Submission
No 7

INQUIRY INTO SUBSTITUTE DECISION-MAKING FOR PEOPLE LACKING CAPACITY

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SUBMISSION TO THE NSW LEGISLATIVE COUNCIL'S INQUIRY INTO SUBSTITUTE DECISION – MAKING FOR PEOPLE LACKING CAPACITY

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INTRODUCTION

The Public Guardian is committed to promoting and protecting the rights, interests and dignity of people with decision making disabilities and reducing their exploitation, abuse and neglect through the provision of guardianship services in the least restrictive manner possible.

Part One of this submission provides the historical context of this legislation in NSW. Part Two of this submission provides an overview of the current policy environment and raises questions on the limitations and scope of the current legislation. Part Three Updates the Role of the Public Guardian and outlines the changes that are required to give effect to the changed thinking and human rights focus that is now prevalent within Australia and in particular the disability sector. Part Four of this submission provides other specific recommendations to amend the Guardianship Act to make it more able to address the needs of people with decision making impairments relevant to the Terms of Reference for this Inquiry.

Graeme Smith
Public Guardian

PART 1

OVERVIEW

The NSW Guardianship Act was enacted in 1987, against a backdrop of the closure of institutions, to protect the welfare and interests of people with disability and to ensure access to the range of community-based services that could provide them with the same opportunities as other people in the community. Originally the Act was known as the Disability Services and Guardianship Act and was seen at the time as welfare legislation and within the genre of protective legislation. The Act aims to protect the welfare and interests of people over the age of 16 years who have a disability and a need for others to make decisions on their behalf. In 1989 the NSW Guardianship Board (now known as the Guardianship Tribunal) and the Office of the Public Guardian were formed.

The Act has been amended on a number of occasions since 1987. For example, in 1998 it was amended to allow for the appointment of enduring guardians. Further amendments to the Act in 2004 enabled decisions made by the Guardianship Tribunal or the Public Guardian to be reviewed by the NSW Administrative Decisions Tribunal

During the 1980s in NSW the Richmond Report played a significant role in the support landscape affecting people with a disability and was part of the impetus that gave rise to Guardianship legislation. *The Guardianship Act 1987* enshrined, what were then, contemporary guardianship principles, in legislation. These reforms were largely driven by the adverse experience of people with an intellectual disability, many of whom lived in large institutional settings. At the time, the Act represented a significant advance in protecting the welfare and interests of people with disabilities and was introduced as part of a wave of disability services reform. In contemplating what might be done to promote and protect the welfare and interests of people with a disability, policy makers at the time were mindful of the need to involve the community much more in the lives of people with disabilities.

PART 2

THE CHANGING POLICY ENVIRONMENT

The *Guardianship Act* is now 22 years old. The society we live has changed a great deal since the Act was first introduced. At that time, it was considered landmark legislation but by today's standards it fails to take into account such things as human rights legislation, international conventions, de-institutionalization and new ways of thinking about supported and substituted decision-making. This is also reflected in the disability sectors' emphasis on the limitations of substitute decision making and the shift towards assisted decision making within a human rights framework.

The profile of people under guardianship has also changed significantly. In 1989 over 95% of people under guardianship had an intellectual disability. In the last financial year only 38% had an intellectual disability, 12% had an acquired brain injury, 18% a mental illness and over 20% had some form of dementia. Over 44 % of the people currently under guardianship are aged 60 years or over.

In 2008, there were an estimated 227,000 people in Australia with dementia, with 57,000 new cases of dementia diagnosed in that year alone. By 2050, the number of people with dementia in Australia is expected to increase by a staggering 330%, while the total population is expected to increase by less than 40%. Dementia is a major determining factor in entering into residential care with at least 60% of people in high care facilities and 30% of people in low care facilities having some form of dementia. The onset of dementia and the questioning of legal capacity through substituted decision–making are significant risk factors for elderly persons.

The application of guardianship laws to an individual may result in the loss of a fundamental human right: the right to autonomous decision-making or self determination. In reviewing the Guardianship Act, we must therefore be mindful of human rights laws and obligations and use these as our starting point. Human rights must be considered up front – at the beginning of our work rather than at the end of a complaints process.

Within both the disability sector and the Australian mind set there has been a shift from a protection mentality towards a clearly articulated human rights focus. Both Victoria and the Australian Capital Territory have adopted a Human Rights Charter. The Australian Government has held a National Human Rights Consultation aimed at seeking a range of views from across Australia about the protection and promotion of human rights. The National Human Rights Consultation Committee's report to the Australian Government is due on 30 September 2009. The Committee has been asked to identify options for the Government to consider which will enhance the protection and promotion of human rights. In July 2008 Australia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). A key element of this Convention is the emphasis that is placed on social inclusion and in protecting the dignity and human rights of all people with disabilities.The principles of the convention include:

- respect for inherent dignity;
- individual autonomy, including the freedom to make one's own choices;
- independence of persons; and
- full and effective participation and inclusion in society.

