

“Nothing About Us Without Us”: National Responses to the CRPD Six Years On

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The King & Wood Mallesons/Castan Centre Annual Human Rights Lecture

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1. Introduction

Good afternoon ladies and gentlemen. It is indeed a huge honour for me to deliver this annual human rights lecture named for Ron Castan QC. I met Ron on several occasions, but we never conversed at any length. I was a young admirer from afar for he was an example to us all on how law could be utilised to enhance and to protect the human rights of all persons, especially Indigenous Australians. Sadly, Ron passed away just a few days shy of his sixtieth birthday, but his work lives on in the Castan centre which focuses upon human rights law, practice and scholarship.

2. The CRPD Committee

I well remember Monday morning 23 February 2009. It was very cold, for my wife, Professor Mary Crock, and I found ourselves in Geneva. We alighted from the tram and walked under the flags at the Palais des Nations, one of the major United Nations buildings. I was excited yet nervous, for this was my first day as an inaugural member of the United Nations Committee on the Rights of Persons with Disabilities, the CRPD Committee. The primary purpose of the CRPD Committee is to monitor the implementation on a world-wide basis of the United Nations Convention on the Rights of Persons with Disabilities² which I shall call the CRPD. We sat there in a large conference room, for twelve of us had been elected to be members of this Committee. As we made our solemn declarations, I wondered what our work would entail, and how would it change my life.

3. The CRPD

The CRPD came into force on Saturday 3 May 2008, the thirtieth day after the twentieth country had lodged its ratification documents with the United Nations.³ Thus the CRPD has been in

¹ Professor Emeritus, Faculty of Law, University of Sydney; and Vice-Chairperson and immediate past Chairperson United Nations Committee on the Rights of Persons with Disabilities. I wish to thank my daughter Ms Kathryn McCallum for assisting me with this lecture and for flying to Melbourne to accompany me to deliver the lecture.

² Convention on the Rights of Persons with Disabilities, adopted on 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008). Full text accessible at: <http://www.un.org/disabilities/convention/conventionfull.shtml>

³ CRPD Article 45 paragraph 1.

operation for just over six years, having been adopted by the General Assembly on 13 December 2006. The adoption of United Nations conventions by the General Assembly requires majority support from the world's nations. This consensus is not forthcoming unless there is a global view that the coverage of human rights should be expanded to bring within its fold one or more groups which require recognition and protection. There are nine United Nations human rights conventions which are listed in figure 1. The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) was adopted in 1979, and it was obviously a result of growth of the women's movement. Similarly, the 1984 Convention on the Elimination of Torture (CAT) flowed from increased concerns about the widespread use of torture and other cruel and inhumane punishments. The 1989 Convention on the Rights of the Child (CRC) resulted from a heightened concern about the needs of children in our world. Finally, the 2006 adoption of the CRPD came out of the struggles of the disability movement which had been gathering pace over the previous forty years. Governments began to recognise that in most countries the majority of persons with disabilities were poor, and lacked access to education, employment and health care. Often, it was also the case that little regard was paid to their human rights.

The purpose of the CRPD as explained in its first article, is to "...promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." It does not grant us new human rights: rather, it recognises that for most of the world's history our human rights, needs and aspirations have been ignored.

Which persons with disabilities are covered by the CRPD? In article 1, persons with disabilities are defined as including "...those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others." This definition gives expression to the social model of disability which underpins the CRPD.⁴ For example, malfunctions of the body like my lack of vision are impairments. According to the social model, my disability arises from the barriers in society which make it difficult for me to, for example, access information which is not provided for in accessible formats like braille or in accessible computer files. Similarly, persons with mobility impediments are required to confront the barriers of accessing buildings and transport to go about their daily lives.

Australia ratified the CRPD on 17 July 2008 and was amongst the first nations to do so. Since then, ratification has continued to gather pace, and now 145 countries and the European Union have signed up. In fact, the CRPD is the second fastest ratified human rights convention, only beaten by the Convention on the Rights of the Child. On 21 August 2009, Australia ratified the Optional Protocol to the CRPD which enables Australians to make direct complaints to the CRPD Committee if their rights under the Convention have been violated. We ratified the CRPD relatively early, in part because the newly elected Rudd Government wished to be closer to the United Nations and to be in the forefront of ratifying countries. By this time, Australia's approach to disability was a bi-partisan one. In particular, I wish to acknowledge the work of the

⁴ The social model of disability is amplified in paragraph E of the CRPD which provides that "...Disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

Hon Philip Ruddock MP who was Attorney-General in the Prime Minister Howard Government from 2003 to 2007 when the Government supported the adoption of the CRPD.

