Response to “ACT Law Reform Advisory Council - Adults making decisions in the ACT”

10 August 2015
Susan Penn-Turrall, Principal Guardian / Deputy Public Advocate
Sue Houghton and Kurt Petrunia, Senior Guardians
ACT Office of the Public Advocate
Executive Summary

This report was written by the Principal Guardian and the two Senior Guardians of the Public Advocate’s Office, ACT.

The following is an over view of what we recommend.

The Principal Guardian and the two Senior Guardian’s recommend:

- The legislation distinguishes between Public and Private Guardians
  - Public Guardians are accountable and can provide those standards and skills required in guardianship
  - Public Guardians in the ACT already work from the perspective of social justice and trauma informed.
  - Supported decision making is the preferred stance of Public Guardians but substitute decision making powers are required.

- Public Guardians are acknowledged by their skills and accountability and given a greater level of protection from interference from outside bodies with their clients.

- Private Guardians are provided with training
  - Public Guardians can provide support and training
  - Public Guardians can provide a central point of support and monitoring within areas which Private Guardians may not be the right choice to monitor such as:
    - Elder abuse concerns
    - NDIS
    - Service delivery standards
    - Complex and possibly dysfunctional family
    - Suggestions of fraud or mis-use of funds
    - Complex mental health oversight

- Substitute decision making remains but with consequences attached to the lack of accountability for meeting the required standard when decision are made.
  - Properly funded Public Guardian service can provide oversight in private guardianship - as well as training

- Supported Decision making should be considered in the form of a support network
  - This reflects what happens in society generally
  - This will require training which can be provided by Public Guardians
  - This will require guidelines and oversight by monitors
  - Public Guardians can step in if there is no network or network cannot act
• Further research into the practicalities of Supported Decision making

• Further research to look at aspects of consent, autonomy, supported decision making in suicidal ideation or other high risk scenarios

• Further research into where and how “more resources” will be applied

• Consideration being given to audit/submit all of the relevant legislation to ensure that it all corresponds to each other — especially where standards and requirements are being set out for guardians — consideration should be given as to whether there is a capacity for private guardians to meet these and what are the consequences for them not meeting these requirements.
Introduction
This response is compiled by Susan Penn-Turrall Principal Guardian/Deputy Public Advocate; Sue Houghton, Senior Guardian and Kurt Petrunia, Senior Guardian of the Public Advocate’s Office ACT. We would like to thank the ACT Law Reform Advisory Council (LRAC) for the opportunity to respond to this important reform of guardianship arrangements for adult people with disabilities in our community.

We would like to first apologise for the lateness of this response and would like to point out that this response is not complete. We have sent it in, unfinished, due to the lack of time resources we have to prepare it. We will be able to complete it – with proper references – at some point later. We are happy to discuss any aspect with LRAC and give examples if required. We have tried to add one or two examples of actual cases (in italics) and incidences in order to illustrate what we are saying but we have many more if required.

We would also like to complement the LRAC for the response booklet format which is both comprehensive and accessible for those across the community wishing to engage in this review.

The PA ACT public guardianship team is currently facing a number of challenges and changes which are to occur over the next 12 months. The ACT Government is in the process of considering a proposal that the PA ACT should be disbanded, with the advocacy section proposed to be placed within the planned New Human Rights Commission structure. The guardianship team, it has been suggested, is to be placed within the existing Public Trustee of the ACT. Placing the public guardians under the Public Trustee would require an amendment of the current legislations in any event and this LRAC review may need to consider this legislative reform within that potential. The PA ACT guardians have responded to the ACT Government discussion paper on the reform of protective services and have written this response paper with a view that other reforms and proposals will directly affect the status and work of public guardians in the ACT. It should be noted the Public Guardian team does not consider being merged with the Public Trustee’s Office to be beneficial to Public Guardianship within the ACT and has suggested a co-location reflective of the NSW model of Guardianship. Whatever the outcome of the public guardian team will continue to produce high quality guardianship work for the ACT.

There are a number of key issues which this legislative reform process allows us to comment on and discuss, not least the dominant narrative around supported decision making and the outcomes of recent pilot studies regarding supported decision making programs. For ease of reference, this paper will refer to Public Guardians as a distinct body apart from Private Guardians. We refer to those who are subject to guardianship orders as “clients” of the PA ACT rather than “protected persons” – which appears to negate the language of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities. We also take this opportunity to discuss some of the difficulties we have encountered with the language and attending reactions to Art 12 particularly around the shift from the medical model to the social model but without the corresponding respect or value placed on the social model interactions with legislation or guardianship application.

---

Overview
We welcome this review of guardianship and would like to take the opportunity to take the discussion of the role of guardianship beyond an academic dialogue on the implications of Art 12 on substituted decision making. We would like to see Guardianship given the resources and status in the ACT which it needs in order to deliver the expectations of both government and those citizens who rely on guardianship. Currently there is little distinction made, in discussions and in legislation, between public and private guardianship, yet the two are very different. It does appear, from reading both the academic literature and the government discussion paper that what little understanding there is of the actual daily work of guardians, the focus of the discussion skips between public and private guardians depending on the issue, without actually citing when this distinction is made. Currently many private guardians take on both financial manager and guardianship for someone they know and love. They are able to do this successfully as they have probably done both roles for many years; they know the social, economic, religious, ethnic, background of the person they act for and they have an idea of what the person they act for ‘is’ as distinct from their medical presentation. Their finances are most likely bound to the family finances and as most families do, they support each other financially and emotionally. Most private guardians approach their role as primarily an advocate for the person they love and care for. There are exceptions and it is these exceptions which highlight the need for greater audit and control over the application of guardianship roles; especially if both financial management and guardianship are held together. What does need to be considered, is the practicality of attaining the skill levels required to do those roles set out in legislation and the mechanisms needed for independent audit of the ever increasing requirements placed on private Guardians. In short – there is no point setting standards and principles if there is no practical means to audit whether these have been achieved, or training to assist in achieving them and no real consequence should the powers of Guardianship be abused.