To ensure that NSW is in line with other jurisdictions and with the UNCRPD we need to consider models such as assisted or supported decision making. Increasingly disability groups have recognized that the amount of support and assistance people seek and receive to make decisions varies depending on the person's ability, personality and life circumstances and on the particular

decision. Disability advocates have suggested that formal support networks for people with disabilities would enable them to make normal life decisions with the support of family, friends and service providers and thus reduce the need for guardians to be appointed.

Supported decision-making principles and values are to some extent already present in law, policy and practice within our community. The current Act, for example, contains a minimal intervention principle. However guardianship is recognized as a significant intervention into the life of a person and a removal of their civil liberties and must be a last resort.

The Convention conceptualizes substitute decision making as a last resort option and that programs of assisted decision making should be available to people with diminished capacity as a first step. In most other Australian jurisdictions this can be achieved with the assistance of the Office of the **Public Advocate**. The Public Advocate can frequently resolve issues through investigation, advocacy, through the mobilization of appropriate human services and alternative dispute resolution without the need for the appointment of a guardian. This is a less intrusive response to assisting people with a degree of incapacity. In some cases the appointment of legal substitute decision maker will be necessary. The Public Advocate can be appointed as the guardian of last resort.

Administration of the Guardianship Act 1987

The Convention moves us toward a society in which all people with disabilities are active citizens and focuses our attention on ability rather than disability. This shift is not about the welfare of people with disabilities but about the civil law's response to issues relating to capacity and incapacity.

The Guardianship Act in NSW is administered by the Minister for Disability. It is considered welfare legislation rather than human rights legislation. In every other Australian jurisdiction the Guardianship legislation, together with provisions for financial guardianship, is administered by the Attorney General or equivalent.

The NSW Act provides for the Public Guardian and the Guardianship Tribunal to report to the Minister for Disability. The Minister for Disability is also responsible for the provision of services to people with disabilities. It is argued that these administrative arrangements represent an anomaly particularly for the Public Guardian who has a role in systemic advocacy on behalf of people with disabilities.

From July 1 2009 the Public Guardian is now located within the NSW Trustee and Guardian, which is administered by the Attorney General and sits within Justice and Attorney General. The Public Guardian is now administratively accountable to the Chief Executive Officer of the NSW Trustee and Guardian. However, the Guardianship Act, providing for guardianship of the person, is administered by the Minister for Disability. Approximately 70% of people with a guardianship order also have a financial management (financial guardianship) order.

The system of guardianship and administration in NSW, from a policy perspective, is fractured.

As stated, the Public Guardian currently reports formally to the Minister for Disability Services. However the Public Guardian is required to act with complete independence in protecting the interests of the people for whom he is guardian. While this situation exists, the Public Guardian and the Minister for Disability Services remain open to a charge of conflict of interest in their dealings with people with decision making disabilities.

It is recommended that the Public Guardian report to a Minister who is not involved in providing or

funding services the services with which the Public Guardian deals on a day-to-day basis for people with disabilities. The most appropriate Minister is the Attorney General to whom bodies such as the NSW Trustee and Guardian already report. This would represent a shift of the legislation into a justice policy milieu and bring the principles of guardianship into line with the principles of the UNCRPD.

PART 3 : UPDATING THE ROLE OF THE PUBLIC GUARDIAN

Part 3 of the submission outlines:

- the advantages and disadvantages of amending the Guardianship Act in NSW to allow the Public Guardian to update its role so that it can pursue better life circumstances for people with decision-making disabilities without necessarily being appointed as their guardian;
- the wide ranging systemic change role that legislation gives to the Public Guardian's interstate counterparts; and
- addresses some other related issues about the current legislation.

GUARDIANSHIP ACT - PART 7 - THE PUBLIC GUARDIAN

Part 7 of the Guardianship Act should be amended to provide for the role of the Public Guardian to be updated to meet the challenges presented by the changing policy environment for people with decision making disabilities including the challenges presented by the ageing of the population and in comparison to the somewhat different roles played by similar bodies in other states

The Public Guardian's existing roles are:

- Acting as guardian for a person with a decision-making disability when appointed by the Guardianship Tribunal or Supreme Court. As well as making decisions for a person about issues such as where they should live, this role includes actively seeking out improved life circumstances such as appropriate accommodation;
- Identifying patterns of problems for people with disabilities that emerge from assisting individuals, and seeking solutions to those problems;
- Providing information and support to family members and other individuals who have been appointed as someone's guardian by the Tribunal; and
- Providing information and education for the community about guardianship issues.

A key feature of Australian guardianship laws, in general, is that a guardianship order should not be made if there is a less drastic way of meeting the needs of the individual. A person's decision-making rights should not be formally taken away except as a last resort.

In practice, it has often been difficult to apply this approach in NSW because the Public Guardian is not able to assist an individual or group of people with decision-making disabilities without first being appointed as their guardian. In contrast, the Public Guardian's counterparts in other states are able to do this.

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Acting as Guardian

The central role of the Public Guardian is to act as guardian of a person with a disability when appointed by the Guardianship Tribunal. This role primarily is to make decisions on behalf of individuals with decision-making disabilities about issues such as where the person should live, and what medical treatment and other services the person should receive. Most guardianship orders made by the Tribunal define the Public Guardian's role in this way.