4. A Road Map of This Lecture

The CRPD has, in my view, acted as a catalyst for the establishment of a national approach to fulfilling the needs and aspirations of persons with disabilities in Australia, which is truly remarkable. In this lecture I wish to catalogue its features over the last half dozen years. On the other hand, the approach of the CRPD Committee has focused upon the human rights of persons with disabilities, and I shall suggest that many reporting countries are less comfortable with its examination through a human rights lens. Put briefly, I shall compare Australia's national needs approach with the human rights stance of the CRPD Committee. In my view, both strategies are to be commended and we can learn from these differing approaches to enhance the lives of Australians with disabilities.

5. Australia's National Needs Approach

The aspects of Australia's needs approach on which I shall comment are our approach to foreign aid, Australia's National Disability Strategy, and the Establishment of the National Disability Insurance Scheme. Obviously, the ratification of the CRPD did not of itself bring about these changes. However, its ratification by Australia gave greater impetus and legitimacy to the national focus on disability.

5a. Foreign Aid

Article 32⁵ of the CRPD is headed International Cooperation, and it exhorts countries to involve persons with disabilities in their international aid programs. To this end, in November 2008, the Parliamentary Secretary for International Development Assistance, Senator Bob McMullan launched Australia's foreign aid disability strategy called "Development for All: Towards a Disability-Inclusive Australian Aid Program 2009-2014". In July and August 2008, AusAid had consulted with persons with disabilities and their representative organisations in developing countries to make sure that our technical support and capacity building strategies were appropriate. In other words, it was essential to ensure that our foreign aid benefitted persons with

⁵ Article 32 - International cooperation

“1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

A. Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities; B. Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices; C. Facilitating cooperation in research and access to scientific and technical knowledge; D. Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.”

disabilities. This disability inclusive approach informed our programs in Cambodia, East Timor, Papua New Guinea, Samoa, and throughout the Pacific. The 2012 mid-term review of this strategy confirmed its success in contributing to increased access to education, employment, health services and law and justice for persons with disabilities. The emphasis on foreign aid has been re-worked by the Abbott Government, which is seeking to involve the private sector more directly in aid programs. However, we have not lessened our concern about disability, and Australia remains a leading country in disability inclusive aid.

5b. Australia's National Disability Strategy

The ratification of the CRPD in July 2008 obliged the Federal Government to adopt a national approach to disability. Of course our Federal, State and Territory governments already ran important programs, but it was clear that a national approach was needed. Interestingly, the Hon Bill Shorten MP, who is now the leader of the Opposition, cut his teeth as Parliamentary Secretary for Disabilities and Children's Services in the Rudd Government. It may have been surprising to some to see this ambitious man take on this portfolio. Bill was a student of mine when I taught at the Monash University Law School and I was heartened by his commitment to we persons with disabilities. In 2008, he established the National People With Disabilities and Carer Council which was ably chaired by Dr Ronda Galbally AO, and of course I was honoured to be one of its members. In 2008 and in 2009, the Council consulted with Australians with disabilities and relevant bodies to understand our needs. These consultations culminated in the Council's 2009 report titled "Shut Out: The Experience of People With Disabilities and Their Families in Australia". This report, from which the National Disability Strategy grew, chronicled through their voices, the lives of persons with disabilities and demonstrated that many felt socially excluded. Many had difficulty in accessing buildings and transport, and in obtaining education and meaningful employment. Put bluntly, many Australians with disabilities felt shut out of society.

On 13 February 2011, the Council of Australian Governments (COAG) endorsed the National Disability Strategy 2010-2020 (NDS) which set forth a ten year plan to improve the lives of Australians with disabilities. The NDS is a high level document giving guidance to governments. It has six pillars around which the strategy operates. They are:

- Inclusive and Accessible Communities
- Rights Protection, Justice and Legislation
- Economic Security
- Personal and Community support
- Learning and Skills
- Health and Well-being.

Put briefly, the NDS seeks to increase access to justice, to transport, to housing, to education and to employment over its ten year period, in a manner conforming with the approach of the CRPD. In the first report to COAG on 30 January 2013, progress with the strategy was noted, but it was recognised that more work was required in the following years.