The irony for the PA ACT Public Guardians currently is that at the same time they notice a lack of direct understanding of the skills and professionalism required to adequately and successfully fulfil the role of a Public Guardian, they are also identifying a sharp increase in both work load and in the complexity of the role required of guardians. In all arenas the Government, legislation and practical service delivery need is setting out more complex and skilled role requirements which are specific and unique to Public Guardians. None of these increases in work load, complexity or service delivery necessity are reflected in resource allocation.

Public Guardians are the guardians of last resort; the people they represent either have no one else to assist them or their families are in conflict and/or have difficulties making decisions for the person which detach from their own views. This is not unique to families. The PA ACT Guardians have acted in a number of cases in which independent advocates have “spoken on behalf of those for whom they act” but it has become apparent in a few of these cases, it is the views and beliefs of the advocate which are being proffered rather than the person for whom they act.

Public guardians are expected to have a wide range of skills in which to successfully engage people, analyse often complex information, negotiate with stakeholders – including medical, Mental Health, NDIA, disability service delivery agencies, Public Trustee, Housing, training establishments, family
members, - and work with the persons individuality taking into account their age, sexual orientation, views and wishes, their religion and spirituality, their ethnicity, and language. Public Guardians need to be cognisant of the person’s trauma history, social isolation and their life experiences in relation to authority including their relationships with and experience of service delivery agents. That the Public Guardian has been appointed indicates that this person could either have some conflict in their lives or that there could be a degree of social isolation. Supporting a person to make a decision is never a “one size fits all” process. Public Guardians commence their engagement with a client on the basis of getting to know the person, engaging with them through a lens of social justice and assessing the entire social context of the person, as well as taking into account the medical aspects, stakeholder opinions and resources available. It would be an alien concept to most public guardians to commence any engagement with a client on the basis of immediate or absolute substitute decision making. Working with the client and creating a relationship in which supportive decision making is possible and safe for the client is the optimum situation.

Each aspect of a client’s life, the micro, mezzo and macro, has to be considered and acknowledged and accounted for in a decision, (or series of decisions), the report of which is placed before ACAT. All of the decisions have to be made through an ethical decision making process which is considered via a framework which requires all Public Guardians to identify and account for decisions and recommendations they are making. This process requires public guardians to engage in supervision and be cognisant of their own pre-existing bias and lens through which they may interpret information.

While the principles of supported decision making appear simplistic:

- Primacy must be given to the wishes and preferences of the person and
- The person should be supported to articulate those wishes and preferences.

Within an existing and supportive relationship between a person requiring support and the guardian/advocate this does not form an issue but in anything other than these situations there needs to be an acknowledgement of the relationship between the person requiring support and the person holding power and authority of decision making. The principles themselves are written as instructions for the person “supporting” and do not explain, acknowledge or identify that from the perspective of the client there is likely to exist issues relating to power and authority, trauma history, social isolation, vulnerability and capacity to distinguish complex outcomes etc which will affect the relationship between the client and the person “allocated” to support the person. Most of the academic papers currently discussing supported decision and the effects of Art 12\(^3\) are being written from the perspective of legal and social theories which are not or have never been applied. They call for more resources to be applied to the statements of equality and access to rights for everyone with a disability; they condemn substitute decision making as if it has no place in the process and refer to supported decision making as if it was a simple matter of applying a process to an existing system – in short these papers are not being written by public guardians. Within the ACT the current Public Guardianship team – the one body of people who daily work in and apply the processes of guardianship – are often

---

\(^3\) See references at the end of this paper for those recent papers read in consideration of this response.
not included in research, forums, working groups or pilot studies looking at legislative reforms for supported decision making, Power of Attorney Act, and other relevant areas of work.

It is an irony the Public Guardians of the ACT are aware of the need to be involved in these research and forums, but they are so under resourced they do not have time to contribute to the area of discussion about which they have the single most experience and professional background in the ACT. This paper has, out of the pressure of work, been written after working hours and during weekends.
The Need for Guardianship

Guardianship derives from the concept that the state owes a duty of care to those who cannot protect or look after themselves, particularly children and anyone with a disability sufficient to impair their ability to look after or protect themselves. Quinn describes adult guardianship as ‘one way that the state fulfils its diverse responsibilities towards people with disabilities who are unable to make their own decisions.’ For the last 30 years, policy makers, researchers, administrators, gerontologists and educators have struggled to reform guardianship to reflect current knowledge of cognition functional behaviour and court process as well as to promote proper due process. What has not occurred however is a suggestion of a viable alternative to guardianship which protects and creates access to rights for the most vulnerable in our society.

So far there has been no serious suggestion within Australia that Guardianship should not exist at all; it should be noted however that the UN Handbook on the implementation of the Convention refers to guardianship in negative terms and calls for a shift away from the paradigm of the substitute decision-making required of guardianship to a paradigm in which a person is provided with whatever support is required in order to exercise their legal capacity to the greatest extent. The negative narrative regarding guardianship has largely been taken up throughout academic discussion on disability rights and undertaken in discussing the use of substitute decision making, setting this at odds with a human rights model.

Public Guardianship in the ACT in its current form represents a set of highly professional and skilled people who work to a principled framework which combines human rights and trauma informed. This framework has been attached for information. Public Guardians are accountable to both the ACT Government and to the legislation which empowers them to act through the ACAT. Their decisions and the processes they use to reach those decisions are open to investigation and accountability.

