

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

The Disability Studies and Research Centre (DSRC) is a national centre in disability studies that applies and promotes a critical perspective of disability in research and education to maximise Australia's capacity to ensure a more equitable, participatory and accessible society for people with disability.

We welcome the inquiry into substitute decision-making. There has been a significant paradigm shift in contemporary approaches to legal capacity that is reflected in international human rights norms and as such we believe a review of current legislative instruments is an essential, and is long overdue. We also welcome this opportunity to contribute our views.

Our short submission is organised to explore the nature of international norms as they relate to legal capacity and how these principles could be reflected in guardianship practice. It will examine Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) and the normative human rights framework it adopts.

1. Convention on the Rights of Persons with Disabilities

The General Assembly of the United Nations adopted the *Convention on the Rights of Persons with Disabilities* (CRPD) and its associated optional protocol on December 13, 2006.¹ At its opening ceremony on March 30, 2007, Australia along with 80 other nations and the European Union signed the CRPD. The Convention entered into force² on May 3, 2009 and Australia ratified³ on July 17, 2009. The Australian government has also indicated its

¹ The CRPD and its *Optional Protocol* were adopted during the sixty-first session of the GA by resolution A/RES/61/611, UN Doc.A/61/611. See *Disabilities – Handbook on the Convention on the Rights of Persons with Disabilities and its Optional Protocol* (OHCHR, Geneva, 2007), available at <http://www.ohchr.org/english/about/publications/docs/ExclusionEqualityDisabilities.pdf> accessed 13 November 2008.

² Article 45 requires 20 ratifications

³ Australia lodged the documents of ratification with the depository in New York on July 17, 2009, following parliamentary review including COAG consultations and JSCOT inquiry

intention to accede to the optional protocol.⁴ The CRPD negotiations are reputed to have involved the highest level of civil society participation of any human rights treaty.⁵ This representation was overwhelmingly that of persons with disability and disabled persons organisations.

The CRPD is the first United Nations (UN) treaty finalised in the 21st Century.⁶ It is also the first binding human rights instrument to explicitly address disability. Up until the adoption of the CRPD, disability had been the missing piece of the international human rights framework. Disability has been invisible within the binding international human rights instruments, none of the equality provisions in the *International Bill of Human Rights*—which includes the *Universal Declaration of Human Rights*, the *International Covenant of Civil and Political Rights* and the *International Covenant on Economic, Social and Cultural Rights*—list persons with disability as a protected class.

The formulation of the CRPD has been hailed as a great landmark in the struggle to reframe the needs and concerns of persons with disability in terms of human rights. The Secretary-General of the United Nations, claimed that it heralded the 'dawn of a new era – an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long.'⁷ Ambassador MacKay, Chairman of the Ad Hoc Committee that developed the CRPD text, characterised the CRPD as embodying a "paradigm shift" away from a social welfare response to disability to a rights-based approach.⁸ The UN High Commissioner for Human Rights has also characterised the CRPD as enshrining this paradigm shift in attitudes. She has conceptualised the CRPD as rejecting the 'view of persons with disabilities as objects of charity, medical treatment and social protection' and as affirming persons with disability as 'subjects of rights, able to claim those rights as active members of society.'⁹

⁴ Joint media release, Attorney General, Robert McClelland and Parliamentary Secretary for Disabilities and Children Services. July 30 2009 [online] http://www.attorneygeneral.gov.au/www/ministers/RobertMc.nsf/Page/MediaReleases_2009_ThirdQuarter_30July2009-AustraliaAccedestotheDisabilitiesConventionOptionalProtocol

⁵ Many officials made this point in addresses to Opening for Signature Ceremony, and in the associated Press Conference. UN News Centre, *Press Conference by High Commissioner for Human Rights on Signing of Convention*, 30 March 2007, available at http://www.un.org/News/briefings/docs//2007/070330_Disabilities.doc.htm.

⁶ The *International Convention on the Protection of All Persons from Enforced Disappearance* was adopted by the GA one week later on 20 December 2006.

⁷ *Secretary General Hails Adoption of Landmark Convention on Rights of People with Disabilities*, Official Statement of the UN Secretary-General, SG/SM/10797, HR/4911, L/T/4400, 13 December 2006,

⁸ Ambassador Don MacKay, Permanent Representative of New Zealand in the UN and Chair of the Ad-Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, Commentary at a High-Level Dialogue, *From vision to action: The road to implementation of the Convention on the Rights of Persons with Disabilities* held in association with the Signature Ceremony of the Convention, UN, New York on 30 March 2007, available at <http://www.un.org/disabilities/default.asp?id=160>

⁹ UN High Commissioner for Human Rights, *Statement by Louise Arbour UN High Commissioner for Human Rights on the Ad Hoc Committee's adoption of the International*

The paradigm shift also involved the centrality of people with disability and their representative organisations in the *CRPD* negotiation process. The *CRPD* negotiations are reputed to have involved the highest level of participation by representatives of civil society, overwhelmingly that of persons with disability and disabled persons organisations, of any human rights convention in history.¹⁰ This centrality of people with disability is reflected in the substantive articles. The formulation of many of the articles embraces the personhood of people with disability and promotes legislative and policy frameworks that engage people with disability as subjects rather than treating them as objects. This approach can be clearly seen in the formulation of Article 12 – Equal recognition before the law. Article 12 embraces the inherent principles of dignity and equality by giving voice back to people to direct their own lives.¹¹

2. *CRPD* Article 12 Equal recognition before the law

This Article deals with concepts at the core of the rights of people with disability as human beings and the exercise of those rights. The formulation of Article 12 is symbolic of the paradigm shift that has been taking place in the disability field over the past 15 years or so. And it cuts to the core of human rights, dignity and equality, the notion that all human beings are ends in themselves and not means to other ends. People with disability have traditionally been viewed as 'objects' to be pitied or managed or worse – and not as 'subjects' deserving equal respect. This cultural default has predisposed us to tolerate intrusions into personhood in the field of disability that would not be accepted by others.¹²

Traditional approaches to legal capacity and guardianship have been based on presumptive approaches where people with disability are deemed to lack capacity. If you are deemed to lack capacity then your legal personhood is stripped away – your destiny is placed in the hands of others.¹³ The process of guardianship removes the individual from core aspects of their lives and could be said to have 'legally disappeared'¹⁴ or sustained a 'civil death'. Article 12 is a significant shift away from traditional substitute decision-making frameworks such as guardianship.

