

INQUIRY INTO SUBSTITUTE DECISION-MAKING FOR PEOPLE LACKING CAPACITY

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Substitute Decision Making for People Lacking Capacity

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*Views expressed by PDCN are not necessarily endorsed by
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1 EXECUTIVE SUMMARY

The Physical Disability Council of NSW (PDCN) appreciates the opportunity to provide comment on supported and substitute decision making for people lacking capacity, as part of the Legislative Council Standing Committee on Social Issues inquiry. As our population ages it will become increasingly important that a legally recognised tool be developed to determine capacity, within a human rights framework.

2 TERMS OF REFERENCE

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. ¹*

3 ABOUT THE PHYSICAL DISABILITY COUNCIL (PDCN)

PDCN is the peak body representing people with physical disabilities across New South Wales representing approximately 700,000 residents. PDCN focuses on issues relevant to people with physical disabilities, such as access to the built environment, transport and access to aids and equipment.

An inclusive society is achieved when people with physical disabilities are involved in every aspect of political, social, economic and cultural life. PDCN is able to represent the needs and interests of people with physical disabilities. Membership of PDCN includes people with a range of mobility issues, from young children and their careers, to aged

¹ NSW Parliament Standing Committee on Social Issues, Substitute decision making for people lacking capacity - Terms of Reference (2009)

people, living across NSW in either Greater Sydney Metropolitan area or rural NSW - all from a wide range of socio-economic circumstances.

PDCN effectively networks with other advocacy organisations on common goals and issues. PDCN strives to bring about significant, permanent and positive changes to the circumstances of people with physical disabilities. PDCN's goal is to secure equal civil and human rights for our constituency.

4 PDCN RECOMMENDATIONS

Recommendation 1: PDCN recommends adoption of the following general principles, similarly to those identified in the Convention on the Rights of Persons with Disabilities:

- Respect to inherent dignity;
- Individual autonomy, including the ability to make one's choices;
- Independence of persons; and
- Full, effective participation, and inclusion in society.

Recommendation 2: PDCN recommends that the Public Guardian report directly to the NSW Department of Justice and Attorney General to minimize existing potential conflicts of interest between the Department of Ageing, Disability and Home Care and the Public Guardian.

Recommendation 3: PDCN recommends that a Memorandum of Understanding be executed between the Department of Ageing, Disability and Home Care, the Trustee and Guardian and the Guardianship Tribunal to protect the confidentiality and privacy of individuals with both a guardianship order and a financial management order.

Recommendation 4: PDCN recommends that a tool be developed to assess capacity, to determine when supported or substitute decision making is required.

Recommendation 5: PDCN recommends that Financial Management Orders automatically be reviewed once per annum without requiring the person who is the subject of an order to seek a review of the order.

Recommendation 6: PDCN recommends that Section 77 of the *Guardianship Act 1987* (NSW) be amended to provide the Public Guardian with the ability to provide assistance without necessarily requiring a guardianship order.

Recommendation 7: PDCN recommends that resources and tools to facilitate supported decision-making be developed and then promoted electronically and in hard copy.

5 PDCN DISCUSSION

a. Convention on the Rights of Persons with Disabilities

Recommendation 1: PDCN recommends adoption of the following general principles, similar to those identified in the Convention on the Rights of Persons with Disabilities:

- Respect to inherent dignity;
- Individual autonomy, including the ability to make one's choices;
- Independence of persons; and
- Full, effective participation, and inclusion in society.

A Commonwealth Government report prepared by the Joint Standing Committee on Treaties into the Convention on the Rights of Persons with Disabilities (CRPD) draws attention to the significance of substitute decision making. In broad terms, substitute decision-making can be defined as a process whereby decisions are made on behalf of people who are considered not capable of being able to make decisions for themselves.

The principles of the CRPD include:

- Respect to inherent dignity;
- Individual autonomy, including the ability to make one's choices;
- Independence of persons; and
- Full, effective participation, and inclusion in society.