While we welcome the opportunity to contribute to developments and changes within guardianship legislation, we caution against making dramatic changes within legislation which, while sounding theoretically advanced, cannot be sustained or applied because they lack resources or their practical applications sit outside what is actually viable for clients.

Many papers and service delivery agencies talk about increasing resources but even within the NDIS and the potential positive benefits the increases in money can bring to some there appears to be a lack of practical processes which monitor and deliver adequate and fair resources. Merely stating that resources have to be increased does not adequately address how this will happen and where these resources will be distributed and what applying these resources will look like. Even if more resources were available nowhere does it appear that ‘experts’ have addressed or given practical examples of how service delivery agents can apply more resources to those who do not have the social connections

---

4 Gardner; Re BWV [2003] VSC 173. Upheld the ideal that Guardianship is the correct system for protecting those who had previously required the protection of the nation.

5 Barbara Carter (2010) “Adult Guardianship: Human rights or social justice” Thomson Reuters, 18 JLM 143-155


and the mental health capacity to safely or practically access more resources – without being
prescriptive. In most scenarios we came up with within our common client context:

- someone somewhere would be needed to assist (or directly) apply for, administer and monitor
  service and resource delivery to those clients
- Someone would need to make decisions (whether supported or not) and choices regarding
  where and when and how services were applied
- Someone would need to monitor service standards and the appropriateness of services and
  this cannot be the same person as the one providing the service.
- Someone would need to be responsible if that service was wrong
- Someone would need to have some power and authority to indicate if changes needed to be
  made or a crisis had occurred and interventions were required.

Guardianship legislation does need reform and a key to this would be to distinguish between public
and private guardianship. The Government is responsible for resourcing and supporting public
guardianship in a way that it cannot do with private guardianship. It is through the status and
resources that the Government places on Public Guardianship which can most clearly demonstrate
the commitment the Government has to applying the theory of access to equality and services for
everyone within the ACT.
Other legislation and changes impacting Guardianship

Currently there are a number of legislative and process changes being undertaken within the ACT which affect Public and Private Guardianship. Each of these reviews will impact the other and require at the very least reviews of references and language after each has been redrafted. The new Mental Health (Treatment and Care) Amendment Act 2014, for example refers to the Guardianship and Management of Property Act, 1991 and the Powers of Attorney Act 2006 which themselves refer to the Public Advocate Act, 2005. All appear to be currently being reviewed independently.

Some of these reviews stated above directly impose new tasks on the Public Advocate, which with the disbanding of the Public Advocate role and Office, will need clarification how the expectation of that part of the section will be fulfilled⁸.

The Mental Health (Treatment and Care) Amendment Act 2014.

The Mental Health (Treatment and Care) Amendment Act 2014, which comes into force in October 2015, has been written with the objectives (set out in section 5) and principles (section 6). Section 5(b) sets out the Acts objective is to “promote the capacity of people with a mental disorder or mental illness to determine, and participate in, their assessment and treatment, care or support, taking into account their rights in relation to mental health under territory law.” ⁹ The principles provided by section 6 are of two types. Sections 6(a) to 6 (i) inclusive each supply a ‘right’ of a ‘person with a mental disorder or mental illness’. For instance, section 6(f)(i) states that each person has a “right to access services that are sensitive and responsive to the person’s individual needs, including in relation to age, gender, culture, language, religion, sexuality, trauma and other life experiences”.¹⁰ It goes without saying but to make this Bill practically applied, it will require services funding and resourcing beyond what is currently available.

Any review of the principles for guardianship would need to be cognisant of the principles contained within the Mental Health (Treatment and Care) Amendment Act 2014. The meaning of decision making capacity is set out in section 7 and the principles of decision making capacity are set out in Section 8 with a presumption of capacity applying to each person. This cuts across aspects of the assessments of capacity in other guardianship areas; consideration will need to be given to how the same person can have different aspects of their decision making capacity considered depending not on whether they have a guardian but on which piece of legislation is being applied.

When a guardian has been appointed for a client, should that person require mental health treatment, in order to give consent for any psychiatric treatment, the guardian must under the new Mental Health (Treatment and Care) Amendment Act 2014, go through the same process of setting out the decision making capacity requirements, as a person with capacity needs to do. In other words a guardian,

---

⁸ For example S3 of the Mental Health (Treatment and Care) Amendment Bill 2014 states that “the responsible person or mental health professional must ensure that the advice and information – is provided in a way that the person is most likely to understand; and (b) if the person appears to be unable to understand the advice or information the public advocate is told of that fact. S 22(5) (d) must advise the person who made the nomination about advocacy service that may be available to provide assistance to the person..Example give 1 Public Advocate.


¹⁰ Full citation for Amendment Act
whether they are a public guardian or a private guardian will need to demonstrate they fully understand and fulfil the following in relation to their client and their psychiatric treatment:

a) Understand when a decision needs to be made:
   
   What is the nature of illness, what is the history of the illness, what are the symptoms, what is the trajectory of the illness, co-morbid physical/psychiatric diagnoses, the impact on biopsychosocial functioning, the trigger for need for a decision and

b) Understand the facts that relate to the decision:
   
   Timeframe/urgency for treatment, care and support; pharmacological and non-pharmacological options available, side-effects, risks, benefits, dosage regime, monitoring requirements and

c) Understand the main choices that relate to the decision:
   
   What will happen if no treatment/care/support, what will happen if the recommended treatment/care/support is consented to, what are the alternatives and

d) Weigh up the consequences of the main choices:
   
   Analysis of all of the above and

e) Understand how the consequences affect the person:
   
   Impact on person’s biopsychosocial functioning and wellbeing of all of the above and

f) On the basis of a) to e) make the decision and

   Communicate the decision in whatever way the person can:
   
   via a formal written consent which articulates the treatment, care or support consented to, the time limits for the consent, the review method for the treatment, care and support.

