People With Disability: Turning Paper Rights Into Realities

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In 2012, 4.2 million Australians (18.5% of the population) were estimated as having a disability.[1] However, as Vik Finkelstein, an English self-advocate has commented, the rest of the population could be labelled as 'not yet disabled', for disability is something that can affect each of us at some point in our life course. While a significant minority of Australians identify as disabled, the label disguises the diversity of people who have been included within it. Over the last two decades, the disability rights movement has gradually recognised and supported the emergence of the individual 'subject', a citizen who should be able to live a good life in the community. That includes 'subjects' with disabilities.

In this chapter I want to provide a context for this shift in the way people with disability have been seen by those around them, provide an account of the different ways in which the movement to rights has been developed both nationally and internationally, and provide some examples of how the UN Convention on Rights of Persons with Disabilities (CRPD) has had an impact on Australian developments in policy and practice. The chapter will conclude with an account of some of the challenges that exist in translating disability rights into realities.

The context

> The institution was situated on a hill, some forty kilometres from the nearest city, and the small town that lay at the foot of the hill had provided generations of workers and also supplied the needs of the people living at the institution. In the past, Hilltop had included a farm that was now largely abandoned. The buildings were surrounded by perfectly kept gardens, but the institution itself was poorly serviced — for example, the central heating with its hissing, gurgling pipes running around the grounds was not introduced until the late 1980s.[2]

I wrote this description of an institution for people with intellectual disability more than 20 years ago at the beginning of its closure. For me, the account of the physical nature of the institution is symbolic of the lives of many people with disability at that time. The institution was a 'total' institution, separated from the community, where it was expected that residents would live and work during their lives. The people living at Hilltop had been labelled as having an intellectual disability, which was seen as an individual problem requiring treatment and management. Many of these people lived their entire lives within the walls of places like Hilltop, largely unrecognised as individuals and, for the most part, forgotten.

For much of the last century, people with disability were constituted in ways that did not recognise their personhood, their rights or their status as citizens. While many did not live in institutions like Hilltop, their lives within the wider community were also often isolated; children went to special schools rather than being included in public education, employment opportunities were extremely limited (when they were considered as a possibility at all), and segregated day centres or sheltered workshops provided life long activities for some. Families were their main support.

People with disability were subject to what has now been termed the 'medical model', which involved some form of assessment or diagnosis that was followed by placement in a system where they were provided with care and/or managed by those trained as nurses or as specialists in a particular disability. However, this was not just a medical model. Advances in psychology and the social sciences generally at the beginning of the 20th century created new forms of assessment such as IQ tests, which were designed to identify and remove from the community those who were seen as not 'normal'.

As with refugees today, once a label was given that marginalised a group, other negative attributes were also assigned to them. So the eugenics theory, based on now discredited research, attributed those labelled with intellectual disability as more likely to have criminal tendencies or to be unproductive, promiscuous or dangerous to the community because they might, through having children, lower the intelligence of society in general. Segregation in closed communities that separated men and women was seen as a means of both protecting people who were vulnerable but also protecting the community from them.

In the general population, knowledge about people with disability was limited. They were rarely seen in the community at large, and for many people, including me as a child, their acquaintance was made through the small statues of children with a hole in their head, or 'guide dogs' that were designed to raise money for services. People were thus not seen as individuals but rather as 'objects of charity' or as figures of pity or danger.

The movement to rights

However, by the 1980s in Australia change had begun to occur. There was an increasing focus on the human rights of other marginalised groups at both a national and international level; for example, in a recognition of the contribution of the Civil Rights

movement in the United States, the rise of feminism and the strug-
gle towards rights by Indigenous people. In relation to people with
disability, new theories and ideas began to focus on the need for
them to live within their home communities. This was combined
with mounting evidence of the poor quality of life offered in large
institutions and a gradual realisation by governments of the cost of
renovating or upgrading ageing institutions (not all change was
driven by rights alone!). The movement towards a stronger rights
framework for people with disability was also shown in the passing
of the *Disability Discrimination Act* in 1993[3] in Australia, which made
it unlawful to discriminate against people with disability.