Good guardianship practice extends beyond simply reacting to, or endorsing, proposals of service providers and others about decisions for a person. In many cases, the practice of guardianship includes actively seeking out appropriate options from which to choose. If a guardian does not take this approach, the person under guardianship will often remain in very inadequate and deprived accommodation or other circumstances. Some guardianship orders made by the Tribunal explicitly give the Public Guardian the role of advocating for the provision of better accommodation and service options for an individual.

The basis for the Public Guardian taking this proactive view of its role is found in writings about guardianship, case law and the principles of the Guardianship Act.

Writings about guardianship have long recognized that guardianship includes the active pursuit of positive life circumstances for the person under guardianship. The Guardianship Act says that a guardian may be given "custody" of a person with a decision making disability and may have any of the functions "that a guardian has at law or in equity".

Both case law about functions of a guardian and other sections of the Guardianship Act suggest that guardianship includes an active process of seeking out appropriate life options, rather than simply a reactive approach of consenting to options that are proposed to the guardian. In the 1986 NSW Supreme Court case *F v R*, Justice Powell quoted approvingly from a number of older legal text books which certainly suggest an active role for a guardian in seeking out appropriate life options.

This is strongly reinforced by section 4[1] of the Guardianship Act which imposes a duty on guardians to observe the principles of the Act. This section implies an active role for the Public Guardian in seeking out life options that will meet these principles.

Also, the Guardianship Tribunal's duty to consider the "practicability of services being provided" to a person with a disability "without the need for the making of a guardianship order" implies that guardianship may be used to ensure that appropriate services are provided.

It seems clear that inherent in guardianship is the role of seeking out appropriate options for a person. For example, a guardian with the function of deciding where a person should live has the implicit function of pursuing an appropriate living option that complies with the principles in section 4 of the Guardianship Act.

Systemic Role

As well as taking a proactive role in seeking out appropriate life options for individuals under guardianship, the Public Guardian undertakes some activities which may improve the availability and quality of services and other life options more generally for people with disabilities.

These activities flow from patterns observed by the Public Guardian in acting as guardian for individuals. For example, the Public Guardian has encountered patterns of problems in the services available to people with eating disorders, people living in boarding houses and people with disabilities involved with the criminal justice system. The Public Guardian has documented these patterns and taken action including:

- Bringing the problem to the attention of relevant Ministers and Departments;

[1] See appendix 1.

- Reporting on problems and raising ideas about solutions in the Public Guardian's annual report and other publications; and
- Participating in governmental committees and public forums dealing with particular issues.

This is the Public Guardian's "systemic" role and is focused on improving systems such as service systems or legal systems

The Public Guardian might also observe problems facing a number of consumers of a particular service. For example, the Public Guardian may be concerned about the way in which a particular residential service deals with the challenging behavior of a number of people under guardianship.

The Public Guardian may then take up this issue with the management of the particular service, or, if necessary seek the intervention of an independent complaints body, such as the Health Care Complaints Commission or the Ombudsman (Community Services Commissioner).

The Public Guardian's systemic role flows primarily from its role as guardian for a number of individuals affected by a common problem. Naturally, the Public Guardian will seek, if possible, a systemic solution rather than just seeking a separate solution for each individual. If a systemic solution is found, it will have the flow on effect of benefiting people with disabilities more generally.

This role of the Public Guardian is also supported by its duty to encourage the community to apply and promote the principles in the Guardianship Act and its obligation to periodically report to the Minister for Disability Services.

The Public Guardian's systemic role is particularly useful to people with types of disability who do not have extensive networks of community groups pursuing systemic issues with government on their behalf.

However the current legislation does not provide a formal recognition of or a broad mandate to pursue the interests of people with disabilities generally.

Support of Private Guardians

The Public Guardian established a Private Guardian Support Service to provide information and support to family members and other individuals appointed as guardians. This was an attempt to give affect the principle of the least restrictive alternative. This role is based on the requirement in the Guardianship Act that the Public Guardian "ensure that information is readily available to members of the public concerning the exercise by guardians of their functions". The role will also help to achieve the requirement in the Act that the Public Guardian should only be appointed as guardian where it is not possible to appoint a private individual.

Community Information and Education

The Act also requires the Public Guardian to "ensure that information is readily available to members of the public" about the guardianship system and to encourage the community to apply the principles of the Guardianship Act. The Public Guardian has a Community Information and Education Team which provides written material, speakers and seminars about guardianship issues.

Public Guardian's Role in Tribunal Hearings

The Public Guardian is a party to all Guardianship Tribunal hearings of an application for guardianship. The Guardianship Act also specifically states that the Public Guardian may make an application to the Tribunal for a guardianship order or for a review of a guardianship order.

Role of the Official Guardian in other States

Beginning with Victoria in 1986, every Australian state and territory, has legislation allowing a court or quasi-judicial tribunal to appoint a guardian for an adult with a decision-making disability.