The actual complexity and skill level required of a guardian, specifically when referring to someone who has co-morbid presentations, and has difficulty communicating, required to accurately deliver these elements of consent should be considered. It is particularly noteworthy to consider that a private guardian, will in all likelihood be a parent or close relative of the person for whom they are assisting in the decision making. They are required to separate what they would like for the person, from what the person may need and may say they want. They will need to approach this from a perspective of balance and non-judgment, from a social justice perspective. They are likely to have a long history with the person, they may well love them deeply but they are likely to have been emotionally impacted by their presentation and their mental health.

Similarly with the NDIS (which is discussed later) the guardians are required to describe the person to the greatest extent of their disability in order to get funding and services. The emotional effect on guardians who are also relatives and loved ones of the person they are acting for, but needing to see
the person from the perspective of their disability, should not be underestimated, nor should it be
discounted in the approach and outcomes taken by guardians.

The PA ACT Public Guardians are commencing training with ACT Mental Health services around aspects
of this new Act and reviewing their assessment frameworks to ensure they are ready and skilled to
cover all the requirements of these elements of consent. It is highly likely however that most private
guardians, who are likely to be parents or relatives of someone in need of psychiatric treatment, will
require some support and/or training in this area if they are to fulfil the requirements of consent under
this section.

There are two key discussion points which arise from this and other legislative reviews: guardianship
is becoming more and more complex and requires skills, training and accountability to execute
correctly; and, Public Guardianship – which already has the skills, training and accountability is under-
resourced to meet the growing needs and requirements of added responsibilities and processes to
ensure clients are safe and retain access to their rights and correct health care. The increased
complexity of the requirements of ‘good’ guardianship will be discussed later in reference to the NDIS
but the legislative and mental health changes should be borne in mind.

**Powers of Attorney Act**

The *Powers of Attorney Act* is currently being reviewed. The Public Guardianship team – which takes
Enduring Powers of Attorney (EPOA) on behalf of the Public Advocate of the ACT, - was not invited to
participate nor included in the initial review of the Act.

There is currently no understanding of how the *Powers of Attorney Act* interacts with the *Mental
Health Act*. Specifically what affect it will have on the views and wishes of those who have made an
advanced agreement and/or directives with the Public Advocate of the ACT as the EPOA which may
then clash with the client’s application within the *Mental Health Act*. At some point there will need
to be legislation which specifically sets out which legislation has priority over the other.

This will need to be made very clear to those who have made or are making EPOA agreements. Most
people who are currently making very specific directives and agreements with the PA ACT as EPOA
for their health care and personal care are unaware there is currently legislative reform in place and
legislation about to be implement which may in time negate or dismiss their wishes.
The UN Convention on the Rights of Persons with Disability (ART 12)

This paper presupposes that the reader has a detailed understanding of the Convention and Article 12. It does not intend to revisit the details here so much as discuss relevant aspects of Art 12 as it pertains particularly to Public Guardians and the current dialogue being undertaken about what this means and how it applies to the ACT.

The UN Convention on the Rights of Persons with Disabilities (CRPD) Article 12 has caused a storm of commentary regarding not only disability rights but the application of those rights through guardianship and relevant legislation attempting to address how a state chooses to deliver rights to its citizens. At the time of its adoption the U.N. High Commissioner for Human Rights heralded the CRPD as a rejection of the understanding of persons with disabilities “as objects of charity, medical treatment and social protection” and an embrace of disabled people as “subject of rights.” In Lord et al (2010) there is a description of how the Article 12 has opened up the debate around “capacity” with Article 12 (2) calls on state parties to “recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” This causes consternation when discussed within the context of the current appointment of guardians requiring evidence of capacity; specifically if the person does not wish or feel they need a guardian. This will be discussed in more detail later, specifically how this impacts the drive for a social model articulated within the UN Convention and the requirements for evidence within the courts which rely on the medical model.

Article 12 (3) directs states to take appropriate measures “to provide access by persons with disabilities to the support they may require in exercising their legal capacity”. It is Article 12(3) which has emerged as a central human rights issue and a social, political and ideological challenge to guardianship laws.

Guardianship remains a means to assist people to access their rights, supports and to access rights through court systems which, even at Tribunal level, rely on “evidentiary standards” to determine outcomes. Within the ACT, the current Guardianship and Management of Property Act 1991 the ACT Civil and Administrative Tribunal (ACAT) has the power to appoint a guardian when the ACAT is “satisfied” that some one has impaired capacity to make decisions for themselves.

---

12 Ibid
How guardianship is perceived

There has been some degree of success with reforms looking to ensure guardianship is both protective and empowering, although there remains complexity around political and academic understanding of guardianship reflected in policy and how this policy then applies in practice. The narrative of Art 12 for example has reinvigorated discussions around how guardianship should look and indeed whether there should be guardianship at all. Policy makers around the world are revisiting guardianship legislation. Amongst other things, a key area these discussions appear not to consider however is the differences between public and private guardianship. This forms a key discussion point in terms of accountability and credibility within the application of guardianship.

Another key absence in these discussions appears to be an acknowledgment of the differences between those societies driven by social justice frameworks as opposed to some countries with practices for whom the UN convention itself would be considered a new way of thinking. This concern regarding the lack of understanding and acknowledgement within legislative drafters and policy makers, of the different applications of guardianship, is of great concern specifically within the Public Advocate of the ACT (PA ACT).

In responding to any discussion regarding guardianship, the public guardians of the PA ACT feel somewhat disadvantaged by what appears to be a lack of understanding or acknowledgement of either the requirements or skills necessary to fulfil the role of a public guardian in the ACT. Incorrect assumptions regarding the use of substitute decision making are inherent in the discussions around Guardianship reform, specifically a lack of understanding that supported decision making has routinely been conducted by public guardians for many years.

