

**INQUIRY INTO SUBSTITUTE DECISION-MAKING FOR
PEOPLE LACKING CAPACITY**

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The Director
Standing Committee on Social Issues
Parliament House
Macquarie Street
Sydney NSW 2000

25 September 2009

Dear Director of the Standing Committee on Social Issues

Re Inquiry into substitute decision-making for people lacking capacity

Carers NSW welcomes the opportunity to respond to the Standing Committee on Social Issues Inquiry into substitute decision-making for people lacking capacity.

This submission will refer to the terms of reference set out by the Committee and will present a discussion of the issues relating to carers and the role that they play in guardianship and decision-making and what needs to be considered in legislation and in practice.

Carers NSW thanks the Committee for the opportunity to comment on the Inquiry into substitute decision-making for people lacking capacity. Carers NSW would also be interested in attending any public hearings that may be held to consult further on this important issue.

If you require any further information about Carers NSW response to the policy, please contact Anne-Marie Taylor, Senior Policy and Development Officer, on 9280 4744 or email annemariet@carersnsw.asn.au.

Yours sincerely

A handwritten signature in cursive script that reads "Elena Katrakis".

Elena Katrakis
CEO
Carers NSW



**Carers NSW Submission to the Inquiry into
substitute decision-making for people lacking
capacity**

September 2009

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1. Introduction

1.1 About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

1.2 Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

Across NSW, there is estimated to be approximately 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

Carers exist in all communities, including amongst Aboriginal communities, those of cultural and linguistically diverse backgrounds, amongst Gay, Lesbian, Bisexual, Transgender (GLBT) communities, and throughout metropolitan, regional and rural NSW.

1.3 Key statistics about caring in NSW

According to statistics on carers from the Australian Bureau of Statistics in 2003 Survey of Disability, Ageing and Carers (SDAC):

- Approximately one-third of all carers in Australia live in NSW
- 40 per cent of primary carers cared for a partner, 29 per cent for a child, 32 per cent for other (eg sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average

- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income.

1.4 About this submission

Carers NSW has referred to the terms of reference provided by the Committee in preparing this submission.

1. That the Standing Committee on Social Issues inquire and report on the provisions for substitute decision-making for people lacking capacity in New South Wales, and in particular:

- a) Whether any NSW legislation requires amendment to make better provision for:
- I. the management of estates of people incapable of managing their affairs; and
 - II. the guardianship of people who have disabilities.

This submission will discuss some of the issues faced by carers of people with a disability and carers of a person with a mental illness/disorder that need to be considered in legislation regarding decision-making and guardianship including the *NSW Trustee and Guardian Bill 2009*.

2. The issues

This submission presents a discussion of what needs to be considered by the Committee in any future legislation that concerns the management of estates of people incapable of managing their affairs and the guardianship of people with a disability.

2.1 NSW policy context: Carers as partners in care

In NSW, the framework that prescribes the types of support necessary for carers now and in the future is the *NSW Carers Action Plan 2007-2012*. One of the five priorities of the action plan is that carers are recognised as partners in care. This is particularly important in regards to being included in the care recipient's care plan and medical matters as well as consulted in larger decision-making processes about the care recipient's wellbeing.

The NSW Mental Health Act 2007, is one of the best examples of legislation in NSW which outlines the requirement for services to include carers, by giving them greater access to information about the consumer while still allowing consumers to have some control regarding who is provided with information about them. This legislation treats carers as partners in care, including involving them in the care plan. The Act achieves this by:

- Enabling consumers to nominate a particular person to be their 'primary carer' so this person can receive information and be involved in treatment planning;

- Establishing a process for identifying who will be the primary carer when the consumer is not able to or does not nominate a particular person; and
- Enabling consumers to exclude a person or persons who they do not wish to receive information about them or their treatment.

The Act also allows a consumer to be assessed and detained on the request of a carer, family member or friend if they suspect the consumer to be relapsing or having an episode.

The importance of treating carers as partners in care directly relates to the interdependence and interconnectedness of the caring relationship. The wellbeing of a person with a mental/illness and/or disability always impacts the carer because they are often engaged in every aspect of the care recipient's life.