In each state and territory, there is also an official guardian who can be appointed where guardianship is needed and there is no private individual available and suitable to act as guardian.

However, the guardianship legislation in the other states and the Australian Capital Territory gives the Public Guardian's counterparts additional roles which can reduce the circumstances in which guardianship applications and guardianship orders are needed.

They can provide assistance to an individual or group of people with disabilities without the need for a guardianship order. They also have broad mandates to pursue the interests of people with disabilities generally.

In Victoria, the role of the Public Advocate includes:

- "To promote, facilitate and encourage the provision, development and co-ordination of services and facilities provided by Government, community and voluntary organizations for persons with a disability...."
- "To seek assistance in the best interests of any person with a disability from any government department, institution, welfare organization or service provider."
- "To make representations on behalf of or act for a person with a disability."
- "To investigate any complaint or allegation that a person is under inappropriate guardianship or is being exploited or abused or in need of guardianship."

In South Australia, the Public Advocate's role includes:

- "To keep under review, within both the public and private sector, all programs designed to meet the needs of mentally incapacitated persons."
- "To identify any areas of unmet needs, or inappropriately met needs, of mentally incapacitated persons and to recommend to the minister the development of programs for meeting those needs or the improvement of existing programs."
- "To speak for and promote the rights and interests of any class of mentally incapacitated persons or of mentally incapacitated persons generally."
- "To speak for and negotiate on behalf of any mentally incapacitated person in the resolution of any problem faced by that person arising out of his or her mental incapacity."
- "To raise with the Minister and the Attorney General any concerns he or she may have over any matter arising out of or relating to the performance of his or her functions." Such concerns are laid before parliament either in a special report or in the Public Advocate's annual report.

The official guardians in the ACT and Tasmania have similarly broad roles.
The Queensland Government has recently proposed changes that will see the amalgamation of the roles currently shared between the Public Advocate and the Adult Guardian.

In Western Australian, the Public Advocate has similar although less expansively expressed roles.

Current Approach to Guardianship in NSW

In Principle

In principle guardianship is intended to benefit individuals and provide them with protection from exploitation, neglect and abuse. Those individuals may also experience the negative aspects of being labeled as a person who is "incapable of managing his or her person", losing their rights, losing their freedom of action and having their privacy intruded upon.

In response to this, all Australian guardianship systems include a provision that a guardianship order is not to be made if there is a less drastic way of addressing the needs of the individual.

This response is based on the principle of "least restrictive alternative" which says that any procedure used for the benefit of a person with a disability should not intrude unnecessarily into the life of the person.

Research on guardianship in Australia, suggests that Australian guardianship should be based on strong respect for the autonomy of action of the individual because intervention to protect vulnerable people or displace individual choice is heavily circumscribed in the general law.

All guardianship systems state that it is only appropriate to appoint a guardian for "people whose lack of ability to make a decision poses an immediate social crisis, and if the crisis is not capable of being resolved by less intrusive measures."

This means that guardianship should only be needed in situations affecting a person with a decision-making disability such as:

- where there is a dispute about a life decision for a person between two available options, or
- where a person is making decisions that are detrimental to him or her or someone else is making such decisions for the person.

Other relevant situations include where a decision needs to be made that requires a certain level of understanding for its legal validity, for example consent to medical or dental treatment, and there is no-one with the power to make the decision.

In Practice

In practice, for the system to avoid unnecessary applications and orders for guardianship, there needs to be a range of less formal and intrusive options than guardianship, to meet the needs of people with decision-making disabilities. Unfortunately, the accompanying range of less formal and less intrusive options has not eventuated and this has had a major effect on the way in which the guardianship system has operated in NSW.

The Guardianship Act in NSW does not provide mechanisms within which supported or assisted decision making, as contemplated by the UNCRPD, could have effect.

There are regular situations in which a guardianship order is made, continued after review, or includes additional functions, for the purpose of giving the Public Guardian the authority to seek improved accommodation, services or other life circumstances for people with disabilities.

Clearly, if a person or group needs assistance to pursue better life circumstances, rather than someone to adjudicate a dispute about their life circumstances, it would be preferable if this could occur without an application to the Guardianship Tribunal and a guardianship order. Guardianship may later be needed if less drastic approaches are inadequate, but the less drastic approaches should be available to be tried first.

Recommendation

Amend Section 77 to provide the Public Guardian with the capacity to assist people with decision making disabilities without a guardianship order

This would enable the Public Guardian to be able to provide a less restrictive option than guardianship to meet the needs of some people with decision-making disabilities. This would give effect to the right to access supported or assisted decision making as a first step rather than having to resort to full substitute decision making.

The Public Guardian could consider taking this role after referral of a case from the Guardianship Tribunal or after being approached by a person such as a family member. Such a change would divert a substantial number of cases from the Guardianship Tribunal and therefore reduce delays in cases being dealt with by the Tribunal.

Naturally the Public Guardian would require the capacity to investigate and manage these non-guardianship referrals. In exercising this role, as with its other roles, the Public Guardian would be bound to comply with the principles in Section 4 of the Guardianship Act.