Most criticism of guardianship per se comes from the communities awareness of when private guardians do the wrong thing. Private guardians can be overly intrusive. Private Guardians can lose the boundary between being a parent and a guardian. The ACAT and the community cannot impose a sanction on private guardians if they do the wrong thing. The Public Guardians could with more resources form a support for private guardians with training and support for them in making decisions and in separating the role of parent and guardian. The Public Guardians could provide welfare checks and support in managing the NDIS process, including assessments and service delivery contract reviews etc. Public Guardians could assist private guardians access supports, negotiating privacy and information sharing, and support them negotiating the new Mental Health requirements. All of this however would need to be resourced adequately. That being said increasing the resourcing (in terms of staff numbers) for public guardianship team and expanding their roles to support private guardians and supported decision making networks or supported decision making leaders would be an efficient and human rights approach to providing a more accountable guardianship system. This becomes more so important when seen in the context of the NDIS environment and how that is impacting the service delivery process.

Policy makers appear not to take into account the minutia of the obstacles of applying a social model to a set of principles while the courts and other areas of authority, retain the requirements of proof and evidence based on a medical model.

“In order to be considered for a level in an NDIS plan the NDIA are requiring “evidence” of need. When experienced social worker/disability workers guardians write comprehensive psycho-social assessments of their clients setting out detailed areas of need and the reasons/history this need exists; the NDIA send the report back with a request for “expert evidence” meaning reports from doctors, psychologist etc. These reports cost a great deal of money, time and say less than the expert reports from guardians.”

Resourcing appears directed through the medical model rather than through the advice of someone who uses both social and medical to recommend resources. One of the consequences of this dichotomy within the system is that respect, power and authority remains within those delivering the medical model (doctors, psychologist, psychiatrists) while those delivering the social response (guardians, social workers, disability workers) remain under resourced with their decisions often left dependent on the reports of ‘experts’ such as doctors. This is directly illustrated in the current narrative of Art 12 while it shifts the dialogue from medical to social, the actual practically applied legislation remains firmly relying on those with a medical voice.

This reliance on the medical model is reflected on the respect and resourcing given to these professions compared to those given to guardianship and social work/disability work.

The public guardians of the ACT submit that there are tensions between the medical model of disability which locates disability in terms of pathology and the social model which views disability as the persons physical or mental condition and the external physical and attitudinal barriers to their full participation in society. From a practical aspect though – one size does not fit all. Academics are reviewing these approaches and appear to find solutions which do not fully comprehend the wide range of issues, practical and attitudinal which exist in terms of service delivery for people with disabilities. These solutions are in danger of being consumed as policy solutions and developed into community or government expectations.

The ALRAC reviews of supported decision making, some academics, the NDIA management dialogues between themselves and service providers all appear to come from the concept that “disability” is almost theoretical. We feel that they have an image in their head of someone who uses a wheelchair and is saintly in their presentation. They merely need support, a ramp and other people in society to be understanding about their disability and everything else will fall into place. We get the impression these reports are written from a perspective of privilege, of education, respect and status rather than seeing this through the lens of the vast majority of the clients of the Public Guardians who fall squarely outside the realms of the social included. Jeffery Chan (2015) and others give a one size fits all solution –suggesting “positive behaviour support” as the solution to dangerous behaviours. The NDIS

---

14 Carter pg 145
15 Chan (2015) “Challenges to realising the convention on the Rights of Persons with disabilities (CRPD) in Australia for people with intellectual disabilities and behaviours of concern” Psychiatry, psychology and law 2
is driven towards “goals” of achievement for clients and some of the planners have never dealt with mental health before. Public Guardians represent a professional and skilled body of people who across the country have vast experience in dealing with

The Australian Guardianship and Administrative Council (AGAC) comments that substitute decision making cannot fully be replaced by supported decision making. The Australian government accepts that position too. Most practitioners in this field are awash with examples of how supported decision making would be a mockery of the term in some circumstances and so far I have not read anything that sets out a practical or pragmatic alternative to having an accountable and principled approach to substitute decision making in limited circumstances. How these circumstances needed to be legislated for should also be the subject to greater discussion. It would be for example worth considering that whilst the Public Guardians of the ACT demonstrate (and indeed are compelled to demonstrate) supported decision making within their guardianship role, this does not appear to occur in the relationship between a parent guardian and an adult offspring. Parents have the greatest difficulty distinguishing what they would want for their child and what they feel their child would choose and what the child, as an adult, would choose for themselves. The relationship between a child with special and complex needs and the parent caregiver is complex. Power and authority, dominance and dependence from the perspective of the person requiring care and from the parent caregiver, complex emotions of fear, loss, anxiety and often eventually overwhelm and work. Placing standards of practice on this relationship and placing an expectation of a standard of “supported decision making” between a private guardian and a supported person is largely impractical. To apply that expectation solely on public guardians is not so impractical but it requires a distinction in law and eventually a distinction from government and community in the understanding of guardianship as being different between public and private.
How guardianship is applied
The nature of Guardianship is changing specifically in reaction to the needs and challenges created in changing landscape of disability care. The National Disability Insurance Scheme (NDIS) has been piloted within the ACT and has given individuals the opportunity to take some control over the services they receive. The Public Advocate Guardianship team has now conducted almost 50 NDIS plans and has the greatest experience of the NDIS of any single body within the ACT system. There are a number of issues however which have been revealed during the first roll out within the ACT. These are in the process of being discussed with the NDIA but some of worth highlighting here as they apply directly to how Guardianship functions and the necessity to consider guardianship within the practically applied landscape of service delivery rather than merely through the lens of theory and academic debate.