Stakeholders responding to this Commonwealth report expressed concern that allowing substitute decision-making was in violation of a persons' right to choose the most appropriate option, and hence contrary to Article 12 of the CRPD. Evidence provided to the inquiry included data from Victoria, showing that health care services too frequently provide involuntary treatment to control people for the medical system, the institutional system, to get what they want done as quickly as they need doing, because the supported model of decision-making does take time.²

As part of the application process to obtain ratification of the CRPD, the Commonwealth Government prepared a declaration regarding substitute decision-making seeking clarification from the United Nations, identifying existing practices and whether these could continue with the implementation of a number of safeguards.

b. Administration of Guardianship Legislation in NSW

Recommendation 2: PDCN recommends that the Public Guardian report directly to the NSW Department of Justice and Attorney General to minimize existing potential conflicts of interest between the Department of Ageing, Disability and Home Care and the Public Guardian.

Recommendation 3: PDCN recommends that a Memorandum of Understanding be executed between the Department of Ageing, Disability and Home Care, the Trustee and Guardian and the Guardianship Tribunal to protect the confidentiality and privacy of individuals with both a guardianship order and a financial management order.

² Australian Parliament Joint Standing Committee on Treaties – Convention on the Rights of Persons with Disabilities (June 2008)
<http://www.aph.gov.au/house/committee/jsct/4june2008/report1/chapter2.pdf>

In June 2009 the NSW State Government introduced the following four amendments to the *Protected Estate Act 1983 (NSW)*, as measures to make legislation more compliant with the CRPD:

1. Inclusion of the following general principles into the *Protected Estate Act 1983 (NSW)* to ensure consistency with the *Guardianship Act 1987 (NSW)*:
 - The welfare and interests of the person should be given paramount consideration
 - The freedom of decision and the freedom of action of the person should be restricted as little as possible
 - The person should be encouraged as far as possible to live a normal life in the community
 - The views of the person should be taken into consideration
 - It is important to preserve family relationships and the cultural and linguistic environment of the person should be recognised
 - The person should be encouraged as far as possible to be self-reliant in matters relating to personal, domestic and financial affairs
 - The person should be protected from abuse, neglect and exploitation
 - The community should be encouraged to apply and promote these principles.
2. Reverse the presumption of incapacity within the *Protected Estate Act 1987 (NSW)*;
3. Increase autonomy of the NSW Guardianship Tribunal; and
4. Limit the period of time of an interim order to six months, provided by the Mental Health Review Tribunal.³

Whilst PDCN acknowledges improvements made to the *Protected Estate Act 1983 (NSW)*, PDCN would recommend the following reforms to guardianship legislation in NSW:

- Ensure decisions are based on the least possible interference with the autonomy of the person;
- Presume capacity for all adults, specifying presumption in relation to persons with impairment and disability;
- Direct the court or tribunal to determine decisions in respect to a specific issue or subject matter;
- Allow orders that provide support or control for part of an estate or affairs.⁴

In NSW the Public Guardian and the NSW Guardianship Tribunal are currently funded through the NSW Department of Ageing, Disability and Home Care (DADHC) and hence

³ NSW Parliament, Hon. John Hatzistergos, NSW Trustee and Guardian Bill (June 2009)
[http://www.parliament.nsw.gov.au/prod/PARLMENT/nswbills.nsf/0/6ced7a02cba51f64ca2575c9001b50d6/\\$FILE/LC%204909.pdf](http://www.parliament.nsw.gov.au/prod/PARLMENT/nswbills.nsf/0/6ced7a02cba51f64ca2575c9001b50d6/$FILE/LC%204909.pdf)

⁴ NSW Parliament Standing Committee on Social Issues, Substitute decision making for people lacking capacity – PIAC submission (2009)
(2009)[http://www.parliament.nsw.gov.au/Prod/parlment/committee.nsf/0/4a68ac91ca3a06b7ca257637008185c0/\\$FILE/Submission%2022.pdf](http://www.parliament.nsw.gov.au/Prod/parlment/committee.nsf/0/4a68ac91ca3a06b7ca257637008185c0/$FILE/Submission%2022.pdf)

report through DADHC. The NSW Department of Justice and Attorney General now house both the Public Guardian (guardianship order) and Trustee and Guardian (financial management). Approximately 70% of people with a guardianship order also have a financial management order, so it is vital that mechanisms be developed to ensure that the privacy and confidentiality of all individuals are maintained between different divisions of the department.

