amy by and DADHC. To this day those expressed concerns have never been responded to, or acted upon, by either DADHC or . See Correspondence including response from Carolyn Mason **at ' Annexure 10.**

(xxvi) DADHC senior managements only response were not about the fears and concerns for our daughters welfare which where outlined in the report from the , but only to complain about the Disability Manager exposing Amy's caseworker from DADHC ( ) comments about me, I quote *"she is never happy"* and that I as Amy's mother, *'was sabotaging things for Amy"* and that the application for Public Guardianship by DADHC was over issues associated with my mental capacity. See report to guardianship tribunal from . NB: Amy's father Reg Mason, and I where witnesses to this conversation because we were sitting in the office with when the call was made and we could overhear the conversation. See **Annexure 1.**

(xxvii) DADHC and did not put in place appropriate plans or positive measures which would have succeeded in helping Amy. Rather what was put in place was designed to fail for many reasons. Some of which have in fact been outlined and reported by the Ombudsman's reports with findings.

xxviiii) DADHC'S failure to maintain existing care/staffing levels when resident numbers at the house increased. See Ombudsman report, OCV report concerns and meeting minutes ~ADHC 5/2/09 at **Annexure 11.**

(xxvii) Failure to put into place a transition plan for Amy when she left school and was entering tertiary programmes. ' reports dated 25/9/08 and 9/10/08 and 20/11/08. See Annexure 12.

(xxviii) Failure of DADHC to meet Amy's support needs re: advocacy files *25/2/09,* DADHC. 'Psychologists and others admitted that they were supplying insufficient funding to support Amy's needs. Doctor's reports dated 25/9/08, 9/10/08, and 20/11/08 reflect this in addition to e~mail. See Annexure 13.

(xxx) Systemic failures by DADHC in recognising the requirements of People needing accommodation with care which led to budget based care decisions by that should not have happened and the persons needs put foremost in all planning.

(xxxi) If DADHC managed the vacancies for this house no client suitability matching was undertaken by them or to ensure that people with complex care needs were not placed in the same location.

(xxxii) Evidence that DADHC Deputy Regional Director in an unauthorised manner and for no lawful purpose released, confidential personal and private information about Amy and our family 'ANOTHER PARTY' (breach of privacy, confidentiality).

CHRONOLOGY 2007 - 2009

- Between May and July 2007 Amy was 'shunted' between different respite homes at . Including wanting to use a motel room as accommodation. (Amy has always been in a share care arrangement since inception i.e. every weekend she was with either her mother or father or both, including some weeknights for dinners). Amy's mother has always washed and ironed her clothes, due to the fact that staff never once ironed her clothes, which were often found dirty and unwashed and Amy's good clothing 'constantly going missing'.

- July 917/2007 moved into empty run down house managed by in (insufficient transition period, ie: 3 days)
- spent four weeks in this house on a shared care arrangement whilst always coming home on weekends,
- 4th August 2007 Amy returned to mothers house after issues with unauthorised use of PRN and other medications by staff (restricted practice) ,
- See attached evidence from pharmacist and recommendations from , to enable to 'get their act together' see Annexure 4.
- Inexperience of staff, Amy scalded by faulty hot water, no screens or locks on windows, only 3 month lease on premises. Moving very stressful for Amy who suffers from Extreme Anxiety Disorder. raises questions

about Amy being better placed, lack of suitable training by staff and other issues regarding . See Annexure 16.

- See copy attached planning minutes dated 23 August 2007. After failed attempts to care of Amy. Note DADHC failed to attend this important meeting attended by doctors, teachers etc, cancelled at the last minute. See Annexure 16.
- 14TH Aug 2007. Letter from DADHC to Carolyn Mason quote, *"I really appreciated the time you took to talk to me on' the phone yesterday. I am always impressed by your level of commitment to Amy and the way you are able to keep going even when is obviously quite exhausting for you. It's clear that your concern for Amy is always a priority for you'* etc. signed and (DADHC). See Annexure 17.
- 21st August 2007 I made a formal request for Advocacy assistance for Amy and family with (PWD) People with Disability Australia and placed on waiting list for service.
- Aug/Dec 2007 Amy stayed back home with her mother for five months while a slow gradual transition could take place. As per planning meeting, recommendations of and Amy's teachers.
- Whilst Amy was at home with her mother, DADHC moved another resident into the house overnight without any transition or compatibility assessment and without any consultation or involvement with Amy or her parents, as recommended by and Amy's teachers. See planning minuted dated 23 August 2007. See Annexure 16.
- 6th November 2007 PWD Advocacy authorisation signed.
- December 2007 17/12/2007 Amy returned to the for five nights because the short term lease on the house .had expired. Amy returned home again for Xmas and New Year. Amy was effectively transitioned into a house that no longer existed.
- parents spent a couple of months canvassing for a new house for Amy and the other resident and eventually found .

2008

- Early January 2008, moved into house no transition and within two weeks DADHC moved another resident into house with very high support needs without any transition or compatibility test, and again after, no consultation with Amy or family or other residents. (See attached file document dated 14/1/2008 from PWD advocate with concerns of no transition for girls or trained staff to cope with new residents high support needs, i.e.: wheelchair, personal care). DADHC were rushing to accommodate the new resident without any concern for the adverse impact this would have on Amy and other residents. See Annexure 18a
- 28TH February 2008 DADHC Case meeting. See Annexure 18b Problems included compatibility, lack structure and consistency around staff roster. Amy needing routine and not coping with lots of changes. Menu planning. Parents will attend next team meetings inform staff about Amy's needs/behaviour and background, *This meeting was ever allowed to take place.* Read advocacy note 7/4/08 Annexure 19. This meeting still not arranged as previously agreed to.