While treating carers as partners in care is often discussed as relating to the sharing of information with the carer about care recipients medical information, including medications, it should also be considered in relationship to the care recipient's ability to manage their own affairs and to make decisions. It should also be considered in relation to guardianship.

Recommendation 1

Carers NSW recommends that the Committee on Social Issues consider the NSW Carers Action Plan 2007-2012 Priority Action Four- Carers are partners in care, in any legislation that refers to the management of estates of people incapable of managing their affairs and the guardianship of people who have disabilities, including the NSW Trustee and Guardian Bill 2009.

2.2 Carers, substitute decision-making and guardianship

Each caring situation is unique. Some carers assist the person they care for with all their daily living activities while others provide intermittent support. Caring tasks can range from administering medication and dressing wounds to personal care tasks such as showering or supervision of daily activities. Carers also provide emotional support day in and day out to some of the most vulnerable, isolated members of our community and they often act as case managers, navigating the service system and organising appointments. Some carers who provide full-time care for many years to people requiring ongoing medical treatment and community support. Other carers care full-time, for people with severe and/or multiple disabilities. The care that carers provide ultimately enables people requiring support and care to live in the community and maintain their quality of life.

Carers NSW actively encourages carers to consider the importance of implementing formal proceedings in regards to substitute decision-making, power of attorney and enduring power of attorney. Often Carers NSW refers carers to the Capacity Toolkit¹ produced by the Attorney General's Department of NSW to help them to know what their rights are in regards to informal and formal decision-making processes. It is usually through case management and succession planning with Older Parent Carers that Carers

NSW staff encourage carers put decision-making processes in order. This is to ensure that carers who do not have formal mechanisms and plans in place for when they are no longer able to care for the care recipient begin to do so. Many carers worry about what will happen to the care recipient when they are no longer able to care because of death or because of incapacity to do so, to plan for the future helps carers to have greater peace of mind about the future.

Carers NSW believes that making formal arrangements for power of attorney, enduring power of attorney and guardianship of the care recipient for carers is essential. It is therefore important that carers are supported to undertake these processes, while also being genuinely engaged through legislative frameworks related to substitute decision-making and guardianship by the Office of the NSW Trustee and the Public Guardian.

Substitute decision-making

Substitute decision-making with, and on behalf of the care recipient can also be a significant part of the caring role. Depending on the care recipients capacity to make decisions regarding any aspect of their lives from their social engagement, workforce participation, living in residential arrangements as well as their ability to make decisions about the management of their estates and financial matters.

As it is stated in the *Who Cares...? Report on the inquiry into better support for carers*:

Under various state and territory legislative regimes, carers, in certain situations, can act as substitute decision makers for care receivers. In instances where a care receiver has a disability which impacts on their decision making ability, carers may seek formal guardianship through state and territory Guardianship Boards and Tribunals. Such powers can provide carers with the authority to make decisions on behalf of the care receiver.²

The Report also recommends that "mutual recognition governing enduring powers of attorney and advanced care directives" can be further utilised by carers³.

When carers act as informal substitute decision-makers they do so using an intimate knowledge of the care recipient as well as with their best interests at heart. Carers NSW would like to see both the person with a disability and/or mental illness/disorder and their carer to be actively engaged by the Office of the NSW Trustee and the Public Guardian.

Recommendation 2

Carers NSW recommends that decisions made by the NSW Trustee consider the interconnectedness of the relationship between the carer and care recipient and that any decisions made regarding the management of estates of people incapable of managing their affairs do not exclude the carer unless directly specified by the care recipient.

Guardianship

There is often contention around the rights of people with a disability and the rights of carers because of the increasing emphasis on the independence of a person with a disability. Carers NSW believes that the rights of people with a disability and the rights of

carers should not be treated as mutually exclusive. Instead, any discussion of rights should take place in reference to the often complex, interconnected and interdependent relationship experienced between carers and the people with a disability they provide care for.

Carers do act as guardians for the care recipient, but it is also important for the carer to make arrangements for guardianship of the care recipient once the carer is no longer able to care. Carers often want to be guardians because they believe that they act in the best interests of the care recipient. Carers NSW believes that if a carer wants to act as a guardian for the care recipient with limited capacity then they should be supported to do so.