If there was a dispute about the authority of the Public Guardian, or the appropriateness of actions taken by the Public Guardian, when assisting individuals or groups, consideration could be given to an application to the Guardianship Tribunal for appointment of a legal guardian. This might be at the instigation of the Public Guardian or by a person such as a service provider who felt the Public Guardian was acting inappropriately.

Also, if the Public Guardian found that less formal intervention was inadequate and that guardianship was needed, it could then make an application to the Tribunal. For example, the Public Guardian might become involved in assisting the residents of an institution that was closing to ensure that the process of relocation met the needs of the residents. The less formal approach might prove adequate for most of the residents. However, applications for guardianship might be needed for some individuals because of issues such as disputes about where they should move or resistance by service providers to appropriate medical reviews.

Recommendation

Amend Section 77 to provide for the Public Guardian to have capacity to investigate the need for a guardianship application

As is common for other official guardians in Australia, the Public Guardian has a statutory power to make an application to the Guardianship Tribunal for a guardianship order. Usually, applications are made by family members or service providers.

However, situations arise where a person is being neglected or abused and, not only is there no one willing or available to make the application, there is no one to bring the situation to the attention of the Public Guardian so that an application can be made.

Currently the Public Guardian cannot be pro-active in identifying vulnerable people who may be in need of a guardian. Even when the Public Guardian is aware of vulnerable people in potentially desperate situations, it can be difficult to assess whether an application should be made due to the Public Guardian lacking the authority or a clear role to investigate the situation, as opposed to simply making the application.

In most other states, the equivalent of the Public Guardian has this role clearly stated in the guardianship legislation. As well as being used to decide about an application to the Tribunal, it could be used to find a resolution to a problem that is less drastic than an application for a guardianship order.

Section 77 of the Guardianship Act should be amended along the following lines
"To investigate any complaint or allegation that a person, who appears to the Public Guardian to have a decision making disability, is being exploited, neglected or abused, or is in need of a guardian".

Recommendation
Amend Guardianship Regulation 2005 to enable the development of a Community Guardian Program

Guardianship Act Section 77(4)

The Guardianship Regulation 2005 should be amended to provide for the development and implementation of a community guardianship program. The Public Guardian submits that there are significant merits in implementing a community guardianship program. Community guardianship offers benefits in terms of increased direct community participation in the guardianship process and more efficient decision making across the Public Guardian's client population. Community Guardian programs currently operate in Victoria, the ACT, Western Australia and will shortly be introduced in South Australia.

Community participation in the guardianship process

Community participation in statutory guardianship addresses, partially at least, principle 4(c) of the *Guardianship Act – such persons should be encouraged, as far as possible, to live a normal life in the community,* and substantially principle 4(h) – *the community should be encouraged to apply and promote these principles.*

The proposed community guardianship program will also meet the objects of the *Disability Services Act* 1993.

Culturally appropriate guardianship services

The proposed model of community guardianship will enable community members from a variety of cultural and linguistic backgrounds to be engaged to deliver a statutory guardianship service in their community of origin. It is envisaged that the pilot program will target aboriginal communities where there are a number of clients under guardianship, as well as individuals from non-English speaking backgrounds. The program will recognize and remunerate the cultural qualifications and experiences of such individuals in addition to their expertise in disability.

Enhanced efficiency in service delivery

At the end of the 2007 financial year NSW reported that there were 1782 individuals under the guardianship of the Office of the Public Guardian. The next most numerous state was Victoria with 727 individuals under Public Guardianship.

The table below provides a comparison of the rate of public guardianship per 100,000 individuals for each state:

State	ABS population Data for 2007	Persons under public guardianship	Rate per 100,000	% Population change over previous year
NSW	6,908,900	1782	25.79	1
Victoria	5,226,400	727	17.20	1.5
QLD	4,201,100	719	17.11	2.2
SA	1,588,500	401	25.24	1.0
WA	2,118,500	288	13.59	2.4
TAS	494,500	119	24.06	.8
ACT	340,300	105	30.86	1.5

As the table demonstrates, aside from the ACT, New South Wales has the highest rate of guardianship amongst the Australian jurisdictions.

The Public Guardian's role is both **investigatory** and **protective**. The Public Guardian's investigatory authority is related to making decisions and taking actions to achieve options for alternative decisions to be made. The Public Guardian's protective authority is not always formally recorded, except perhaps in client file notes. The Public Guardian has a legitimate and ongoing role to protect the client from the detrimental consequences of alternative decisions being implemented by others with a vested interest. Typically in the context of familial conflict, the Public Guardian will make an investigative decision related to a lifestyle domain. The party, or indeed the client, who perceives the decision is not consistent with their interest will seek either overtly or subtly for an alternative decision to be made.

The Public Guardian in making the original decision will usually have determined there is no merit in the alterative proposal, with the focus of guardianship being on ensuring that the resistant party does not take action to undermine the decision. In these matters, in the absence of ongoing guardianship, the person may be placed at risk of harm through a less than preferable decision being implemented.