At the same time in the United Kingdom there was a radical
shift driven by people with physical disability to reject the 'medical
model' in favour of one that constituted people with disability
quite differently. The 'social model' made a distinction between an
impairment and a disability: the former was seen as a difficulty
experienced by an individual (physically, sensorily or cognitively),
while the latter was constituted by the barriers that prevented the
person from living fully in wider society. Disability moved from
being a problem of the individual to being a failure on the part of
society to accommodate its diverse citizens appropriately. If social
barriers were removed, the advocates of the social model argued,
then people with impairments would be able to live full lives as
citizens. While the social model has been criticised for its failure to
take into account adequately the impact of impairment, it does fit
within a rights model of disability and undoubtedly has had a
profound influence on government policy and practice over the
past ten years.

The focus on the individual and his or her rights was also
developed through new policies such as personalisation, in which
the person with disability, their aspirations and needs became the
focus of planning and support. Similarly, the movement towards
individual budgets that gave people with disability, at least

nominally, more power in deciding what kinds of support they needed and wanted, exemplified this shift. Both of these policy movements signalled a move away from the previous forms of service provision for groups of people with disability in favour of an approach in which an individual would have more choice and control in their lives.

The UN Convention on Rights of Persons with Disabilities

The UN Convention on Rights of Persons with Disabilities (CRPD) was initiated in 2002 within the United Nations with the formation of an Ad Hoc Committee on the subject. The Committee was established because of international concerns that there was no binding international law that recognised and asserted the human rights of persons with disability. While there had been a number of UN non-binding declarations and standards relating to people with disability,[4] there was concern within the disability movement that these had failed to provide adequately for the rights of this group of people. The Convention has been described as a paradigm shift for people with disability, and this can be seen not only in its content but also in the process of drafting it. For the first time, people with and for whom a Convention was to be drafted were integral to its development. Forty country delegations and 400 disabled people's organisations had a strong and continuing role in the drafting process.

The importance of recognising the dignity and personhood of people with disability and the expertise demonstrated in the Convention's drafting is clearly evident in its character and articles. In summary, its key features are:

- Unlike other UN Conventions, it includes civil and political rights, and social, economic and cultural rights, recognising that these are indivisible in people's lives.

- The CRPD demonstrates a strong commitment to the importance of societal barriers being removed so that

people with disability can live in ways that allow them to participate actively socially, economically and politically. Like the social model of disability it makes a clear distinction between impairment and disability.

- The CRPD does not seek to establish 'new rights' for people with disability but to 'tailor the existing suite of human rights to the specific situation of persons with disability'.[5]

- 'The principles of equality and non-discrimination run through the Convention like a red thread.'[6] These form the foundation of the eight guiding principles of the CRPD:

  a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

  b. Non-discrimination;

  c. Full and effective participation and inclusion in society;

  d. Respect for difference and acceptance of persons with disability as part of human diversity and humanity;

  e. Equality of opportunity;

  f. Accessibility;

  g. Equality between men and women;

  h. Respect for the evolving capacities of children with disability and respect for the right of children with disability to preserve their identities.

- Its articles include the rights to a good standard of living, access to employment, justice, health, education, housing and a family life, freedom from abuse, equal access and status in relation to the law, as well as in article 19, a strong statement of the right to participate and live in the community.

- The importance of the recognition of legal capacity of people with disability is central to the CRPD. Article 12 affirms the right of people with disability to make decisions in their lives and to receive appropriate support to do so. This is particularly important given a history in which people's will and preferences were often disregarded or ignored.

- Article 19 is also central to the CRPD as it states clearly the centrality of choices as to how, where and with whom people with disability live in the community and the importance of the provision of appropriate supports for them to be able to participate equally in their communities. It places responsibility for ensuring that this can occur on ratifying states.

- The importance of the involvement of people with disability and the importance of their preferences and will are also demonstrated in the processes by which the CRPD is to be implemented and monitored.[7]

- Governments ratifying the CRPD and the Optional Protocol are accountable to the UN Committee on Rights of Persons with Disabilities for their progress towards implementing the Convention's terms.