5c. The National Disability Insurance Scheme

Perhaps the most exciting and innovative development at this time, was the establishment of the

National Disability Insurance Scheme (NDIS) in 2013.⁶ Prime Minister Julia Gillard pledged funding for the NDIS on 30 April 2012. Initially, four experimental launch sites were chosen which covered the Newcastle area in New South Wales, Geelong in Victoria, together with The States of Tasmania and South Australia. These launch sites commenced operation on 1 July 2013, and on 1 July this year, the Australian Capital Territory became the fifth launch site. Put briefly, the NDIS, which in part builds on earlier governmental programs, seeks to provide individual funding packages to enable persons with disabilities to fully participate in the community. For example, funding can be used to assist with self care, or to pay for therapy for children with disabilities. The National Disability Insurance Agency (NDIA) operates the NDIS. It is of course early days, but in my view this scheme is a significant breakthrough in enhancing the lives of Australians with disabilities.

What is truly remarkable is that in May 2013, the Prime Minister Gillard Government announced that to pay for the NDIS, the medicare levy which was set at 1.5% of taxable income, would be increased to 2% on 1 July 2014. Even though increases in taxation are almost always contentious, the Tony Abbott Opposition agreed with this change to the levy. Perhaps both the Government and the Opposition recognised that money would have to be found to fund the NDIS, and that this was a reasonable measure. Within a few short years, policies to assist Australians with disabilities had become a central concern of the Australian Parliament and they had a bipartisan status, unusual in the Australia of today.

6. The Human Rights Approach of the CRPD Committee

6a. The Monitoring Role of the CRPD Committee

Under article 35 of the CRPD,⁷ ratifying countries must deliver a report to the CRPD Committee, initially two years after ratification, and then every four years. These reports detail how the country is implementing the CRPD. The CRPD Committee then considers these reports,⁸ and conducts what are known as Constructive Dialogues. Put briefly, the CRPD Committee members read the report, gather further information from alternative reports usually written by disabled persons organisations from that country, and then have a delegation from the government appear before it in Geneva. A Constructive Dialogue then takes place where CRPD Committee members question the delegation and receive direct replies. At the conclusion of the constructive dialogue, the CRPD Committee prepares what have become known as its Concluding Observations. These documents are usually a little over three thousand words in length and consist of recommendations to the State Party on ways to better implement the CRPD.

⁶ *National Disability Insurance Scheme Act 2013* (Cth).

⁷ Paragraphs 1 and 2 of Article 35 of the CRPD provide: “1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned. 2. Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.”

⁸ Paragraph 1 of Article 36 paragraph 1 of the CRPD provides: “1. Each report shall be considered by the Committee, which shall make such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The State Party may respond with any information it chooses to the Committee. The Committee may request further information from States Parties relevant to the implementation of the present Convention.”

This reporting and constructive dialogue process is used by all of the committees which monitor the nine human rights conventions.

The CRPD Committee, owing to the increase in the number of ratifying countries,⁹ is now comprised of eighteen members. Interestingly, seventeen of the eighteen members of the current Committee are persons with disabilities. We are blind, hard of hearing, have mobility problems, lack upper and lower limbs and have psychosocial impairments. The ratifying countries have put up candidates with disabilities, and have elected a Committee which is overwhelmingly comprised of members with disabilities. Thus, the CRPD Committee members are rights holders under the CRPD, and in monitoring the implementation of the CRPD, members rely in part upon their lived experiences as persons with disabilities. The CRPD Committee marked a change in the representation of persons with disabilities throughout the United Nations bodies. Never before had so many persons with disabilities played such significant roles in the human rights treaty bodies system.

The CRPD Committee has conducted constructive dialogues with thirteen countries including Australia, which appeared before it in September 2013. In the 12th session this September/October, constructive dialogues will take place with six countries, including New Zealand. It is not possible to discard the individual nuances in all of the constructive dialogues. After all, the thirteen nations with which constructive dialogues have taken place vary in size, geography, history and in their economic capacities. They range from China, to Sweden, to Tunisia when it was caught up in the Arab Spring. It is also the case that many questions asked in these constructive dialogues flow from the particular interests of the members. For example, the current CRPD Committee is deeply concerned about the plight of children with disabilities around the world, including their well-being and their capacity to access inclusive education. However, when one reads the Concluding Observations from these constructive dialogues, I suggest that a pattern emerges. Obviously, the CRPD Committee is concerned about access to transportation and to buildings, and also about inclusive education, employment and health care. However, much of the Committee's focus is also upon the human rights of persons with disabilities.