The other protective role for the Public Guardian arises when exercising authority of a guardian on an annual basis to maintain the status quo. These cases typically focus on the use of restrictive practices and / or a locked door. Here on-going monitoring and consent is required, however the complex issues surrounding the use of such practices have often been resolved. The typical circumstance is where, following a rigorous decision making investigation, the Public Guardian has determined that the least restrictive option for a person under guardianship is a strategy, which, but for the consent of an appointed guardian, would be unlawful.

Delivering a guardianship service to these protective clients may be more effectively and efficiently achieved through delegating the Public Guardian's decision making powers to a community member who has been trained and appropriately assessed. Whereas guardianship staff have responsibility for responding, as a priority, to the investigative active clients, a community guardian's priority would be meeting the protective decision making needs of less intensive clients.

A community guardian, located in the community of the client and dedicated to providing a protective guardianship service, is ideally positioned to obtain information, not just from the written record, but also experientially. This information adds to the credibility of the community guardian in communicating decisions to interested parties and is likely to reduce complaints and concerns arising from communication breakdowns. The community guardian's interest is exclusively on the person in need of a guardian. Their focus is not divided between those clients whose decision making needs are protective and those clients who require an investigatory, active and urgent decision made on their behalf.

The capacity of a community guardian to access a client, to experience the world of the client, and to focus on the life of the client within the context of the client's environment, and not just the information contained in the official record, should result in the correct and preferable decision being made; and this decision being effectively communicated in the minimum time because the community guardian knows the client.

Such a program, as has been demonstrated in other Australian jurisdictions, has the potential to enhance the efficiency of guardianship service delivery as well as the quality of the service provided to clients in the community. The number of clients under public guardianship will inevitably increase on an annual basis. The implementation of a community guardianship program can assist in the management of increasing client numbers through the appropriate referral of protective guardianship matters to community guardians.

Community guardians will have the opportunity of developing close professional relationships with clients in the community. This should result in the correct and preferable protective decision being made efficiently.

Amend Guardianship Act Section 78 (1)

This section should be deleted as it is now redundant following recent amendments to the Guardianship as a consequence of the passage of the NSW Trustee and Guardian Act 2009 (See 77(4).

Amend Guardianship Act Section 78 (2)

Amend this section to remove the reference to "members of staff of Office of the Public Guardian" and insert instead "members of staff of Justice and Attorney General".

Part 4

Other Proposed Amendments to the Guardianship Act 1987

Guardianship Act - Part 1 – Preliminary

Amend Guardianship Act Part 1 – Preliminary
Amend Section 4

It is recommended that General Principles of the Guardianship Act be amended. In particular principle (e) "the importance of preserving the family relationships and the cultural and linguistic environments of such persons should be recognised" be amended to change "family" relationships to "personal relationships" to take account of those people in same sex relationships and or other personal relationships that are preferred to the family relationships.

***Amend Guardianship Act - Part 2 – Appointment of Enduring Guardians to provide for the* registration of Enduring Guardianship Appointments**

The *NSW Guardianship Act* provides for the appointment of enduring guardians. Adults in NSW, who have the capacity to make their own decisions, can appoint another adult as their enduring guardian. Enduring guardians are not authorized to make decisions about money or property, rather they are appointed to make decisions about life areas such as accommodation, health care or medical treatment. This appointment only takes effect when the person loses their capacity to make their own decisions. This loss of capacity may happen as a result of a disease such as dementia or a traumatic event such as a stroke or brain injury. The process of appointing an enduring guardian is similar to that of granting power of attorney or completing a will. An appointment form is filled out by the appointee and the person they wish to be their guardian. The appointment form will specify the areas of decision making and can include any specific instructions or wishes that the person has. This form needs to be witnessed by a legal practitioner, and once signed it becomes a legal document. There is currently no requirement for the document to be registered, and the person and their enduring guardian are encouraged to keep copies of the appointment with their important papers.

Case study:
Mrs Jones was recently widowed, when her husband with dementia passed away. As Mr Jones's dementia became more severe, Mrs Jones and her children had to make many decisions regarding his medical treatment and care, as he was unable to make these decisions himself. Because Mr Jones had not made any plans for his future, or discussed his wishes with his family, decision-making was complex and difficult.

Mrs Jones decided that she wanted to avoid any possible problems in her own future, and after speaking to her family about her wishes, she appointed her son as her enduring guardian and her daughter as her enduring power of attorney.

The Public Guardian has taken many calls from people wanting to register their appointment. People are concerned that in an emergency, the relevant documents may not be available, or may not be recognized by health professionals or service providers. Enquiries have also been received from hospitals and other professionals, concerned about the validity of enduring guardianship appointments and wanting to check whether a person is under guardianship. We would suggest,

therefore, that the issue of registration should be reviewed.