The CRPD and Australia

The CRPD was accepted by the UN in 2006 and Australia became one of the early countries to ratify both the Convention (2008) and the Optional Protocol (2009). The success of the CRPD has to be assessed according to the extent to which it is implemented at a domestic level. To my knowledge, there has not been any Australian research that has explored this issue. However, a consideration of some recent governmental policies and programs reveals that the CRPD has been used both as a mirror to reflect our current position in relation to the rights of people with disabilities and to

provide guidance for significant new policies and programs that position people with disabilities as central in decision making about their lives. As such, it can be seen as influential in 'socialising the Australian State to the right behaviour'.[8]

In 2013, when Australia appeared before the UN Committee for a discussion of its progress in implementing the CRPD,[9] it received praise for the development of a National Disability Strategy and the National Disability Insurance Scheme. Both of these developments were influenced by the CRPD explicitly in policy documents and in their programmatic plans and measures.

National Disability Strategy 2010–2020

In 2009, *Shut Out: The Experience of People with Disabilities and Their Families in Australia* was produced following a national consultation. It provided a devastating picture of the lived experience of many people with disabilities and their families in Australia, drew upon the rights articulated in the CRPD and concluded that the current disability service system was broken.[10] The report informed the National Disability Strategy (NDS) developed by Commonwealth, State and Territory governments under the auspices of the Council of Australian Governments (COAG). The purposes of the NDS include to:

- establish a high-level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy;
- drive improved performance of mainstream services in delivering outcomes for people with disability;
- give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability; and
- provide national leadership toward greater inclusion of people with disability.[11]

The NDS covers six key policy areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing. All of these are explicitly aligned with articles of the CRPD and were developed in line with its emphasis on involvement of people with disability. The Australian government viewed the NDS as a policy that was central to the domestic implementation of the CRPD:

> Australia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008. The Strategy will play an important role in protecting, promoting and fulfilling the human rights of people with disability. It will help ensure that the principles underpinning the Convention are incorporated into policies and programs affecting people with disabilities, their families and carers. It will contribute to Australia's reporting responsibilities under the Convention.[12]

The National Disability Insurance Scheme

In 2010, in response to governmental concerns about weaknesses in the then current disability services system, the Australian Productivity Commission was commissioned to examine the feasibility and character of a national disability insurance scheme. This was one of the crucial ingredients of the NDS and was seen to be important in developing Australia's implementation of the CRPD.

In August 2011, the Productivity Commission (PC) released its report, *Disability Care and Support,*[13] which found that 'current disability support arrangements are inequitable, underfunded, fragmented and inefficient, and give people with a disability little choice'.[14] As a result of its recommendations, a National Disability Insurance scheme was established to provide insurance cover for all Australians in the event of significant disability. The government accepted the recommendations of the report, and in 2013 the *NDIS Act* was enacted. The NDIS is administered and monitored by the National Disability Insurance Agency.

The NDIS is remarkable for the planning and thought that has gone into its development. It is not expected to be fully rolled out until 2018, but is being trialled at a number of sites throughout Australia with the view to learning from these experiences and fine tuning the final program.

Once accepted into the program through an individual assessment, people with disability are involved in a planning process that aims to keep the focus on the individual, their aspirations and their support needs. An individual budget is provided for the consumer, one objective of which is to allow them choices and some control over how the money is used. Management of the budget can be by the person with disability, a trusted supporter or a trust. The program, with its focus on individuals with disability and their preferences, is consistent with the principles of the CRPD.

While it is early days still in relation to the NDIS, a preliminary actuarial study of the trial sites has revealed that for those involved in it, there have been positive impacts, particularly in relation to life domains of choice and control, health and wellbeing. [15]

The challenges: rights and realities.

> … the Convention (CRPD) removes the invisibility of people with disabilities and partners them with government in moving the reform process forward. [16]

In this chapter, I have argued that the movement towards a recognition of rights of persons with disability, culminating in the CRPD have led to an increased focus on individuals removing them from the label of a disenfranchised group — the disabled. However, we have a long way to go before paper rights are fully translated into realities for all people with disability. Some of these challenges are outlined below.

The tension between rights and resources

More than 20 years ago when Hilltop was finally closed, half of the former residents went to other institutions because of limited

resources to support them in the community. We still now, in spite of the research and the journey towards rights, maintain some large institutions for people with disability.