- March 2008 issues including, Amy being fed inadequate meals such as toast for evening meal, her clothes going missing and never being ironed, dirty washing not being done. At no stage have ever ironed one item of Amy's clothes at any time.
- On one occasion after Amy had just had braces placed on her teeth, along with other orthodontic work. The staff at would not give her a Panadol and in doing so, let her suffer from the pain for two days. See advocacy file notes. See Annexure 19.
- Through neglect in Amy not being properly cared for and inadequately nourished, she lost a lot of weight. See attached e-mail and report from (21/08/08) expressing his concerns. A report of this incident also placed on the PWD advocacy file. See Annexure 20.
- I made a Request to PWD advocate to place group home on waiting list for Official Community Visitor (OCV) to Visit house
- 16th May 2008 See *report (16/5/08) of his concerns about Amy being tense and anxious because of dynamic problems within the group - home, given respective personalities of co-residents. See* Annexure21.
- House Manager given total control by to employ any staff she chooses, such as employing her mother and friends. Employing staff who were too young, inexperienced, untrained and unprofessional to 'work with someone like Amy who has complex needs.) poor management and lack of proper and safe recruitment practices to meet with disability service standards.

SEPTEMBER/DECEMBER 2008

- September 2008 Conflicting views and reports from DADHC and regarding Amy's support needs and her grouping assessment report. Amy was not receiving 1: 1 support to be maintained at all times as reported in Ombudsman by dated 10/10/08. See Annexure 22.
- 7th October 2008 (OCV) The official community visitors attends house
- Lodges a report to Regional Manager about her concerns. She did not meet with house residents or with concerned parents, only speaks to House Manager.

- 10th October 2008 First Complaint made by me to NSW Ombudsman. see report and findings dated 20/1/2009. See Annexure 22.

- Oct 2008 Parents raised issues with DADHC when denied reduction to staff hours and staffs to client ratio, staff hours were reduced and their staff resignations because of this issue.

- staff wrote a letter of complaint about the above issues to

- Refer emails of complaints and concerns from other parents about the above issues. see Annexure 23 and reports from , Official Community Visitors (OCV) report. See Annexure 11@ 12.
- 19th NOV meeting at DADHC senior manager access stating to me, **Amy does not require 1:1 support** and that the concerns were to push ahead with a 4th resident at the group home in . Dismissing not only my concerns but the recommendations and concerns from Amy's doctor and the

(OCV) community visitor's report of concerns. i.e.: Amy not being supported appropriately, no transition plan in place and that staff levels were not to be increased with another resident moving in. See previous annexures 11@ 12 of medical reports, 25/9/08, 9110/08, 20/11/08 reports from OCV (official community victors) which contradict DADHC officer email. Email from discussing the above. See Annexure 24.

- Nov 2008 DADHC focus still only on moving in yet another resident into a dysfunctional house ignoring concerns raised by Amy's Doctor and the community. visitors Ombudsman's office concerns that there will be no increase in staffing levels which will considerately impact on care needs of residents and;
- The house was too small to accommodate all residents and concerns that no transition had been planned developed for the new resident.
- 27th November 2008 (OCV) official community visitor receives an inadequate response from Regional Manager in regards to her report of concerns dated 7/10/.08. She also mentions her surprise to see that the report had been sent to a number to other people at DADHC. She make several calls me and then requests to organise a meeting with myself and other parents regarding my concerns and tell me she is going to visit the house' again that week. I also suggest she call our advocate from PWD. Annexure 11
- OCV returns to the residence and speaks with House Manager and Regional Manager She never at any stage speaks with MY DAUGHTER OR ANY OTHER RESIDENTS. My meeting with her never takes place from this day forward I never heard from the community visitor again. I spent the next three weeks leaving messages that were never returned. I an attempt to find out why after her two phone calls requesting to meet with me now after her visiting the house and subsequent meeting with the house manger and Regional Manager my calls were no longer returned. I spoke to the Team leader at the community visitors office and asked why my calls were not returned and I could no longer make contact with the visitor? He replied that the visitor has the right to decide not to' have meeting with parents/residents. I then went on and explained that I was returning calls form her previous requests to meet personally with me to discuss my concerns and that of other parents more 'fully. And that this sudden turn around in interest did not make sense to me. See email to advocate ANNEXURE 13
- 12 December 2008 received a call from Amy's case worker DADHC to say she was going on leave. I expressed my concerns regarding Amy's health and anxiety, support needs etc, and my concerns where again dismissed as a joke, because the pathetic, uncaring response from (Senior Manager DADHC to caseworker DADHC was *'lets wait for the next instalment'. Cheers.* (Copy of email) See Annexure 25. Note stating' 'it is interesting mentioning Amy has an Extreme Anxiety Disorder'. This is mentioned in many of Amy's medical reports sent to after each visit to . Why did DADHC fail to take Amy's diagnosis into consideration see Annexure 43. reports?

JANUARY/FEBRUARY 2009.

- January 7th 2009 Amy was left vulnerable and at risk after being dumped and abandoned by staff at She was left alone by staff that had left the hospital contrary to professional advice provided on the day from Hospital , Hospital Social Worker and her father. (Complete failure of duty of care). See Annexure 26.
- January 13th 2009 Due to the inaction of DADHC I notified the National Abuse Hotline. See Annexure 27.
- January 14th 2009 around this time a report was received from Therapy Centre who advised that Amy had arrived at the Centre in a *drowsy/drug* induced state and telephoned me to come and collect Amy. Amy could not stand up or speak, and staff had to help me carry her to the car. My main concern is that staff sent Amy to the Centre that day in that state and condition. She should have been taken to hospital or at least taken to a Doctor. See independent report at Annexure 28. re independent statement from a parent .
- A request was made by PWD Advocacy to and to investigate this matter internally. A response was received after being signed by . The report from contains false information from the house Manager was not a balanced reflective view of the facts, contradicted evidence contained in Police reports and also contradicted advice given by Doctors, and also contradicted Amy's hospital records. The report effectively contradicts its own findings. See copy of letter. See Annexure 26. The internal investigation was totally ineffective in it's findings and failed top glean the true facts of the matter.
- (See Amy's hospital file) It states among other things, that Amy was *'at risk being left at the hospital and did not require admission this would not benefit her'.* Etc house manager telling Doctor I was obstructive and encouraging Amy not to have Medication etc) again giving false information to discredit me.
- *The hospital file on Amy that day records that she had bruising all over her arms and yet nothing in that regard was mentioned in report. How did she sustain these injuries?*
- Amy was intimidated, frightened and scared being left in the care of unsupervised, untrained and mostly unknown large male staff (sometimes alone). See evidence in file notes, Large Male to work alone with Amy. See evidence in file notes stating, *'large males to work alone with and also to transport Amy alone.'* This practice also contradicts own report on Amy's Strengths and Development reviewed *8/9/08,* stating, *'Amy does not always respond well to unexpected stranger visits particularly males to the home.'* See Annexure 29.
- Case report 5/2/09, A report of concerns from another parent about this practice was sent to the Ombudsman but then passed to to address. (March 2009) Reports from Amy's day programme files.