Case study:
An elderly man collapses in the street and is brought to the local hospital Accident and Emergency department. He is identified as Mr Smith, and diagnosed as having had a stroke. Mr Smith is going to require ongoing treatment, rehabilitation and possibly nursing home care. His son arrives at the hospital, and tells staff that he has been appointed as Mr Smith's enduring guardian. He cannot produce any documents to substantiate this appointment. Later, Mr Smith's younger son arrives at the hospital and states that he wants to be involved in decision making for his father. He states that he is not aware of his father ever making an enduring guardianship appointment. In the face of this conflict, the hospital staff are unsure who to consult as a decision maker. The hospital social worker rings the Guardianship Tribunal for advice, and they inform her that the enduring guardianship appointment is not registered, and if paperwork cannot be produced by the son, they may need to commence a guardianship application.

The Public Guardian has also received many calls from people unsure who can witness enduring guardianship appointments and what the responsibility of the witness is. Section 6C(e) of the Act states that the appointment takes effect when "*each witness certifies that the person or persons whose execution of the instrument is witnesses executed the instrument voluntarily in the presence of the witness and appeared to understand the effect of the instrument".* The Act defines eligible witnesses as legal practitioners and clerks of local courts. Many people in the community choose to approach local courts as witnesses, as there is no cost attached.

Local courts have expressed concern that clerks are not qualified to assess the capacity of people signing enduring guardianship instruments, particularly where these appointments contain complex directions to guardians. Particular issues have arisen for Jehovah's Witnesses, who wish to include specific directions regarding medical treatment in their enduring guardianship appointments, such as not accepting blood products. Local courts have expressed concern about the capacity of clerks to deal with the complexity of these issues. It is suggested that this issue is clarified in the legislation review.

Amend Guardianship Act - Part 3 – Guardianship Orders
Amend Section 21A Power to enforce guardianship orders

Currently the Guardianship Tribunal may make orders to enable the guardian to enforce the orders of the Tribunal. Such orders will typically provide for the guardian to determine where the person may reside and where necessary for the person's safety and well being, the guardian may authorize others including members of the NSW Police Force and the Ambulance Service of NSW to:

1) Take the person from their present location to a place of residence consented to by the guardian;
2) Keep the person at that place of residence; and
3) Bring the person back to that place of residence should the client leave it.

Example 1
Mr. X had absconded from his place of accommodation, which involved 24 hour supervision, to his mother's home. Mr. X was considered to be a danger to himself and others in the community. The Public Guardian and the Police knew Mr. X was at his mother's home, however the Police were not satisfied with the authority given to them under the Guardianship Order. The Order stated:

"To determine where the person may reside. Where necessary for the person's safety and well being, the guardian may authorize others including members of the NSW Police Force and the Ambulance Service of NSW to:

1) Take the person from their present location to a place of residence consented to by the guardian;
2) Keep the person at that place of residence; and
3) Bring the person back to that place of residence should the client leave it"

The Police argued that the order wasn't specific enough to allow the use of reasonable force, particularly in a dwelling other than the person's in question. Because of the lack of authority the Public Guardian had to apply to the Tribunal who made a two week Order authorizing the use of "all reasonable force" to remove Mr. X from his mother's house.

It is recommended that Section 21A be amended to enable the Tribunal to specify in its orders the authority for Police to use all reasonable force. This will bring this provision into line with other provisions in the Act such as Sections 11 and 12 of Part 3 Division 2 which apply prior to the Tribunal making an order.

Amend Guardianship Act - Part 5 –Medical and Dental Treatment

This part of the Act provides a mechanism through which a medical or dental practitioner can obtain a valid consent to undertake treatment on a person who lacks the decision making capacity to consent to their own medical or dental treatment. Central to this consent scheme is the "Person Responsible".

(Explanatory Note) Guardianship Act - Part 5 –Medical and Dental Treatment
Section 33A (4) - Person responsible for another person:

There is a hierarchy of persons from whom the "person responsible" for a person other than a child or a person in the care of the Director-General under section 13 is to be ascertained. That hierarchy is, in descending order:
(a) the person's guardian, if any, but only if the order or instrument appointing the guardian provides for the guardian to exercise the function of giving consent to the carrying out of medical or dental treatment on the person,
(b) the spouse of the person, if any, if:
(i) the relationship between the person and the spouse is close and continuing, and
(ii) the spouse is not a person under guardianship,
(c) a person who has the care of the person,
(d) a close friend or relative of the person.

Amend Guardianship Act - Part 5 –Medical and Dental Treatment
Amend Section 33A (4) - Person responsible for another person to provide clarification of the hierarchy of Person Responsible

Under the NSW Guardianship Act, treating medical and health care practitioners have the responsibility of identifying a person responsible to provide substitute consent to medical treatment, where a patient is unable to provide their own consent. The Guardianship Act outlines a very specific hierarchy for determining who can be considered person responsible. Occasionally there are two or more people who meet the criteria for person responsible, and the legislation does not provide direction on how a person responsible should then be selected.

It is recommended that the legislation be clarified in this regard.

Case study:
Mr Jones is brought to hospital following a stroke. His two daughters Mary and Susan come to the hospital, both actively involved in Mr Jones's life and wanting to be considered as person

responsible. The treating doctor is recommending starting a course of medication to prevent further strokes. Mary agrees with this treatment and is keen to start the treatment straight away. Susan is against the treatment, and wants to hold off making a decision until she can find out more about risks and side effects. If the treatment is not commenced in a few hours, the benefits will be lost. Both Mary and Susan have equal status as person responsible.