The achievement of rights must necessarily occur within the wider context of political priorities and scarce resources. While the NDIS is conceived as a universal scheme, it relies on individual assessment for eligibility. When it is fully rolled out it will be available for 450,000 people with disability. This is a major achievement. However, that will still leave three and a half million people not covered by the scheme and who will be directed to existing services. At the moment it is difficult to know what the result of this will be. It is inevitable but regrettable that, as in every major social reform, the rights of many will still be ignored or compromised owing to a lack of adequate resources.

Translating rights into realities

It takes time to move from 'darkness' into 'light'. But sometimes the time taken and the steps can be very slow. While Australia was praised by the UN Committee on the Rights of Persons with Disabilities for actions taken in relation to the NDS and the NDIS, the Committee also made a number of comments and recommendations with respect to women and children with disability, supported decision making, access to justice, medical intervention and restrictive practices, education, work, voting and data collection.[17] These are yet to be addressed. There have also been criticisms of the NDS from disability advocacy organisations for slowness and lack of adequate accountability mechanisms with respect to implementation. We still have a long way to go.

Are rights enough?

Rights are a necessary but not a sufficient condition for people with disability to live good lives. While the CRPD recognises the relational nature of personhood in its articles (see particularly article 12 on supported decision making) it is difficult to include a

focus on interdependence and our interrelatedness within a rights framework. We need to give consideration to how we develop what has been called an 'ethics of care'.[18] This is not a retreat to the old medical model, but rather recognises the need for all of us to be able to acknowledge and work with each other in what Rogers describes as care-ful work and to replace care-less spaces with ones that include, recognise and respect all of us equally in our separate individuality. So, for example, the right to be included in public education may be asserted, but if children and their families are then subject to bullying or to being rejected or ignored by the school community, the right becomes a paper one and not a reality.

Conclusion

The title for the book in which this is a chapter is *Humane Rights*. And rightly so! We need to recognise our common humanity through the protection and advancement of human rights but, at the same time, to comprehend our interdependence and our need for an emotional as well as a reasoned response to our diversity and its associated difficulties. Only in this way will we move towards the full realisation of our human potential.

Endnotes

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3   Available at https://www.humanrights.gov.au/our-work/disability-rights for accounts by people with disabilities of the impact of the Act.

4   Declaration on the Rights of Mentally Retarded Persons, GA Res 2856, UN GAOR, 3rd Comm, 26th Sess, UN Doc A/RES/2856 (20 December 1971); Declaration on the Rights of Disabled Persons, GA Res 3447, UN GAOR, 3rd Comm, 30th Sess, UN Doc A/RES/3447 (9 December 1975); Standard Rules on the Equalization of Opportunities for Persons with Disabilities, GA Res 48, UN GAOR, 3rd Comm, 48th Sess, Agenda Item 109, UN Doc A/RES/48/96 (20 December 1993).

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7   UNCRPD Article 33.

8   G Quinn, 'Resisting the "Temptation of Elegance": Can the Convention on the Rights of Persons with Disabilities socialise states to the right behaviour?', in G Quinn and O Arnardottir (eds), *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian perspectives*, Lieden, Martinus Nijhoff Publishers, 2009.

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10   National People with Disabilities and Carers Council, Shut Out: The Experience of People with Disabilities and Their Families in Australia, 2009.

11   Australian Government, National Disability Strategy 2010–2020.

12   Ibid.

13   Productivity Commission, 'Disability care and support', Vols. 1 and 2, July 2011.

14   Productivity Commission, 'Disability Care and Support', Overview, 2.

15   NDIA, 'National Disability Insurance Scheme outcomes framework pilot study: summary report', 1 September 2015, retrieved from http://www.ndis.gov.au/sites/default/files/outcomes-framework.pdf

16   G Quinn, 'The UN Convention on the rights of persons with disabilities: towards a new international politics of disability', *Texas Journal on Civil Liberties and Civil Rights,* vol. 15, no. 1, pp. 33–52, 2009.

17   Australian Law Reform Commission (n.d.), retrieved from Legislative%20and%20regulatory%20framework%20_%20ALRC.htm

18   C Rogers, *Intellectual disability and being human*, London, Routledge, 2016.