- Staff entered Amy's room on at least three (3) occasions and removed her belongings without the consent or knowledge of Amy or myself whilst moving Amy around back and forth between and houses. See emails of our concerns to . See Annexure 30 -
- Many of Amy's good expensive clothes and other valued items 'went missing, presumed stolen' and were never seen again.
- 29TH January 2009 report discussing Lack of Funding and staff, concerns about male staff, quote *'THE MANAGEMENT PLAN HAS FALLEN INTO COMPLETE DISARRAY.* Very few of the recommendations outlined in Amy's BIS plan are currently being implemented. Etc Annexure 43
- February I request to see copy of policy and procedures manual at group home. Told by staff there is only one copy kept in the office for staff use only. I asked to see resident/house copy but they didn't have one. I then asked to see Amy's file had to make formal request in writing but I did not get to see the file as requested.
- 4TH February email sent to the Mr Paul Lynch MP (Minister of Disability and Aged Care) expressing our concerns for Amy's care and seeking an urgent review and response to our concerns. See Annexure 31.
- February/March 2009 Amy is scared, being anxious about-being picked up from her day programme by House Manager, her Mother and male staff and returning to the house with them. (see notes from Amy's day programme file)and report from consultant Psychiatrist (family in mind) Annexure 42
- No routine structure in place, no proper roster drawn up and Amy not knowing who will pick her up from College from one day to the next caused Amy extreme anxiety. See College e-mail sent to about concerns about lack of routine for Amy. Annexure 32 @ 43 Doctors concerns for above issues
- MARCH 26TH 09 e-mail from House Manager sends to her manager at and to PWD Advocate, who then sends this to the caseworker DADHC telling them she had a feeling I was standing behind college staff whilst they where speaking on the phone to her and that I had never permitted college staff to contact with group house before and this call sounded quite strange.(this is an example of a false allegation, hearsay being spread around.) Annexure 32

MARCH 2009

- 11. March. We were told officially by DADHC that Amy was no longer welcome back to House re: incident 4 March report written by House manager and not the staff member involved, false claims and exaggerations.
- Reason given was Amy not compatible with both other residents. This *statement is a complete fallacy. The incompatibility as with one other resident.* Amy and other resident are still good friends and with no incidents being reported at all. This also' contradicts there own Grouping Assessment Report House dated 11/9/2008 stating, 'Relationships between all the current residents have been formed and they generally get on very well.' See Annexure 33.

- 22nd March House manager writes a false incident - report about me threatening her with my fists and threatening violence to staff and residents at house. This was when she came to pick Amy up from home and Amy refused to go with her. There was another staff member present that day, I have since contacted that staff member and I now have written confirmation/evidence that the claims made by House manager were false. She then made recommendations to Management and DADHC that they should seek guardianship with the intention of providing Amy with a healthier-less threatening role model Annexure 8
- (Regional Manager) Email 23/3/09 response to DADHC about the above false incident quote 'Guardianship should be put back on the agenda, and if I don't attend meeting, they should take a hard line with me. Annexure 8
- 23rd March 2009 House Manager makes another false incident report about me. This day I am allegedly in 'two places at once'. On the phone telling staff, to pick up Amy from our home and at the same time she reports I am at the house with Amy threatening to drive the van through the garage to kill staff See previous referred Annexure 8 contains various emails including 24/3/09 House Manager sends to both her Regional manager and PWD advocate, quote 'their ability to push staff down our stair case' etc
- 23rd March.2009 Director General DADHC receives my complaint made to NSW Ombudsman asking for information to be provided by DADHC about Amy's care etc. This is passed down to to draft a response for Director General to sign. Two (2) examples of DADHC's lack of responsibility. See Annexure 31. .
- 25TH March. DADHC make an URGENT application to Guardianship Tribunal for public guardianship and financial management of Amy.
- Reason 1. *I was supposedly a missing person and urgent decisions need to be made about Amy's' accommodation these claims were unsubstantiated and incorrect.*
- Reason 2. *My mental capacity, see emails Annexure 10 see email* 17 *June 09 DADHC now telling guardianship tribunal the day before hearing they here misquoted and that the application for guardianship of Amy was about service provision.* Annexure 10
- 26th March PWD (people with Disability senior Advocate) informs College also known as that an application for guardianship was lodged as there was no legal decision maker in place. That I was missing. She then recommends not informing me. I was at the college when this call was made.

