

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

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The Director
Social Issues, Legislative Council
Parliament House
Macquarie Street
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Re: Inquiry into substitute decision-making for people lacking capacity in NSW

Thank you for the opportunity to make a submission to the Standing Committee on Social Issues' Inquiry into substitute decision-making for people lacking capacity in NSW.

Terms of reference

1. That the Standing Committee on Social Issues inquire into 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.
2. That the committee report by February 2010.

About the Brain Injury Association of NSW

The Brain Injury Association of NSW (BIA NSW) is the peak advocacy body in NSW for people with acquired brain injury and their carers and families. The Association has been operating for over 30 years, and has a broad membership base comprising people with acquired brain injury, carers and family members, service providers, and other interested members of the community.

BIA NSW's purpose and mission focus on systemic advocacy. In addition, BIA NSW runs an Individual Advocacy Service, available for people with an acquired brain injury, assisting people with processes such as completing forms through to more complex legal or service-provision matters. We have worked with more than 50 people in this capacity over the last 12 months.

The Association's connection with its constituents, and its focus on both systemic and individual advocacy, makes it well placed to provide a submission to this Inquiry.

Rachel Merton
Chief Executive Officer

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Summary of our submission

The Brain Injury Association of NSW believes that NSW legislation, in particular the Guardianship Act 1987 (NSW) and the newly enacted NSW Trustee and Guardian Act 2009 (NSW), urgently require review and amendment in order to better meet the support and protection needs together with the human rights of people with disabilities who lack capacity in NSW.

Further, we support the Attorney General's suggested legislative amendments in his letter dated 30 June 2009, which we believe would introduce greater flexibility, and enable the system to respond better to an individual's circumstances and any changes over time.

Submission

We welcome this Inquiry at this time, although it would have been useful to finalise this process prior to the enactment of the NSW Trustee and Guardian Act 2009 and its associated restructures. This would have enabled adequate consultation to occur with the disability sector into this process, as well as to incorporate the principles and Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities ('the UN Convention') into the new Act.

BIA NSW's submission has at its core a human rights framework, which is informed both by our direct experience with advocating for people with an acquired brain injury, as well as our strong social justice principles and support for legislative reform that aligns policy and practice with the principles of the UN Convention.

We acknowledge the complex issues surrounding the question of substitute decision-making. These include the tension that exists between the inherent removal of a person's human rights when a substitute decision-maker is appointed and the necessity of such an appointment at certain times to protect people from exploitation and ensure decisions are made in their best interests.

We are aware that people under guardianship are among the most vulnerable and excluded people in our community, in need of safeguards and protection, but equally our Governments have obligations (that we support) to ensure all people have equal rights under the law and that all people should have as much say as possible in decisions that affect their own lives.

Assisted decision-making

From our experience with individual advocacy, there is no doubt that the most challenging situations arise when people do not have social or family networks to support their everyday and life decisions, regardless of their level of capacity. Like everyone in the community, people with disabilities need to explore options and canvas advice and opinions to inform their decisions. Of course, people's capacity varies with their level of disability, but the impact of having nobody to assist with such decisions cannot be overstated, and for many people, in fact decreases their decision-making capacity.

We believe there is a strong need for systemic change to provide assisted decision-making for people with disabilities who do not necessarily require the appointment of a guardian. This is also consistent with the principles of the UN Convention.

We provide the following example by way of illustration. We were recently working with a person whose estate was being managed by the (former) OPC. Her home was quite dilapidated and needed numerous repairs she could not afford, so she was given an option to sell it and purchase a new home. However, due to complex cognitive disability as a result of her acquired brain injury, she was unable to easily identify what she would like in a new home, or even the area she wanted to live. She needed significant assistance to go through the decisions, planning, and processes of moving house: both practical and emotional. This person was socially isolated, with no people she could identify to assist her to make these very personal and quite significant decisions. The challenge for our advocate was to make the judgement about how much to support her in making these choices and identifying possible

new places to live. Clearly, it was outside the role of the OPC to work with her to make this choice, but it is also outside the scope of a resource-limited community advocacy service. This person did not need guardianship, nor did she need this level of assistance with other decisions in her life.

If the system is to support people with disabilities in making significant life decisions, then it must be flexible enough to be able to respond to different people's level of capacity. There is a strong case for substitute decision-making to be in place for some people with very limited capacity, but this should be the option of last resort.

To enable the provision of assisted decision-making, we are aware of two possible options for systemic restructures that could operate in NSW: a) that the Public Guardian's role be reviewed to allow differing levels of assisted decision-making as required by individuals, without the need for the appointment of a Guardian; or b) that a Public Advocate be established, with similar roles to those undertaken by Public Advocates in other Australian jurisdictions. In either case, the outcome should be that people with varying levels of capacity should be supported to have as much say as possible in their individual circumstances when making significant life decisions.

Acquired brain injury

An estimated 113,000 people in NSW have an acquired brain injury with an activity limitation (AIHW 1999), and people with an acquired brain injury are forming an increasing proportion of the population under guardianship throughout Australia.

People with an acquired brain injury may have a diverse range of long term effects, including:

- Physical Changes (such as paralysis, balance problems, epilepsy, and headaches);
- Cognitive Changes (such as being easily confused and overwhelmed, short attention span, memory problems, and difficulties with planning and organisation);
- Behaviour and Personality Changes (such as being more impulsive, impatient, unable to control emotions, or unmotivated); and/or
- Social Isolation (including loss of relationships and difficulties establishing new relationships).

People with an acquired brain injury tend to have more complex needs than people with other forms of disability, and are significantly more likely to need help with cognitive tasks, including planning and organisation (AIHW 2007).

This means that they are more likely than most other people with disabilities to have the combination of social isolation and limited capacity to make a decision, even where overall their capacity is not at the point of requiring guardianship.

An added complexity for people with an acquired brain injury is that they may have a vastly altered life and level of capacity compared with the life they lived prior to sustaining the brain injury. This can be both a challenge and an advantage for decision makers (both substitute decision-makers and those assisting with decision-making). Previous life choices and lifestyles can paint a clear picture of a person's wishes and preferences, but there can be degrees of misalignment between previous choices and present possibilities to pursue those same choices.

These are questions that need to be considered, and will be different for each individual. Again, this points to the need for a wholistic approach that takes into account and responds to the individual's full circumstances and degree of capacity.

Conclusion

Thank you for the opportunity to provide these comments for the Committee's consideration. If you require further information, please contact Rachel Merton on 02 9868 5261 or email: ceo@biansw.org.au.