Convention on the Rights of Persons with Disabilities, New York, 5 December, 2006, available at <http://www.ohchr.org/English/issues/disability/docs/statementhcddec06.doc>, accessed 13 November 2007.

¹⁰ Many officials made this point in addresses to Opening for Signature Ceremony, and in the associated Press Conference UN News Centre, *Press Conference by High Commissioner for Human Rights on Signing of Convention*, 30 March 2007, available at http://www.un.org/News/briefings/docs//2007/070330_Disabilities.doc.htm, accessed 13 November 2007.

¹¹ An address by Professor Gerard Quinn at the Symposium on the legal capacity of persons with disabilities in light of the UN Convention on the Rights of Persons with Disabilities (CRPD), 4 June, Brussels [online] <http://www.efc.be/projects/disabilities/default.htm>

¹² Ibid

¹³ Ibid

¹⁴ Ibid

Based on the premise of personhood article 12 firstly reaffirms that persons with disabilities have the right to recognition everywhere as persons before the law and that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.¹⁵ The article then challenges states to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. To develop mechanisms that truly support people with disability in decision-making without infringing upon their dignity or autonomy.

Central to this is a recognition that capacity is not a binary concept – you either have it or you lack it – but that it reflects a diversity of levels at which people can engage in the process utilising a variety of modes. The challenge is to provide frameworks that provide mechanisms for support that are proportional and tailored to an individual's needs and incorporate safeguards that are proportional to the modes of support.¹⁶

3. Domestic Harmonisation with CRPD

Recent analysis of domestic legislation has highlighted that the level of compliance through the implementation of some domestic legislation could fail to meet CRPD standards. In 2008 the departments of Families, Housing, Community Services, and Indigenous Affairs, and Attorney-General funded a series of Consultations with Australian representative organisations governed by persons with disability, disability advisory councils, and the disability legal services network on the impact of ratification of the Convention on the Rights of Persons with Disabilities. The report¹⁷ released in March 2008 raised several areas of concern.

One area highlighted in the report was guardianship laws with respect to the absence or ineffectiveness of procedural safeguards; the failure to implement in some cases the principle of the least restrictive alternative; and the failure to ensure the effective promotion and support of alternatives to substitute decision-making.¹⁸ While all jurisdictions provide for a variety of guardianship arrangements that incorporate active engagement of the person in question¹⁹ these options are essentially still a mechanism of substituted decision-making. There is little or no development of supported decision-making as promoted by Article 12 of CRPD.²⁰

Whilst Australia has been acknowledged as having relatively progressive

¹⁵ CRPD 12(1)(2)

¹⁶ CRPD 12(3)(4)

¹⁷ Phillip French, Disability Studies and Research Institute for the Australian Task Force on CRPD Ratification. Final Report of Consultations with Australian representative organisations governed by persons with disability, disability advisory councils, and the disability legal services network on the impact of ratification of the Convention on the Rights of Persons with Disabilities. March 2008

¹⁸ Ibid

¹⁹ All Australian jurisdictions incorporate enduring guardianship advanced directives where individuals can decide how decision will be made at times when the person does not have capacity to do so themselves.

²⁰ Op Cit Supra note 85

guardianship regimes²¹ and as noted earlier have developed mechanisms to support the participation of people with disability in decision-making. Some of the mechanisms that have been in place such as enduring guardians and advanced directives are still inherently substitute decision-making and as such do not move the practice of guardianship into broader dimensions of supported decision-making. There is significant room for reform and to develop supported decision-making options in line with CRPD.

4. Conclusion

The formulation of Article 12 of CRPD creates a fundamental shift in respect to many countries' approach to legal capacity and people with disability including guardianship practice in Australia. Many guardianship regimes are premised on notions of deficit and assumptions about people with disability's capacity. In many instances the default is that people with disability lack capacity. This denies the variety of modes individuals may utilise to express and convey their wishes.

Article 12 seeks to embrace the acceptance of human diversity by recognising that capacity should be seen as a continuum. That people with disability present with varying degrees of ability and can make decisions utilising a variety of support mechanisms. Article 12 requires states to recognise first and foremost that people with disability have legal capacity on an equal basis with others and that states shall take appropriate measures²² to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Thank you, again, for the opportunity of contributing our views. We would be pleased to discuss any of the issues we raise further if this would be of assistance.

Yours sincerely



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²¹ See for example; An address by Professor Gerard Quinn at the Symposium on the legal capacity of persons with disabilities in light of the UN Convention on the Rights of Persons with Disabilities (CRPD), 4 June, Brussels [online]

²² Article 12 contains a level of constructive ambiguity as to the nature of the measures that should be adopted to support people with decision-making disability to exercise their legal capacity. Australia responded to this ambiguity with an interpretative declaration with its understanding that CRPD provides for substitute decision making as a last resort and subject to safeguards.