ACCOMMODATION IN SUTHERLAND

- 28th March 2009 Amy was then placed in temporary accommodation in , (restricted practices continued without consent, knowledge or approval of parents or restricted practices panel (see report .from College staff, witnesses reports. Complaints made to DADHC and management which were never acted upon). Refer to documents obtained under FOI referring to Amy living in the house alone with no other friends or residents. See Annexure 34. and Annexure 8 Caseworker running records etc

- 31ST March 09 Amy's day programme staff reporting Amy was scared and frightened of returning to house. Telling staff she didn't want to go with staff to . See reports from College staff witness regarding the mistreatment of Amy and their reported concerns to their Manager, . Reports sent by college to Management and DADHC to this day have never been acted upon. See Annexure 1.
- 28th March to 11th April 2009 Amy was completely isolated in this house and left by herself. The staff locked themselves in the main office/ bedroom and watched TV for the whole shift, without any visual sight of Amy. When Amy knocked asking for help she was ignored by staff *Amy was locked in, left to fend for herself,* with no help or assistance from staff, to sit with her during meals, no TV provided no help by staff to shower her or to wash her hair, or to
get dressed, or to ensure that she went to bed at a reasonable hour. "
- This was the catalyst of in writing her report after observing Amy wearing the same dirty clothes each day and her hair being kept dirty and untidy etc, when she arrived at College. Annexure 8
- Amy was denied access by Management and staff to telephone or to contact her parents, (similar to prisoner being kept in Guantanamo Bay type conditions), Annexure 29.
- Locked in and left alone over night with a male unknown to her. See Annexure 29 controls measures to contain etc
- *Amy was told by House Manager she wasn't going to see her parents ever again and that her mother didn't care about her. Amy scared of going with staff. Independent evidence from Amy's Day Programme staff.*
- 11 April 2009 Reg, (Amy's father and I) removed Amy from the house when Amy told us of the abuse happening there and begged us not to return.
- 22 April 2009 see email where Amy's Advocate asks Amy's Caseworker DADHC for Amy's current address. Caseworker told the advocate it is . . Note, Amy had moved from those premises on the 11th April and living back in her family home. (Some eleven days prior). DADHC Caseworker and PWD advocate didn't even know where Amy was living. The was closed down by then Annexure 40.

FURTHER ISSUES

- April 2009 lease expired on . Amy's belongings had been packed up by before we arrived. Amy's belongings had been thrown, i.e.: (not packed) into boxes and placed on the front veranda prior to our arrival. Amongst the boxes we found filthy, dirty clothes of Amy's which had never been washed, folded or ironed, some of her " possessions jewellery missing were smashed and broken (a lamp). Amy's belongings were treated worse than general household rubbish. Some photos taken.

- 7th May 2009 Amy's belongings evicted from by House Manager. We were denied access to Amy's room and her belongings after making a previously arranged appointment with management who informed us that he would permit me to pack Amy's belongings. House Manager had thrown all of Amy's possessions all over the front lawn. Again some of her treasured personal items were missing/stolen, damaged and. broken. Staff did not have the decency or respect to even venture out of the office to speak with either Amy's father or I. Our daughter had requested many times a key to lock her room when she was away from the house. This was never given to her.
- 25TH May emails sent to Mr Paul Lynch MP Minister of Disabilities expressing my concerns of abuse and mismanagement concluding the above. A copy was also sent to the advocate at PWD see Annexure 46
- emails sent to Regional Manager and copy sent to DADHC about the above matters and also both our concerns of the unprofessional behaviours of House Manager and her Mother who she employed and that we didn't want either of them working with Amy again etc. because Amy was scared and intimidated of them. See Annexure' 30.
- 11 June 2009 response received from Director DADHC to my emails sent 25th May to Mr Paul Lynch Minister of Disabilities and PWD Senior Advocate. Annexure 44
- . over all response was in inform us what and . DADHC and had addressed all our concerns and that were acting in my Daughters best interests.
- 16 June 2009 see Advocate File. When regional Manager was questioned by Advocate about the' above incident 27 May where my daughters belonging 'were thrown' on the front lawn by the house Manager he 'declined· to comment.' See Annexure 35.
- 17 June 2009 Dismiss PWD senior advocate the day before guardianship hearing as she had ever made contact or even consulted with Amy or myself about the guardianship hearing even though her mime appeared as person supporting DADHC Guardianship application dated 25th march 2009.
- Sequentially Amy appointed an Advocate from Carer's Voice who knew and had met with my daughter and consulted with her as to her wishes.
- 18 June 2009 application by DADHC for the appointment of a Public Guardian and Financial Management and restricted access dismissed by Guardianship Tribunal. See copy of decision at Annexure 36.
- 22 June 2009 FOI request by myself giving Mr Andrew Constance MP (Shadow Minister for Ageing and Disability) access to Amy's file held by DADHC
- 29 June 2009 2nd Ombudsman report received from complaint made January 2009 at the National Abuse Hotline. See previous Annexure 3
- 27th July 2009 I request a review and further investigation by the Ombudsman see correspondence. Annexure 3
- 3rd August second request to DADHC to release all of the requested documents held on Amy's file as requested on 22nd June 2009.
- 28th October 2009 3rd Ombudsman's report re review and further investigation request dated 27th July. See Annexure 37.
- 10th November 2009 written request to (FOI) to obtain access to Amy Mason file. See **Annexure 38.**

- 23 November 2009 Letter requesting Ombudsman to include Amy in their current investigation surrounding the house and House Manager. Allegations of abuse of residents and staff reported to and ADHC and NSW Ombudsman. Annexure 47.
- 2 December 2009 Letter from Ombudsman refusing to include my daughter in current investigation of House and Manager because of the one review only policy held by the NSW Ombudsman. Annexure 48.
- Late December 2009 house manager sacked. Her Mother also a staff member resigns.
- 15th February 2010 After Three months I obtain Amy's file from as requested (didn't contain most documents I requested) see FOI request
- 18th February 2010 Meeting takes place at Parliament House with Mr Jim Moore CEO DADHC, DADHC, Mr Andrew Constance MP Shadow Minister Disabilities, and Advisor to shadow Minister, Advocate Carers Voice, Mr Reg Mason and Myself
- 24th March 2010 Letter of expressed apology received from Mr Jim Moore (CEO ADHC) for distress caused to Amy and myself and family etc. See Annexure 39.