One key problem with engaging with the NDIS/NDIA is the need for family members to negotiate care with a variety of service delivery providers. Service agreements are individual and private guardians have noted a variety of concerns in how they manage these administrative tasks. A similar concern has incidentally been reflected by smaller service providers. NSW Public Guardian has noted those with a public guardian negotiating their NDIS agreement resulted in them receiving a far more comprehensive plan than those negotiated with a Private Guardian.

These plans are required to be reviewed every twelve months and service agreements should constitute contracts for services which require monitoring and auditing regularly. This is an onerous task for some people. It is rare for someone who requires an NDIS plan to live a life that is straight forward and predictable – obviously no one’s life is predictable but those who require NDIS plans can feel certain that they face additional challenges. Some people who have complex family dynamics (their Private Guardianship arrangements are tenuous) or have complex needs may require more review than others. This places the responsibility for managing contracted services and standards of service delivery on those who negotiated the service – the Guardians. Even the ability to add a case coordinator as part of the plan is divided into a payment taken as a percentage of time in the individual service provider. Given the very tight budget constraints in this environment each agency would have to set aside a percentage of their time to “case coordination”. Once that money/time ran out, regardless of what else was happening for the client, there would be no further ability to pay for this work. Even at this early stage of NDIS implementation, the Public Guardians are being called on to cover this short fall and to advocate for and case manage those cases in which there are gaps. Case management is a skill which Public Guardians have and use regularly. The success of case management is based on the Guardians understanding of the client needs, views and wishes, the service environment in which the services are being accessed and being able to manage often competing and complex priorities. There is a level of taking and accepting responsibility for managing both the decisions and outcomes regarding clients, including those decisions which are made by the clients themselves, which Public Guardians will do regularly in the course of their work. The realities of ensuring adequate and appropriate support not just during decision making but through to outcomes

---

16 It should be noted that recently the NDIA has discarded the title “case management” as they felt that it was not in keeping with equality within disability services. Case management however is a recognised “skill” and there are accredited “case managers”. It is this level of complex service and support management which is needed in many cases. Unilaterally removing the title from the NDIA language and therefore from the service descriptions has created a difficulty for those trying to negotiate or describe the level of service and ongoing “management” that services and supports require.
and evaluation, are being made very apparent in the NDIS process. The multiple skills required of and demonstrated by Public Guardians, to ensure the best possible outcomes for clients, are being highlighted within the NDIS process. It is not surprising that a number of parent/guardians are struggling with this process.

In situations where there is a group home with some residents who have a Public Guardian and some with Private Guardians, it is noticeable that most Private Guardians are turning to the Public Guardian for assistance. The Public Guardian is more often not only managing their own client’s needs but assisting others with the difficult task of working through a number of complex service agreement, care plans, projected needs assessments, and contracts with service providers; not to mention assisting with paper work and negotiating with NDIA planners. What this highlights is the core and under-resourced, often overlooked skills of the Public Guardians.
Guardianship and the law

Guardianship needs to have oversight by legislation, both in the application of those powers and in the appointment of those orders. The courts therefore need to have some guidance to assist in the making of orders; in deciding on whom a “guardianship” order should be made. Considering under what circumstances a guardianship order is made should be decided by using a balanced assessment of both the medical model of disability or the social model. The medical model uses biomedical explanations which locate disability within the individual in terms of pathology. The social model views disability as arising from the interaction between a persons impairment (physical or mental conditions which directly limit a persons ability to enjoy a major life activity to a relatively normal degree) and the external physical and attitudinal barriers to his or her full and effective participation in society on an equal basis with others. The CRPD embraces a social model of disability, concentrating the disability experience not in individual deficiency but in the socially constructed environment. It is fair to say at the outset however that the courts, prefer and insist upon medical evidence of “capacity” and err towards the medical model to support the requirements of making guardianship orders, if not looking towards the medical profession to provide care for those in guardianship. While the social model of disability is reflected in the Convention the tensions between the framing of disability within a medical model and the conceptualisation of disability as social construction are not fully resolved by the Convention.

To take the application of the CRPD to deliver a human rights approach to anyone with a disability would necessitate not only an enormous increase in resources but at some point a declaration that the consequences of conditions in which someone lives their life, have made it impossible for them to access areas which are determined obligatory in the Convention.

An example is in the recent pilot schemes for supported decision making programs. Those who could not provide for themselves someone to support them through the (pre-accepted) decision-subject, were allocated a support person to assist them make a decision. There is no discussion that the training for this role as support person considered skills required to engage with people, the trauma informed model or the concepts of power and authority in this role. Piers Gooding (2015) refers to this potential noting that those “paid” to support someone – whether it is deliberate or not- open that...
relationship up to manipulation and abuse if only because the experiences of those needing supports are social isolation, trauma and vulnerability. General Comment 1 in the CRPD calls this issue “undue influence” but does not give particularly strong guidance on how this can be countered or acted against. It is interesting that this “issue” is being discussed in the context of the need to bring in external people to assist supportive decision making but is not currently adequately addressed in terms of unaccountable private guardian relationships or indeed the relationship between vulnerable people and advocacy agencies such as ADACAS for example. While it could exist in the relationship between a public guardian and a client – the decision making process and the relationship itself has to be accountable and is discussed in supervision and as a public guardian unit, not to mention is reviewed regularly by ACAT. Part of this internal review is for the guardian to articulate the power dynamic and to recognise the client's trauma history and therefore the potential that trauma may exist and therefore may affect their safety in relationships and decision making. It is less likely, although not impossible, that undue influence can be exerted from a public guardian/client relationship.
The need to distinguish between Public and Private Guardianship

Within legislation and within community expectation there is a need to distinguish between public guardians and private guardians. Much of the commentary around substitute and supported decision making, mental health and disability service application etc does not distinguish between Public and Private Guardianship arrangements. The current legislation, which specifically gives power and authority to the Public Advocate does not do anything to define the application of that power as distinguished from the power and authority allocated to private guardians. The current principles for example are the same as those given to the Public Trustee – this has been taken by some to infer the roles are similar or the same. The actual “powers” assigned to Guardianship as distinct from financial management are very different – they require a different and more direct set of principles to apply these and as discussed earlier, a radically different skill set.