Building carers capacity to be substitute decision-makers and guardians

When guardians are assigned to a person with a disability or mental illness/disorder in order to make decisions on the persons behalf, they receive training and professional support in order to do so. Carers NSW believes that

While advocating for the implementation of mechanisms to enhance and build carers capacity to be guardians may be outside the scope of the current legislative framework, it is an important practicality that needs further consideration by the Office of the NSW Trustee and the Public Guardian.

The benefits of building carers capacity to act as guardians and/or substitute decision-maker are manifold, and include:

- The carer learns how to best honour the independence of the person with a disability while also utilising their intimate knowledge of the care recipient
- The carer has skills and tools to help the care recipient to engage in assisted participatory decision-making
- The carer is able to adapt a whole-of-family approach to decision-making.

The *Who Cares...? Report on the inquiry into better support for carers*, also recommends a national education campaign be implemented to raise awareness about the need for, and benefits of, enduring powers of attorney and advanced care directives in the general community and among health and community care professionals.⁴

Furthermore, the NSW Guardianship Tribunal's submission to the Inquiry into better support for carers states that:

...it would be beneficial to provide accessible and extensive community education to increase awareness of the legal options available for the appointment of substitute decision makers. Increased community education about enduring guardianship and enduring power of attorneys would be beneficial. It is important that such education also clarifies the duties and obligations of appointed substitute decision makers to always act in the best interests of the person with a disability.⁵

In addition, The House of Representatives Standing Committee on Legal and Constitutional Affairs report on *Older people and the law* recommends that education is

conducted nationally in this area, particularly in relation to advance health care planning and preparing advance care directives.

Carers NSW believes that carers would greatly benefit from education about substitute decision-making processes and guardianship.

Recommendation 3

Carers NSW, in line with the NSW Guardianship Tribunal, recommends that a public education campaign about how to be a substitute decision-maker as well as a guardian, be offered to carers who are providing care for a person with limited capacity in order to enhance the carers capacity and skills when undertaking the role of substitute decision-maker.

2.3 Defining Capacity

Currently, the legislation and the Committee label people with a disability or a person with a mental illness/disorder as "people lacking capacity" when they are considered unable to manage their own affairs.

When people are defined in terms of what they cannot do, instead of what they are able to do which is inferred in the term "people lacking capacity", it limits them to what they are lacking as well as suggesting that their situation is static.

Furthermore, because a person's capacity for decision-making and management of their affairs is not static, particularly when a person has a lifelong intellectual disability, terminology needs to reflect this. For example, a person at aged eighteen may not be able to make decisions regarding their affairs, however, at aged twenty-five they are likely to have developed the capacity to make that type of decision. Capacity is something which can be learned and can be developed through education and support. *The UK Mental Capacity Act 2005 Code of Practice* defines capacity as:

Throughout the Code, a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made⁶.

It is therefore important to consider capacity as something which can be enhanced through support and in the case of a person with a mental illness/disorder or disability can be periodically disrupted, given the episodic nature of some conditions.

There is also evidence to suggest that across NSW the tests for capacity are not always consistent. Any legislation that applies to a person's capacity to make decisions and manage their own affairs should articulate a standardised and regulated working definition for capacity and how a person's capacity is assessed. The House of Representatives Standing Committee on Legal and Constitutional Affairs report on *Older people and the law* recommended that:

...the Australian Government propose that the Standing Committee of Attorneys-General and the Standing Committee of Health Ministers develop and implement a nationally consistent approach to the assessment of capacity⁷.

Carers NSW believes that the standardisation of the assessment of capacity is important because it ensures equality across the system and it is not left open for interpretation.

Recommendation 4

Carers NSW recommends that the Committee on Social Issues consider a more appropriate term than "people lacking capacity" in order to reflect the fluid nature of capacity as well as to create a term that is ultimately more inclusive.

Recommendation 5

Carers NSW recommends that the Committee on Social Issues, inline with the recommendations made by The House of Representatives Standing Committee on Legal and Constitutional Affairs, create a standardised assessment or test for capacity across NSW.