To minimize this risk it appears from the Guardianship Tribunal 2007/ 08 Annual Report that the Tribunal intended to prepare a Memorandum of Understanding, with DADHC, the Trustee and Guardian and the Guardianship Tribunal, though evidence of this document could not be located on the Internet.⁵ It is recommended that a Memorandum of Understanding be prepared to establish a common understanding between these institutions.

Currently an anomaly exists between the NSW Department of Justice and Attorney General and DADHC whereby the Public Guardian is funded and administered through DADHC, but provides systematic recommendations on services and institutions operated and funded by DADHC. This risk could be minimized if the role of the Public Guardian was moved from DADHC to the NSW Department of Justice and Attorney General. Additionally this would provide users with greater transparency when lodging a complaint.

C Determination of Capacity

Recommendation 4: PDCN recommends that a tool be developed to assess capacity, to determine when supported or substitute decision-making is required.

To assess a person's ability to be self-reliant in matters relating to personal, domestic and financial affairs a practitioner needs to be able to determine the individual's capacity to conceptualise and respond to his or her surrounds. Research conducted by the Public Interest Advisory Council has identified the need to develop clear legal definitions to determine capacity to implement formal substitute or supported decision-making where capacity is absent, limited or episodic. Once developed, this tool needs to be promoted and incorporated into all legal training.⁶

d. Individual Assessment of Abilities

Unless practitioners can accurately determine a persons' overall capacity, and the particular life skills in which the person may have limited or no capacity, the risk of either over estimating or under estimating the individual is extremely high, with the corollary risk of inappropriately suggesting substituted decision making. For a person needing financial management, legal practitioners need to recognise the different skills and risks associated with managing regular banks, mortgages, shares and large investments. Any advice or treatment needs to enhance independence and ensure that it is based on the least possible interference with the autonomy of the person.

⁵ NSW Guardianship Tribunal 2007/ 08 Annual Report Page 2

⁶ Public Interest Advisory Council - Are the rights of people whose capacity is in question being adequately promoted and protected? R. Banks. E. Golledge, C. Berry (2006)

e. Review of Financial Management Orders

Recommendation 5: PDCN recommends that Financial Management Orders automatically be reviewed once per annum without requiring the person who is the subject of an order to seek a review of the order.

Unless a guardianship order is for a fixed period and is reviewed at the expiry date, it is very difficult for a person subject of an order to seek a review of that order. The process for review will depend on who has issued the order—Guardianship Tribunal, the Supreme Court or the Mental Health Review Tribunal—with different rules applying for each. Considering the inconsistencies in processes and the difficulty of managing the legal processes it is not surprising that estate management orders without an expiry date are rarely revoked and usually operate on a perpetual basis. In 2007-08, the Guardianship Tribunal processed 370 reviews of financial management orders of which only 35 percent were revoked.⁷

f. Increase availability of options

Recommendation 6: PDCN recommends that Section 77 of the *Guardianship Act 1987 (NSW)* be amended to provide the Public Guardian the ability to provide assistance without necessarily requiring a guardianship order.

Currently all applications and orders for guardian need to be approved as legal under the *Guardianship Act 1987 (NSW)*. There needs to be a range of less formal and intrusive options other than guardianship to met individual needs. Guardianship in NSW would be more compliant with the CRPD, if Section 77 was amended to provide greater choice to individuals by providing the Public Guardian with the ability to assist individuals without needing a formal hearing in the Guardianship Tribunal.

g. Promotion of supported decision making tools

Recommendation 6: PDCN recommends that resources and tools to facilitate supported decision-making be developed and then promoted electronically and in hard copy.

Currently tools and resources to promote supported decision making are not promoted. Greater access to resources and tools to facilitate supported decision-making will become ever more necessary as an increasing proportion of the general population and the population of persons with disabilities find themselves challenged by the effects of ageing.

⁷ Public Interest Advisory Council – Least restrictive alternatives. B. Bailey (2009)