

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

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The Hon Ian West MLC
Committee Chair
Standing Committee on Social Issues
NSW Legislative Council

by email: socialissues@parliament.nsw.gov.au

Dear Mr West

Inquiry Into substitute decision-making for people lacking capacity

I write in support of the submission made to this Inquiry by the NSW Council on Intellectual Disability (NSW CID). The submission by NSW CID covers the particular aspects of the legislation that have to be addressed to make the legislation compatible with the current the human rights standards for people with intellectual disability.

I would also like to take this opportunity to comment on two further matters; the Capacity Toolkit published by the the NSW Attorney General's Department and Article 12 of the UN Convention on the Rights of Persons with Disabilities.

It is important that the Capacity Toolkit be acknowledged as a practical and theoretical resource so that it is not duplicated and that people are aware that they have a guide as to the issues involved and how they might be resolved.

The Capacity Toolkit is not only a very practical resource for guiding people through the difficult task of supporting people with cognitive impairments to make decisions, it provides a good framework for an understanding of the theoretical and human rights issues involved. The Toolkit's emphasis on seeing people as able to make decisions until it is demonstrated otherwise and on maximising support so that they can develop the skills and experience to make their own decisions, is compatible with the UN Convention on the Rights of People with Disabilities.

Article 12 of the UN Convention on the Rights of Persons with Disability has the potential to become controversial for people with intellectual disability specifically the issue of substitute decision making. It is not my intention to debate the range of views in this letter

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to the Inquiry, though it is important to recognise that there are a variety of views some of which the Committee may be asked to consider. National Council on Intellectual Disability is able to provide further information if necessary.

Article 12 of the UN Convention on the Rights of Persons with Disability does not explicitly mention substitute decision-making and this is being read as the Convention prohibiting it. In place of substitute decision-making the concept of supported decision making is being taken to the extreme where the notion of 'totally supported' decision-making is being used.

It is a basic right of people with intellectual disability that those who are responsible for supporting them do so in an honest, respectful and accountable manner. Where a person is not the explicit decision maker it is not only appropriate but essential that a distinction be made between when a person with intellectual disability makes the decision with support and where another person makes the decision, even if the decision maker takes into account (from their knowledge and experience of the person) the person with intellectual disability preferences. This explicit recognition must be reflected in the words used. In this context the phrase 'substitute decision maker' is useful and should be retained.

Yours sincerely

Mark Pattison
Executive Director

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