When countries appear before the CRPD Committee, naturally enough, they wish to expound upon their programs giving assistance to and enhancing the needs of persons with disabilities. However, the language of the CRPD Committee is rooted in human rights values, and it is important for governments to comprehend this approach and to be prepared to discuss the human rights of persons with disabilities within their realms.

6b. Examples of the Human Rights Approach

I have selected three human rights issues which illustrate this type of human rights approach. They are: legal capacity; the sterilisation of women and girls with cognitive disabilities; and voting in elections by persons with cognitive and/or psychosocial disabilities, issues that correspond with CRPD articles 12, 17 and 29 respectively.

The CRPD Committee is concerned that all persons with disabilities have their legal capacity recognised in line with article 12 of the CRPD. Article 12 paragraph 1 states that countries must

⁹ See CRPD Article 34 paragraph 2.

"...reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law." Paragraph 2 provides that countries must "...recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Article 12, together with other relevant articles, obliges countries to ensure that all persons with disabilities, including those with cognitive and/or psychosocial disabilities, can give or withhold consent for medical treatment, are able to access justice, can marry and may vote in elections. The CRPD Committee has been especially concerned with this article as it was the subject of the Committee's first General Comment, published in April this year.¹⁰

The CRPD Committee has also stated that measures must be taken to replace guardianship mechanisms of substituted decision-making, and to replace them with regimes of supported decision-making and to establish wide ranging measures which respect the autonomy, will and preferences of persons with disabilities. Regimes of supported decision-making require some elaboration. Briefly put, these regimes of supported decision-making use family members and friends to assist persons with cognitive disabilities to make their own decisions in accordance with their will and preferences. In the case of Australia, the CRPD Committee commended the pilot programs in South Australia and in New South Wales on supported decision-making. The Australian Law Reform Commission's inquiry titled "Equality, Capacity and Disability in Commonwealth Laws" which will be completed in a few weeks was also noted by the CRPD Committee.

In Australia, it is still the case that women and girls with severe cognitive disabilities may be sterilised without their full and free consent, provided curial or tribunal permission is obtained. In July 2013, the Senate's Community Affairs References Committee handed down its report.¹¹ While this report recommended further safeguards and educational programs, it did not recommend that this practice should be abolished. Article 17 of the CRPD states that "Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others." The CRPD Committee is strongly of the view that no person with disabilities should be sterilised without her or his full and free consent, other than perhaps in life saving situations. Not only has the CRPD Committee recommended that Australia enact legislation to end this practice, but the CEDAW Committee and the Human Rights Council have also recommended that this practice cease.

Section 93(8)(a) of the *Electoral Act 1918* (Cth) provides that if a person is "...of unsound mind, [and] is incapable of understanding the nature and significance of enrollment and voting..." she or he cannot vote in Federal elections. In other words, this provision places an individualised capacity test upon persons with intellectual and/or psychosocial disabilities. No other group of persons such as those who have attained advanced age, are required to undergo this test. Other countries, like New Zealand, have not put such a test in their legislation.¹² In the view of the CRPD Committee this type of test contravenes article 29 of the CRPD. This article is a lengthy

¹⁰ Committee on the Rights of Persons with Disabilities, "General comment No. 1 (2014) Article 12: Equal recognition before the law" (19 May 2014). Full text accessible at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

¹¹ The Senate Community Affairs References Committee, "Involuntary or Coerced sterilisation of People with Disabilities in Australia", Parliament of Australia, July 2013.

¹² *Electoral Act 1993* (NZ).

provision, however, it clearly and unequivocally guarantees the right to vote to all persons with disabilities. If a person with a cognitive disability wishes to have her or his name placed upon the electoral roll and to vote, she or he should be entitled to vote without being required to pass a test administered by an electoral official. These tests amount to impermissible discrimination against persons with disabilities. Furthermore, the Australian individualised capacity test which is administered by untrained electoral officials, obviously only utilises impressions and untested evidence from family members and should be repealed. The CRPD Committee recommended that Australia do away with its capacity test. In September 2013, the CRPD Committee dealt with this same matter under the Optional Protocol in the case of *Szolt v Hungary*¹³. The Committee recommended that Hungary repeal provisions which placed an individualised capacity test on Hungarians with mental disabilities.