Amend Section 33A (4) - Person responsible for another person to provide for the expansion of the role of person responsible

Often the person responsible is the closest relative or friend to the person with decision making incapacity. They will be responsible for the day to day care of the person, and make regular decisions regarding their medical care. The person responsible is therefore often best placed to assist the person to make other significant life decisions, such as accessing services or deciding where to live. However the legislation does not authorize the person responsible to make substitute decisions in any other areas.

It is recommended that a review consider whether to expand the legal authority of a person responsible to other decision making areas.

***Amend Section 32 – Objects to provide clarification of the law concerning* end of life decision making**

The law in NSW concerning who can consent to the withdrawal of life sustaining treatment in cases where continued medical intervention is determined to be futile has been problematic. See for example FI v Public Guardian [2008] NSWADT 263. In this decision the Administrative Decisions Tribunal determined that a guardian with authority to make decisions for a person in regard to their health care can make decisions to withdraw life sustaining medical treatment where to continue such treatment would not be in the patient's best interests.

However, this decision means that the **Person Responsible** provided for in the Guardianship Act does not have the power to consent to decisions to withdraw medical treatment no longer considered to be in the person's interest. The Person Responsible would normally be the person's spouse or person who has the care of the person. The existing structure of the medical and dental consent provisions in Part 5 of the current Act did not anticipate this outcome. It was never intended that families, those closest to the dying patient, would not play the same role in this type of decision making as they do in relation to other medical decisions. The Guardianship Act needs to be reformed to address this unintended consequence. The following amendments are recommended. It is proposed that Section 32 (b) be amended to remove the phrase "*for the purpose of promoting and maintaining their health and well-being*" and instead insert the phrase "*for the purpose of ensuring the best interests of the person*".

Amend Guardianship Act Part 5
Amend Section 33 - Definitions

It is proposed that Section 33 be amended to include within the definition of medical treatment, *"medical treatment includes the withdrawal of medical treatment considered to be futile and not in the patient's best interest".*

Conclusion

The Public Guardian submits that the suggested reforms and amendments referred to above reflect the changing policy environment in Australia which is characterized by a movement away from a welfare approach to supporting people with decision making disabilities to an approach characterized by recognizing the fundamental human rights of people with decision making incapacity.

The administration of personal and financial guardianship in NSW needs to be located in a single appropriate policy milieu where the full range of civil law responses to issues of capacity and incapacity can be brought together.

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Summary of Recommendations

Section of Guardianship Act 1987	*Recommendation*
Part 7 Section 77	*Amend Section 77 to provide the Public Guardian with the capacity to assist people with decision making disabilities without a guardianship order*
Part 7 Section 77	*Amend Section 77 to provide for the Public Guardian to have capacity to investigate the need for a guardianship application*
Part 7 Section 77(4)	*Amend Guardianship Regulation 2005 to enable the development of a Community Guardian Program*
Part 7 Section 78(1)	Delete
Part 7 Section 78(2)	Modify
Part 1 Section 4	*Amend Guardianship Act Part 1 – Preliminary* *Amend Section 4*
Part 2	*Amend Guardianship Act - Part 2 – Appointment of Enduring Guardians to provide for the* registration of Enduring Guardianship Appointments
Part 3 Section 21A	*Amend Guardianship Act - Part 3 – Guardianship Orders* *Amend Section 21A Power to enforce guardianship orders*
Part 5 Section 33A (4)	Amend Guardianship Act - Part 5 –Medical and Dental Treatment Section 33A (4) - Person responsible for another person:
Part 5 Section 33A (4)	*Amend Guardianship Act - Part 5 –Medical and Dental Treatment* *Amend Section 33A (4) - Person responsible for another person to provide clarification of the hierarchy of Person Responsible*
Part 5 Section 33A (4)	*Amend Guardianship Act - Part 5 –Medical and Dental Treatment* *Amend Section 33A (4) - Person responsible for another person to provide clarification of the hierarchy of Person Responsible*
Part 5 Section 33A (4)	*Amend Section 33A (4) - Person responsible for another person to provide for the expansion of the role of person responsible*
Part 5 Section 32	*Amend Section 32 – Objects to provide clarification of the law concerning* end of life decision making
Part 5 Section 33	Amend Guardianship Act Part 5 Amend Section 33 - Definitions

Appendix one

Table 1.
Principles of the Guardianship Act, 1987

It is the duty of everyone exercising functions under this Act with respect to persons who have disabilities to observe the following principles:

(a) the person's welfare and interests are paramount;
(b) the person's freedom of decision making and freedom of action should be restricted as little as possible;
(c) the person should be encouraged, as far as possible, to live a normal life in the community;
(d) the person's views should be taken into consideration;
(e) the importance of preserving family relationships and cultural and linguistic environments should be recognised;
(f) the person should be encouraged, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs;
(g) the person should be protected from neglect, abuse and exploitation;
(h) the community should be encouraged to apply and promote these principles