FINAL CHAPTER

- DADHC arbitrary attempts to have Amy placed under public guardianship away from loving parents. Evidence presented to the Tribunal to refute information supplied by DADHC and that their application was flawed and based on a lot of false information.

- I have collected an abundance of conclusive evidence (e-mails.letters FOI documents etc) to suggest that and DADHC have engaged on a path of planned activity to purposely and deliberately discredit me, to make me out to be to an unfit person responsible because I was seen as being an interfering parent, and a hindrance. However at all times I was only acting and advocating on Amy's behalf and her best interests to desperately help and protect her against the abuse and all the 'injustices' that were being bought to bear against her by (DADHC and).

- I have evidence that former House Manager has been deemed to be a liar and an abuser of the disabled. These are some of the reasons which I believe were behind her services being terminated by .

- Compelling evidence of coercion/collusion between House Manager and her Mother also a staff member, (question of employment, conflict of interest etc over employing her mother) in regards to conspiring with Regional Manager, and and PWD Advocacy to discredit me in an effort to gain control of Amy and effectively 'put me out of the picture' (eg derogatory, condescending e-mails about you)

- The decision of Guardianship "Tribunal was unanimous in its decision to dismiss DADHC's application based on overwhelming evidence to support our case. the Tribunal Chairperson was critical of DADHC's overall performance in regards to Amy's care. DADHC's attempts to appoint a public guardian over Amy; (whilst she had two parents who were loving and caring and had always supported her) *is reminiscent of the past era of the 'stolen generation' issues with young Australian aboriginal children being taken away forcibly from their parents.*

GUARDIANSHIP TRIBUNAL

- Guardianship application by DADHC for the appointment of a Public Guardian and Financial Management Control of Amy was 'dismissed' by the Tribunal. Tribunal Chairman, Mr Simpson quoted, *'The tribunal saw thinking in relation to ongoing DADHC service provision as unrealistic. In light of the degree of conflict in recent times, it would not be realistic to expect the Masons to be able to work with DADHC services in the near future. The Tribunal was inclined to think that bringing the Public Guardian into the situation, as appeared to be suggesting, would have been an unnecessary and probably counterproductive intrusion* ".
- I question that none of the reported instances regarding abuse of our daughter and the subsequent ongoing abuse of other residents have not been reported to the Police by DADHC and/or . This would give someone the distinct impression that the organisation is 'covering up' serious issues such as these. DADHC and had a duty of care to report these' instances to the relevant authorities for proper assessment and/or investigation.

OVERVIEW LISTING MAJOR CONCERNS AND CONCLUSIONS

It is my opinion what happened to my daughter and our family as a whole, is a case of total system failure., We used every avenue and mechanism available to us in a vein hope of having our concerns, and fears addressed, thoroughly investigated and acted upon. There were also professional people who also had their concerns for our daughters welfare ignored and not acted upon.

I believe this highlights an urgent need for accountability, greater regulation and improved monitoring of both ADHC and in particular non government accommodation and respite services directly funded by ADHC. There is a need for a new system to be developed such as an independent arbitrator with legislated powers to fully and comprehensively investigate serious complaints about both government and non- government services. For example as in cases of breaches of NSW disability service standards, the use of restricted practices, and the non-compliance with practices, procedures and guidelines which govern these issues. At the moment there seems to be no accountability extracted and little action of any real consequence taken against a service provider that has breached legislated imperatives, which are tantamount to Human Rights abuse.

There is also an urgent need for a proper comprehensive and standard accreditation system for all disability accommodation and respite services and this must include all

support staff having some form of professional tertiary qualifications. Similarly as we now see in aged care and child care service facilities in the state.
I feel this is a must as the majority of new accommodation and respite services being set up are now privately run.

Too often we see inexperienced, untrained and unprofessional people who do not have the' knowledge or comprehensive training needed to be equipped to work successfully with people with complex needs, multiple disabilities and often associated mental health issues such as those often housed. in supported accommodation (Group Homes).

NSW Disability Services Standards are not worth the paper they are written on if they are not rigidly followed and practicably applied in every day service provision to clients. There needs to be a better system for enforcing and monitoring their use.

There are to many people with disabilities and family/carers unaware of their very existence. There seems to be a lack of staff knowledge and training in the use and importance for not only complying with but implementing these standards in their everyday care role and service provision.

Both ADHC and dismissed most all Disability standards in their service provision to my daughter and our family, either has been held accountable or has there been any consequences of their failings, which have adversely impacted on my daughter and others.

Perhaps it, should be mandatory for all service providers to not only display disability standards in their service but to explain and provide information to service users and family/carers when first entering their service provision explaining their rights and how the service endeavours to implement disability standards in their service provision and of their legal obligation in doing so .

ADHC does not have authority to directly investigate complaints about the very services it .chooses to fund. The mechanisms for handling complaints concerning ADHC funded services are totally inadequate, ADHC refers complaints back to the service provider so effectively allowing an internal investigation with often little or no consequences. There is the National Abuse and Complaints Hotline which only has the power to record a complaint not investigate, it is merely a referral agency. Referrals are then sent on to the NSW Ombudsman for investigation. It is a slow process which in our case took over two months before the ombudsman received and commenced action.

ADHC staff did not follow their own policy and procedures for complaint handing and what happened to my daughter clearly shows breaches of legislated disability standards and restrictive practices with no accountability extracted from the service provider or there auspice authority ADHC.

In my experience the NSW Ombudsman doesn't appear to have the legislated power, funding or resources or to be able to conduct a through policing style investigation. At the moment there seems to be little more than "he said - she said" desk top investigation. Where often the statements and documentation of the service providers and staff are accepted without question over the service user, their family members and independent witness accounts. Just because a service provider can produce a piece of documentation that states they are following correct procedures and policy etc ... And so appearing to be doing a great job, doses not prove that the information contained within is factual. This was the very case with my daughter's abusive situation.