The Public Guardians in the ACT (PA ACT) have developed a human rights/trauma informed framework and apply it to their work – it would be unusual however to find a private guardian who had considered concepts of social justice, empowerment, choice, safety, trustworthiness, and collaboration within each interaction with the person they act for. Further the actual mechanisms for applying these principles require training and understanding of theories of practice. To continue to use these principles of client intervention to an adequate standard they require supervision and ongoing training.

As well as the actual empowering legislation neither the Mental Health (Treatment and Care) Act 2014 nor other processes, policies which requires guardians to behave in a certain manner and cuts across service delivery, identifies the difference between Public and Private guardianship. The problems with this lack of distinction go both ways – the legislation does not protect public guardianship from outside interference because it does not recognise the specialism, accountability and expertise under which public guardians work. Conversely the expectations of accountability, monitoring and - in terms of the NDIS – service plan creation and implementation placed on guardians are universal. This means that private guardians with little or no experience in psycho-social assessment, stakeholder management or even the requirements of ethical supported decision making are being held to a standard which most cannot hope to meet. That being said there is little consequence to them failing this standard apart from removing them as guardian and placing the Public Guardian in their place. The first issue exposes public guardians to both the same criticisms of incidents and issues found in private guardians. This means that “guardianship” is roped in as one unified body and criticism levelled against those areas which are vulnerable to abuse, including financial abuse, are laid at the door of the public guardians.

Not having a separate Public and Private guardianship legislation exposes the work to other influences such as the occasional interference from private/semi-government funded advocacy agents.

The need to separate and have a clearly distinct set of standards, rules, obligations etc between Public and Private Guardians reflects the reality of guardians service in practice. It also provides a base from which Public Guardianship can apply for and give evidence to the need to have more funding and an increased status. Within our suggestion that there be a form of support network set up to assist those who require support in making decisions – there is a role for the public guardians to deliver training, ongoing support and perhaps a level of oversight for these network teams and the decisions being
made. This would require funding in the form of more public guardians but under these circumstances the training roles could be extended to provide private guardianship support across the Territory. Public Guardians if they are properly funded can provide a central point for supporting aged care concerns (Elder abuse), monitoring support services within the NDIS for the ACT, welfare checks on private guardianship and engaging productively in research and reviews in the areas of guardianship, consent, autonomy, supported decision making, mental health, NDIS etc.

### Supported decision making

Public Guardians already approach each case through the lens of social justice and trauma informed. In order to actually consider any decision through these principles requires guardians to consider the person as an individual and as a person in the context of their own lives. We are a bit taken aback that there appears to be an assumption, within the current community and academic narratives, that supported decisions are not made if they can be made. The public guardians in the ACT ensure that any substituted decision making goes through, after through assessment, a process of expertise, colleague & peer review, and auditing against our standards and principles.

The Public Guardians of the ACT would be happily involved in any working group or discussions around supported decision. A primary issue for us however is that we are currently being swamped with the core client work and we do not have the time and resources to dedicate what is needed to this important research. We feel very passionately about being involved in these discussions and contributing to the thinking and development of supported decision making in the ACT but at the same time we do not have any resources to give to anything other than client work.

### Support network

The Public Guardians of the ACT would argue that within the community (private guardians) there should be a support network created for people who require support, rather than a singular support person. This network (possibly on the same lines as the Canadian model) should be adequately resourced, have access to training and have assistance or oversight if needed, for the more complex decisions, from a public guardian or social worker. Resourcing should include financial assistance to attend training. The concept of having a support network reflects what happens generally in society – this ties in to the concepts of autonomy and what defines as truly adult autonomy on decision making. We generally take advice from a variety of people and we are influenced by people in our lives. Supported decision making should reflect as closely as possible what happens in society generally – obviously with sensitive reflection of the individuals culture and spirituality, age and individuality. The Public Guardians could provide training and ongoing monitoring and support of such networks. They could step in if necessary and possibly hold roles not dissimilar to a case conference chair making sure that all parties are heard and that the focus remains on the client.

In situations when the person does not have access to a support network then the Public Guardians can become the persons Public Guardian. This means that the Public Guardian would support the person to make those decisions. As with everything the Public Guardians do, they are accountable and work through a professional framework. They could provide a network of supports for the person to access other opinions and supports – including ADACAS and other services – but retain the role of
guardian which would ensure that the person remains protected and retains access to all other human rights – and ensuring the decisions are not catastrophic.

Throughout the discussion on supported decision making there has been little focus on the issue of suicide – specifically within psychosis, depression or drug induced psychosis. Whatever process is developed to implement and carry through supported decision making will need to have protections in place – for both the client and for the support people – to assess and risk manage suicide. There will need to be consideration given within the legislation to what constitutes a protection against poor practice for support people – specifically when suicide or other negative impacts occur with a direct relation to poor practice or deliberate harm by the support people.

Dignity in failure does not apply equally to those who have had a life time of social exclusion and injustice. Failure is not comparative and does not affect those similarly - so who is to judge what is a risk or not in these circumstances?

There should be a central and accessible body to de-brief or support private guardians or support network members for if/when decisions go wrong, the person they are supporting dies or something happens where they feel they need extra support.
Substitute decision making.