2.4 Building the decision-making capacity of people with a disability and/or mental illness/disorder

If capacity is considered as something which is not static, and treated as something which can be enhanced then it is appropriate for the Office of the NSW Trustee and the Public Guardian to consider how their activities may encourage the further development of capacity in decision-making for people with disabilities who require this type of assistance.

Moreover, if a person with limited capacity for decision-making cannot have their capacity enhanced, then they should be involved and given the opportunity for assisted participatory decision-making. Assisted participatory decision-making means that the person with limited capacity are provided with a space to voice their needs and decisions can be made in reference to these needs.

Recommendation 6

Carers NSW recommends that the Office of the NSW Trustee and the Public Guardian develop and run education for people with limited capacity to be educated about decision-making in order to enhance their capacity for decision-making and management of their own affairs.

2.5 The Human Rights of people with a disability and people with a mental illness/disorder

Carers NSW supports the Rights of Persons with Disabilities as they are set out in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which Australia ratified in July 2008. The CRPD applies to all people with a disability or those with long-term mental and intellectual impairment⁸.

Carers NSW believes that any legislation that deals directly with the rights and capacity of a person with a disability or mental illness/disorder should refer to the CRPD and correspond to the civil and political rights that it dictates. Carers NSW believes that the Committee on Social Issues must ensure that the *NSW Trustee and Guardian Bill 2009* corresponds to the CRPD.

Recommendation 7

Carers NSW recommends that the Committee on Social Issues ensure that the NSW Trustee and Guardian Bill 2009 adheres to the United Nations Convention on the Rights of Persons with Disabilities.

2.6 Code of Conduct

The *UK Mental Capacity Act 2005 Code of Conduct*⁹ provides information for those with a formal or informal role in caring for a person with a disability and/or mental illness/disorder. The value of a Code of Conduct is that can advise how carers to act as substitute decision-makers and guardians. It would also apply to professionals and this would be of direct benefit to the care recipient.

Recommendation 8

Carers NSW recommends that the Committee on Social Issues review the UK Mental Capacity Act 2005 Code of Conduct in order to develop a Code of Conduct for NSW which represents best practice in the area of guardianship and decision-making.

3. Conclusion

Carers NSW thanks the Committee for the opportunity to contribute to the Inquiry into substitute decision-making for people lacking capacity. This submission has sought to create awareness of the issues relating to carers and the care recipients capacity to manage their own affairs and make decisions as well as guardianship. Carers NSW hopes that the Committee will consider carers, the *NSW Carers Action Plan 2007-2012* and the *NSW Mental Health Act 2007* in any further amendment of legislation relating to issues of decision-making capacity and guardianship including the *NSW Trustee and Guardian Bill 2009*. Overall, Carers NSW would like to see a legislative framework in NSW that acknowledges the rights of carers and care recipients and supports people's capacity to make decisions regarding their lives to the benefit of all involved.

¹ Attorney General's department of NSW (2008) Capacity Toolkit, Sydney.

² The Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth, April 2009, *Who Cares...? Report on the inquiry into better support for carers*, Canberra.

³ The Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth, April 2009, *Who Cares...? Report on the inquiry into better support for carers*, Canberra.

⁴ The Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth, April 2009, *Who Cares...? Report on the inquiry into better support for carers*, Canberra.

⁵ NSW Guardianship Tribunal, Submission 659, p2. In The Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth, April 2009, *Who Cares...? Report on the inquiry into better support for carers*, Canberra.

⁶ *United Kingdom Mental Capacity Act 2005 Code of Practice* Office of the Public Guardian (2007) for the Department of Constitutional Affairs, United Kingdom.

⁷ Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Legal and Constitutional Affairs (2007) *Older people and the law*, Canberra.

⁸ United Nations Convention on the Rights of Persons with Disabilities,
<http://www.ohchr.org/english/law/disabilities-convention.htm>

⁹ *United Kingdom Mental Capacity Act 2005 Code of Practice* Office of the Public Guardian (2007) for the Department of Constitutional Affairs, United Kingdom