I cannot accept that the NSW Ombudsmen's comments from the review report dated the 28th October 2009 into my daughters abuse and poor management, I quote "Under our legislation, i.e.: Community Services (complaints reviews and monitoring) Act 1993, our obligation is resolve complaints and issues for the benefit of service receivers, with a focus on service improvement. We do not have the authority to look at funding of services or industrial issues such as which staff decides to employ or keep at a particular residence" its then goes on to say "We believe that recent changes made by have addressed the concerns we identified through your complaint". Despite these reassurances from , the abuse was still continuing.

I believe due to the lack of legislative powers by the Ombudsmen to conduct a through more professional police style Investigation such as interviewing witnesses and staff and residents etc. The ombudsman has effectively allowed the on going abuse of other residents left residing in the group home. The system if failing when the "citizen's defender" cannot protect these very vulnerable citizens.

It was beyond the aken of to properly manage staff or conduct any sort of investigation. They chose to dismiss reports and continue to employee the House manager and her mother thus allowing their abusive, unprofessional and inappropriate behaviour including that of 'young impressionable staff that had been trained' and managed by her.

The Ombudsman's official community visitor's scheme also totally failed not only my daughter but the other residents left residing at this group home. It appears the visitor did not meet or have any consultation with residents at the house nor did she meet or listen to any concerns of family members. It appears from documentation that the recommendations initially made by the visitor were dismissed by ADHC and there is little evidence these were even considered by .

It appears the community visitor only consulted with the House Manager and her Regional Manager from during a meeting at the house. Surely the visitor should meet and consult with services users and/or family members, depending on the person's abilities. After all service users are the people they are paid to protect and act in the best interests of. Surely there has to been some scepticism on the part of a visitor when dealing with a service provider.

I now ask who then can we turn to for the protection of the rights of the disabled and to have tighter controls and monitoring of funded service providers and the staff they choose to employ?

There is clearly no clear avenue for service users to make complaints about support staff as to have any hope of being taken seriously or even listened too. There is often fear of retribution by staff.

In the situation which often occurs when support staff workers often work alone, there also remains significant risk of abuse and neglect. In particular females left alone with a male support worker, this is not always appropriate to their gender needs.

Where else is society would it be accepted practice for young women to have no choice but to accept an unknown male person to assist with the most private personal care needs even if she felt embarrassed or uncomfortable with the situation. This is not a medical situation involving professionally trained medical staff in a hospital setting even in this circumstance we have should have some say and right of choice.

People with disabilities living in group homes have no choice or say as to what staff is employed to work with them, remembering this is supposedly their home. Nor do they have a choice as to who they are forced to reside with or in fact any choice as to where they are housed.

It concerns me that run down rental properties with limited lease options are accepted as long term options for people living in supported accommodation. This accepted practice by non-government organisations such as . It is of great concern that there can be no guarantee for provision of permanent accommodation where modifications and appropriate environmental considerations can take place and provide a continuity of living. Having to pack up your belongings and move every time the lease expires every year or two sometimes less, is extremely hard for most people to cope with, let alone people with disabilities such as autism where any changes to routine or structure often triggers major behavioural problems. How many people with disabilities are living in supported accommodation funded under emergency funding for up to ten years, constantly being moved around while left waiting for recurrent funding and permanent housing and placement?

DADHC AND ATTEMPTS AT GUARDIANSHIP

Had DADHC's attempt to have my daughter placed under Guardianship been successful, my daughter would have been sent back into the care of an abuser and an extremely poorly managed service provider. Her life would have been destroyed, and her freedom and personality taken from her. Restricted practices placed on her, chemically restrained, locked in and restricted from access to her family and friends and community, and transported in a locked caged vehicle and also denied basic access to a telephone. Her quality of life would have totally diminished and also been non existent.

Now that my daughter is living back at home with her family she does not need to be sedated, she is not locked up, or restricted access to any part of the home or community. She continues to attend her day programme successfully and is friendly and popular with other service users and staff. She does not need to travel in a locked caged vehicle. She travels in the family car. She is not locked and caged in vehicles when travelling on community access days with college friends. She attends many recreational and social activities with family and friends and is well known and liked within our community.

Unfortunately my daughter still wakes most night screaming out, "mum, mum" then wakes and will then repeats, "1m ok, 1m ok", and seeks my reassurance.
She will repeat, "no more nightmares no more nightmares", when I ask her about her dreams, she answers, "the nightmare house".

I hope that DADHC should never again be allowed to take loving and caring families to the Guardianship tribunal to have their rights removed to advocate and participate in decision making and planning for their family· member. DADHC presented their case which included unsubstantiated evidence, hearsay and liars in a legal forum. In my daughters case we were trying to protect her from an abusive carer, arid poorly managed service provider and a government system that was totally failing her and thus instrumental in the deterioration of her mental health and well being. The stress brought to bear on my family and I from this action by DADHC was insurmountable abuse.

DADHC however thought they knew better than the expert professionals and chose to ignore the advice that was provided by those people. The evidence indicates however that were more intent and focussed on embarking on the campaign to destroy my character as a fit, responsible and proper person, in order to take control of my daughters life through the Guardianship application.

HOW MANY OTHER FAMILIES HAVE BEEN TAKEN TO THE GUARDIANSHIP TRIBUNAL SIMPLY TO GIVE SERVICE PROVIDERS AND DAHC GREATER CONTROL OVER THE LIVES OF PEOPLE IN CARE? as the case with my daughter. I wonder if anyone has ever looked at statistics on the number families DADHC take to guardianship each year under similar circumstance..

What also concerns and alarms me is that if this type of abuse and poor quality care could take place at a residence which was under the scrutiny and watchful eye of family members I FEAR FOR PEOPLE WITH DISABILITIES LIVING IN SUPPORTED ACCOMMODATION WHO DON'T HAVE FAMILY TO KEEP WATCH? How many other victims are there out there slipping under the radar? I fear this abuse and negligence may be wide spread. Are group homes becoming mini institutions?