This has to be, as is from the perspective of Public Guardians, considered as a last resort but there are far too many cases within the Public Guardians client context to dismiss this as never being needed. The Public Guardians of the ACT work from the perspective of a social justice framework – they are accountable in their decision making process to ACAT and to the community. They can and do articulate under what context they made a decision for a person instead of with them. Substitute decision making is not the first and only response and is made in circumstances which can and are demanded to be accountable for.

This is not so within Private Guardianship. It is not that Private Guardians are necessarily inflicting their will on to others but it is usually a natural progression from being a parent and making decision for someone as a parent to making those same decisions and forgetting that although they require support, the child is now an adult. The problem remains that without consequence in legislation or without giving the training and monitoring of private guardians resources and standards – there will always be private guardians who use their powers and authority to make decisions for someone without going through a human rights or social justice principled or ethical decision making process. They will make those decisions to suit their own aims or because they cannot distinguish between being a parent and reacting like a parent and being the guardian of an adult.

There are too many cases where substitute decision making is essential – the most obvious is those who are suicidal because of mental illness and/or drug and alcohol.

Public Guardians make substitute decisions for people but these are not consistent to the person and they are placed against a risk matrix of harm to the person and harm to others.

Decision making is not linear and decisions are not singular in the context of requiring a guardian or assistance or support. It is doubtful that legislation can cover this complexity – so in the absence of that legislation should identify a skill base to apply these. Removing substitute decision making because it does not appear to comply with a human rights model leaves those who work within the necessity of having to apply substitute decision making.
<table>
<thead>
<tr>
<th>PRINCIPLES:</th>
<th>HUMAN RIGHTS/ SOCIAL JUSTICE</th>
<th>BEST INTERSECTS AS A PARAMOUNT CONSIDERATION</th>
<th>SAFETY</th>
<th>TRUST WORTHINESS</th>
<th>CHOICE</th>
<th>COLLABORATION</th>
<th>EMPOWERMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engagement &amp; Assessment (Intake)</td>
<td>Has the actual right been articulated? How does this right translate into a practical service delivery for this client? Has the client had their rights recognised?*</td>
<td>Has the application of best interests been considered within the individual's context (bounded by capacity) including “culture, spirituality, age, gender identity, economics and education”? Is there a need to invoke the paramount principle? Why? Has this been explained to all and evidenced in the report? Have I articulated the negated effect of the Human Rights Principle.?</td>
<td>Did we listen to the client without interrupting, judging or tell what to do before getting all the facts? Did we recognise the client’s idea of safety? Did we gain an idea of the client’s need for safety? Did we feel we had to act to keep the client safe? Did we do it?</td>
<td>Did we provide clear information on what we do and what we could not do? Did we provide information as to where the client could go for help we could not provide? Could the client do this or did client need assistance to follow up? Did we provide the assistance? Did we provide information about confidentiality, reporting pathways and options?</td>
<td>How much choice did we offer? The choice of contact? Was the client able to make choices or need further support to make choices? Did we provide that extra support if needed?</td>
<td>Did we ask the client for their next steps? Were these steps in line with safety? If not in line with safety did we act to provide safety? Was the client able to come up with next steps or need assistance in developing them? If not able to make them, did we provide support?</td>
<td>Did we recognise the client’s strengths? Where these strengths in line with safety? Did we validate them and encourage the client to use them? Was the client able to use them?</td>
</tr>
<tr>
<td>Working with Clients</td>
<td>Has each of the individual (including language) identifiers of the client being recognised?</td>
<td>Did we reference the client’s ideals for their future?</td>
<td>Did we do what we said we would do?</td>
<td>How supportive were we to offer choice?</td>
<td>Did we acknowledge the client is one of the expert in their care?</td>
<td>Did we ensure all contact was directed at empowerment?</td>
<td></td>
</tr>
<tr>
<td>Has the power and hierarchies been defined?</td>
<td>Views and wishes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have the expressed wishes been placed into the clients narrative – in the context of their “life”?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What steps have been taken to allow the client to express themselves and what has negated that – including education, language, etc</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Securing safety**

| Is the client aware of the outcomes? | Has tension between rights and best interests been articulated? | Has the decision making process been clearly set out? | How did we support the client with the decision? | Where these in line with client’s strengths, abilities and plan? | Have the services we provided been what we expected? | Did we acknowledge views and wishes | Have they been in line with what the client expected? | What services did we offer? | Was the client able/willing to utilise them? | If not, what action was taken? | Do we allow clients to direct their own services? | Can client do this? | If not, what have we offered? | Are we developing skill-building? | How are we doing this? |

*Human Rights as an active application of a legal statement is a complex balance between often competing concepts. Application of the Best interest principle of those who are vulnerable, is as much a core application of Human Rights as any other element. If there is an apparent or real conflict between Human Rights and “Paramount Principle” then bring this to supervision or discussion. It is important to have these ideas articulated and worked through as they are learning examples for all of us as well as necessary tensions in which we work.

Principles do not always determine clearly what is right and what is wrong. This requires the exercise of judgment. All those applying these principles to the clients of the Public Advocate must do so within the authority set out in the Act and using ‘professional’ judgment and all those skills that title demands they apply.
References

Blanck, P & Martinis J (2015) “The right to make choices: The National resources Centre for supported decision-making” Inclusion, Vol 3 no. 24-33


Chan, J (2015) “Challenges to realising the convention on the rights of persons with disabilities (CRPD) in Australia for people with intellectual disabilities and behaviours of concern” Psychiatry, Psychology and Law,


Ferguson, C (2008) “Promoting Social Integration” UNDESA, Finland 8-10 July


Siemon, D; Hurme, S & Sabatino C (1993) “Public Guardianship Where is it and What does it need?” Clearinghouse Review, October