7. Summation

It is clear that Australia's ratification of the CRPD has been a major factor in developing Australia's approach to disability over the last half dozen years. The needs-based initiatives of the Australian Government have been truly remarkable. In particular, the NDS and the NDIS will lead to a more inclusive society for we persons with disabilities. These programs have gone a long way to upholding the human rights and inherent dignity of the one in five Australians who are persons with disabilities. Of course, much more work is required, especially in the fields of inclusive education and employment. Nevertheless, Australia has made strong efforts to comply with its obligations under the CRPD.

From my experience as an inaugural member of the CRPD Committee, I have noticed a common pattern in State Parties that have appeared before us. Their initial focus is usually upon the living needs of persons with disabilities, including accessibility, health, education and employment. At this stage, less attention is given to those less tangible human rights which ensure the integrity of persons with disabilities through their full participation in society on an equal basis with others. In my view, Australia is transitionning towards this human rights approach. By adopting a human rights approach, the CRPD seeks to alter old-fashioned attitudes and to eliminate social barriers which prevent persons with disabilities from leading useful and full lives on an equal basis with others.

¹³ *Szolt v Hungary*, Communication No. 4/2011, CRPD Committee, 10th session, 2-13 September 2012.

8. Appendix

Figure 1

Year	Instrument (<i>/Treaty body</i>)	Adopted (<i>/First session</i>)	Entered into force	Australia ratified <i>/acceded</i>
1965	International Convention on the Elimination of All Forms of Racial Discrimination	21 Dec 1965	4 Jan 1969	30 Sep 1975
	<i>Committee on the Elimination of Racial Discrimination (CERD)</i>	1970		
1966	International Covenant on Economic, Social and Cultural Rights	16 Dec 1966	3 Jan 1976	10 Dec 1975
	<i>Committee on Economic, Social and Cultural Rights (CESCR)</i>	1980		
	Optional Protocol to the Covenant on Economic, Social and Cultural Rights	10 Dec 2008	5 May 2013	-
1966	International Covenant on Civil and Political Rights	16 Dec 1966	23 Mar 1976	13 Aug 1980
	Optional Protocol to the International Covenant on Civil and Political Rights	16 Dec 1966	23 Mar 1976	25 Sep 1991
	<i>Human Rights Committee (CCPR)</i>	1977		
	Second Optional Protocol to the International Covenant on Civil and Political Rights, aiming at the abolition of the death penalty	15 Dec 1989	11 Jul 1991	2 Oct 1990
1979	Convention on the Elimination of All Forms of Discrimination against Women	18 Dec 1979	3 Sep 1981	28 Jul 1983
	<i>Committee on the Elimination of Discrimination against Women (CEDAW)</i>	1982		
	Optional Protocol to the Convention on the Elimination of Discrimination against Women	6 Oct 1999	22 Dec 2000	4 Dec 2008
1984	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	10 Dec 1984	26 Jun 1987	8 Aug 1989
	<i>Committee against Torture</i>	1988		
	Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	18 Dec 2002	22 Jun 2006	Signed 19 May 2009, not ratified
	<i>Subcommittee on Prevention of Torture (SPT)</i>	2007		
1989	Convention on the Rights of the Child	20 Nov 1989	2 Sep 1990	17 Dec 1990
	<i>Committee on the Rights of the Child</i>	1991		
	Optional Protocol to the Convention on the Rights of the Child on the Involvement of Children in Armed Conflict	25 May 2000	12 Feb 2002	26 Sep 2006
	Optional Protocol to the Convention on the Rights of the Child on the Sale of Children, Child Prostitution and Child	25 May 2000	18 Jan 2002	8 Jan 2007

Year	Instrument (/Treaty body)	Adopted (/First session)	Entered into force	Australia ratified /acceded
1990	International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families	18 Dec 1990	1 Jul 2003	-
	<i>Committee on Migrant Workers</i>	<i>2004</i>		
2006	Convention on the Rights of Persons with Disabilities	13 Dec 2006	3 May 2008	17 Jul 2008
	Optional Protocol to the Convention on the Rights of Persons with Disabilities	13 Dec 2006	3 May 2008	<i>21 Aug 2009</i>
	<i>Committee on the Rights of Persons with Disabilities</i>	<i>2009</i>		
2006	International Convention for the Protection of All Persons from Enforced Disappearance	20 Dec 2006	23 Dec 2010	-
	<i>Committee on Enforced Disappearances</i>	<i>2011</i>		