It should never be accepted practice to physically and/or chemically restrain as a substitute for professional care and treatment or to simply make the job· easier for poorly trained, inexperienced or unprofessional staff or in the absence o f quality care and service provision and person centred planning. Restraint should never be used as a solution which removes the need to properly address the causes for behaviours.

I quote from an alarming statement made to me by psychiatrist who specialises in working with the intellectually disabled and has many years of experience "Ninety percent of group homes could not function without the use of medication".

Our experiences with this organization have lead me to the conclusion that this is not the leading quality service provider it so portrays itself to be.

When it comes to the proper care, support and service to people with disabilities, not only is the competency of the organisations managers' and staff questionable but, in relation to the manner in which our Daughter and we her parents were treated there is a clear lack of professionalism displayed by the Managers, staff and this reflects poorly on the organisation as a whole.

It was not until my third complaint to the NSW ombudsman dated 28/10/09 did even admit there where even some concerns in the way it supported our daughter. The report goes on to' list steps already taken over recent months because of my complaint.

Such as a commitment to obtain written consent form persons responsible for all prescription medication. Surely the even most novices of service providers would enforce the vital importance of insuring correct policy and procedures are in place and strictly followed in the use of medication. For the safety of it service users this should be paramount and of the highest importance to any service provider. Such incompetence has serious consequences, putting service users at great risk, like Amy experienced and also has the potential to put lives at risk .

The report goes on to list five other major changes-such as:

- A new Corporate Governance structure, including changes to management structure
- A written board and lodging agreement
- Compulsory training and induction of staff in policies and procedures on a regular basis.
- Recent audit on quality management systems
- A new Quality Assurance system. and, so on

But despite all of these new steps and their reassurances to the Ombudsman, nothing really changed for the residents and staff at the group home from which my daughter was housed. still did not investigate the abuse and intimidation, harassment, and it was allowed to continue by Management. The CEO was also aware of problems surrounding this house.

HAS BEEN IN OPERATION SINCE 2002. HAVE ALL THESE SYSTEMS FAILURES BEEN OVERLOOKED FOR THE PAST EIGHT YEARS? Surely if this organization is being spruiked as a leading service provider, then all the above practices should have been well established. This organisation receives millions" of dollars in Government funding and has received accolades from a previous Disability Minister.

These serious failures and inadequate services seemed to have slipped under the radar of any Government Scrutiny. This organisation has been allowed to grow from its roots in NSW to most states in Australia in a matter of a few short years of establishment. Why have many long and well established and proven disability services been over looked? Many crying out for funding to open and expand on their already proven quality service provision ... Yet many have not been successful with tenders I know of two such organisations in my local area.

I find it offensive this organisation is winning awards and accolades for being the fastest growing company in the region. It appears to me to be at the expense of providing quality care and service provision to the disabled. Surely the main aim and focus of any quality disability services provider is to provide professional quality care first and for most.

I believe that has grown too fast too quickly and is not accountable for expenditure of public monies. Their focus is entirely concentrated on expanding their business empire. This has directly jeopardised the quality of care and services given to vulnerable people in their care and has probably lead to budget based decisions with little evidence of any real person centred planning. Since its inception is 2002 its spread its services throughout Australia at an alarming rapid rate.

- On reading goals, they talk of their successes stemming from as example- .
- a solid grounding in person centred values,
- commitment to outcomes that are meaningful for-each individual ,strong links with families,
- commitment to the recruitment and retention of the best possible staff. Etc ...
- person centred solutions and promote community integration and participation and ultimately enhance the overall quality of life for people we support, their families and carers and of close" collaboration with other services.

These few examples paint a completely different picture to the care and service provision provided to our daughter and our family or in fact any of the other residents and families residing with my daughter. On talking with families of residents there is a general consensus of opinion that these statements are far fetched to say the least.

DADHC AND CASE MEETINGS.

My experience was that of an arrogant culture of what could only be described as a" BOYS CLUB". During meetings and discussions held it became apparent to me that many management had been former staff officers of DADHC. There was air of collusion and a feeling of intimidation "them against us" a David" versus Goliath situation. There was an attitude of 'we know better than you' with little respect shown for the mere parent. *"We know your daughter better than you, even though we have never even met or spoken with her".*

There where many 'matey emails' bouncing between and DADHC managements, PWD advocate and of course the house Manager. The TEAM, as they called themselves, all working together gullibly believing all information given from the house manager without question or any scepticism out so ever.

INDIVIDUALISED FUNDING AND SELF MANAGEMENT

Should our daughter have been offered individualised funding by ADHC we would have had a choice of service provision and could have taken her funding to another service provider.

If the choice to self manage, direct funding had been possible this would have given us greater options, control over choices of the services and type of supports needed, including the control and choice of support staff needed to assist me in supporting my daughter to have remained in the family home. It would have also given our daughter greater choice in where she lives and the flexibility to. alter assistance needed as circumstances change. It is important and empowering to a person with a disability and to their family/carers to have direct control over their own life.

Interestingly enough in an email obtained from my daughters ADHC file a senior manager at DADHC is stating to our daughters day programme service manager, that once a public guardian was appointed, their role would include accommodation including CHOICE OF SERVICE PROVIDER. Why did my daughter and family not have any right to choose her service provider but a public guardian does?

The management of college had asked to assist my daughter and our family by providing some respite service to the family as they had great success and no incidents when supporting Amy in her day programmes. This offer was declined by ADHC as they were wanting to continue to fund . **Annexure 7**
At the guardianship hearing ADHC had written in a report that we could not change service providers as were ADHC'S choice of preferred provider as they were the only service capable of handing our daughter. **Annexure /**

(PWD) PEOPLE WITH DISABILITY ADVOCACY SERVICE

Provided one of their Senior Advocates to assist my daughter and family.

I found this advocacy service extremely poor, they provided very little assistance-to my daughter or myself and I found their service counter productive. At times they acted unprofessionally and inappropriately. I do not feel they acted in any way to protect my daughters rights. The advocate actions only assisted DADHC in their endeavours to have Amy placed under guardianship. On reading emails she appeared to be spreading unsubstantiated information given to her by the house manager.

On commencing Advocacy services I signed authorisation form that states I on behalf of my daughter authorise PWD to act as Amy's Advocate in relation to:

- obtaining appropriate accommodation
- Obtaining appropriate disability support services ...
- With the following exception
- Any actions or decisions made are, always in consultation and agreement with Amy's parents.
- The advocates actions I believe clearly breached the signed service agreement.

Our daughters advocate lacked both scepticism and transparency when dealing with House Manager and both senior management of and DADHC. The advocate's efforts directly contributed to the threat of our daughter being placed under guardianship and then sent back to care to face 'more abuse'.

As previously outlined in the chronology of this submission this advocate never once met with our daughter to discuss with her any concerns or ways in which she could assist her. She never held any private meeting with Amy or either parent at any stage of the Advocacy.

Prior to any DADHC case meetings there was never any consultation with Amy or her parents to discuss concerns we wanted addressed by DADHC OR ?

Since obtaining my daughters advocacy files it has now by revealed by me that she would often arrive prior to our arrival at meetings and have private discussions with both ADHC and without our knowledge or input. When attending meetings she would sit there and say very little. And I remember asking her if at meetings she could participate more and assist me further in helping to express my concerns for our daughter inadequate services and care.

As previously mentioned she never told our daughter or me about the guardianship application by ADHC in fact she told other service providers involved with our daughter not to inform me.

The advocate never once consulted with our daughter or family to discuss the guardianship application or how she could assist our daughter to express her views at the tribunal hearing. In fact she never initiated contact at any time during the three month period from when DADHC first lodged their Guardianship application until two days prior to the hearing when she sent an email mentioning her intention to attended the hearing, *apparently she was listed as a person who would support the guardianship application.* At this stage my daughter terminated PWD advocacy service.

After obtaining our daughters PWD Advocacy files in August last year, I requested an independent Advocate to read over my daughters advocacy file with her consent, with the purpose of reviewing the file, and providing us with their opinions and comments on the advocacy service given to our daughter.

Bear in mind when these comments were written the house Manger had not yet been investigated and was still working at the group home. And I had not yet obtained either DADHC or Files at this stage.

Some of these findings I have previously quoted in my submission, here is an extract from this report.

"The advocate has clearly demonstrated that they are trying to resolve the situation but has, in my opinion; occasionally overstepped their correct area of participation with dangerous results. These oversteps are best dealt with through The Draft National Disability Advocacy standards.

Standard: 2 Individual needs

People with disability receive advocacy that is designed to meet their individual needs and best interests.

2.3 In meeting the needs of a person with disability, the advocacy agency will seek to minimise conflict of interest or to deal with it transparently

Standard: 3 Decision -making & CHOICE

People with disability have the opportunity to participate as fully as possible in making decisions about the advocacy activities undertaken.

There are other areas where the extra activities are more border-line. In general there appears to be some over interpretation of what 'Ethical boundaries' are. There is also complete faith given to everything the DADHC and have recommended. Healthy scepticism is surely a key attribute of any advocate".

Conclusion

There are certain facts that can only be construed by seeing what continual themes within this case are as follows:

1) Amy Mason was responsive and behaving well, as documented in report 15th April 2008. Situation was relatively stable up to or rear to Christmas 2008.
2) In my opinion Amy should never have never been placed in the house with (Resident R) who had. complex situation of her own. The house was further reported to be too small with a distinct lack of storage.
3) There have been key systemic failures by the government to recognise the requirements of people needing accommodation with care. This has led to budget based care decision by that should not have happened and the person needs put foremost in all planning.
4) There have been awful lot of matey emails bouncing around, including from the advocate, which have acted as a vessel to spread unconfirmed

information. This rapidly escalated the situation that may not have needed to happen.

5) There has been scant regard by all parties for the stability of Amy's mother. Her desire to have participation in her daughter's life has been looked upon as a hindrance to getting things done, this contravenes almost all service standards.

INDEPENDENT ADVOCATE QUOTE: "There are may more conclusions that can be drawn but as I have said I am mindful that I do not have all the information but will state that reading the file was a shocking experience as I could see the situation spiralling out of hand and the increase in negative comments about Amy's mother that should not have been said".

In finality I will say that this nightmare that was forced upon my daughter and family would never have happened if the option of individualised funding had been made available to us. If only I had been given a self managed package of supports individually tailored to meet both my daughters and families circumstances and needs, this story of abuse and bureaucratic bungling would have never been allowed to have taken place.

My daughter was fifteen years old and it was the first time that I asked for any assistance from the ADHC. I suddenly found myself not only a single mother of two teenagers but a single carer of a disabled child and with no respite available and no services available as to enable me to work fulltime. I now found myself in the position of not only exhaustion from relentless role of fulltime carer and mother but now also having burden of imposed poverty placed on the family.

Unable to find *before and after school care* for my daughter, in which the situation has not changed now that she has left school and entered adult services. There is still no care available out side of the nine to three hours which means single carers can not hold a fulltime job even if they need to and want to work to support their family.

There is still need for more quality respite places at affordable costs to families and there is and urgent need for extension of hours of school and adult day programmes. Allowing carers, particularly single carers the right and choice to work and earn a dignified income to have a better quality of life and to be better able support and provide financially for their disabled child and family.

I think this is an important and timely inquiry and I trust that the committee will make appropriate recommendations to address the issues that I have outlined.

Additionally I would very much appreciate the opportunity of being granted leave. to appear as a witness before the inquiry and being able to address the committee on the compelling circumstances concerning Amy's mistreatment by DADHC and

I have only forwarded some Annexures to support information contained in this submission. Some of the other Annexures are quite voluminous in content and can be produced to the Inquiry upon request.

Respectfully