

AUSTRALIAN LAW REFORM COMMISSION

Legal Barriers for People with Disabilities

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1.0 Introduction

Youngcare is an organisation established in 2005 to tackle the national tragedy of 7,500 young Australians across the country forced into aged care because there is nowhere else for them to go.

For most people the choice of where they live and who they live with is taken for granted. However for many Australians with high care needs that right in effect does not exist. Due to a wide range of factors many young Australians with disability end up in residential aged care, which is no place for a young person.

The path that leads these people to this point is a dynamic process and many factors contribute. Whilst the process is complex, it is possible to identify points at which key interventions can avert this process – a process which is fundamentally degrading to human dignity and a denial of freedom. Whilst some of the factors are not matters primarily of law and justice – economic factors such as the high correlation between disability and poverty in Australia – this paper will show that there is considerable interrelation between all areas of possible intervention and the legal framework surrounding people with disabilities and their rights.

2.0 Legal and Policy Background

A number of laws and key documents form the basic legal framework surrounding disability issues in this country. There is the *Disability Discrimination Act 1992* (Cth) (hereafter, the *DDA*), the United Nations *Convention on the Rights of Persons with Disabilities (CRPD)* of which Australia is a founding signatory, the National Disability Strategy and the *National Disability Insurance Scheme Act 2013* (Cth) and associated Federal and State legislation. In addition to these disability-specific aspects of the framework a great deal of other legislation significantly contributes to the treatment and the living conditions of people with disability in Australia. This submission will discuss, for example, the role of the *Competition and Consumer Act 2010* (Cth) in relation to the medical aids and equipment

market. Additionally the provisions of the *Human Services (Centrelink) Act 1997* (Cth) have key ramifications for people with disability.

As a starting point in any discussion of the rights and equal status before the law of people with disabilities, the UN *CRPD* is a good choice. Its stated purpose 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.” This then is the object in mind in the following submission.

3.0 Potential for Reform

The Australian Government has maintained the view since the signing and ratification of the *CRPD* and its Optional Protocol that the current body of Australian law serves to meet Australia’s obligations under the *Convention* (though Australia did issue an Interpretative Declaration in relation to Article 12 of the *CRPD*). However Youngcare feels that the *DDA* falls short of ensuring Australia meets the requirements of Article 19 of the *Convention*. By contrast the *Americans with Disabilities Act 1990* provides a working alternative that does provide Article 19 protections for the rights of people with disabilities.

The full text of Article 19 of the *CRPD* reads as follows:

Article 19

Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

In a case that went to the United States Supreme Court, *Olmstead v. L.C.*, 527 U.S. 581 (1999), the court ruled that unjustified segregation of people with disabilities constitutes discrimination under Title II of the *Americans with Disabilities Act 1990* (*ADA*). The segregation here referred to was

institutionalisation when it was appropriate and reasonable that the State provide community-based alternatives.

In Australia the relevant act is the *DDA*. The stated Objects of the *DDA* are:

- (a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of:*
 - (i) work, accommodation, education, access to premises, clubs and sport; and*
 - (ii) the provision of goods, facilities, services and land; and*
 - (iii) existing laws; and*
 - (iv) the administration of Commonwealth laws and programs; and*
- (b) to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and*
- (c) to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community.*

Whilst the *DDA* is by no means a transplant of the *ADA* to Australia, in the framing of the *DDA* the *ADA* was an influence, as observed by Elizabeth Hastings, the former Disability Discrimination Commissioner. In *Olmstead* the most pertinent provision of Title II of the *ADA* reads:

Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity. §201, as set forth in 42 USC §12132

For comparison s.29 of the *DDA* reads:

It is unlawful for a person who performs any function or exercises any power under a Commonwealth law or for the purposes of a Commonwealth program or has any other responsibility for the administration of a Commonwealth law or the conduct of a Commonwealth program to discriminate against another person on the ground of the other person's disability in the performance of that function, the exercise of that power or the fulfilment of that responsibility.

Whilst both provisions deal with discrimination by the State or its agents, the *ADA* is more specific in outlining what precisely constitutes discrimination and in presenting concrete rights for the disabled. This had profound implications for the *Olmstead* case and led to a court ruling that enshrined the rights of the disabled to live amongst the community where it was reasonable.

“Reasonable and necessary” is the standard of support that the *National Disability Insurance Scheme Act 2013* (Cth) aims to provide for participants (3.1(d)).

KEY OBSERVATION

Forced segregation of young people into residential accommodation exclusively designed for elderly people is an infringement of the rights afforded to all Australians and those enshrined under the *CRPD*, specifically under Article 19. Whilst the *DDA* is the key plank by which Australia claims to meet its obligations under the *Convention* it does not achieve this as effectively as the alternative provided by the *ADA*. There is potential to strengthen the protections provided to Australians by looking to the *Convention* and the US example to ensure the segregation of many Australians, including the 7,500 young people in nursing homes, does not continue.

4.0 Further Issues

People with 24-hour care needs have it tough. Their condition leaves them ill-placed to participate in the workforce and this means that they are often faced with the prospect of dire poverty. A report by PricewaterhouseCoopers in 2011 found Australia had one of the strongest correlations between disability and poverty amongst OECD nations. Additionally family members frequently end up providing care services. The extent of care required means that these family members are often also removed from the paid workforce, further exacerbating the issue of poverty. Whilst carers are also eligible for support from the government in the form of the Carer Allowance or Carer Payment, these are minimal.

Compounding this problem is the requirement for often expensive medical aids and equipment tailored to the highly specific needs of people with profound disability. Whilst in each state and territory there exist subsidy schemes for these aids and equipment, these frequently have significant gaps. Furthermore they will often provide basic items, but not the vital modifications needed to make them appropriate – and indeed usable – by people with very specific conditions. It must be stressed that these specific requirements are not a luxury, but are fundamentally vital to people's ability to stay in the family home and to participate in society.

While statistics show that a significant portion of carers are family members, the requirement for care is often decades. If the carers are parents it will become more difficult to provide the necessary care as they themselves age. According to the Australian Bureau of Statistics a large proportion of carers themselves have disabilities. This sometimes means that unpaid carers reach a point where they can no longer provide the care needed. At this point it may well become necessary for people with high care need to move into a care facility – often the only option is residential aged care.

Thus there are numerous points where people can find themselves with no choices left. If they cannot access the equipment they need, if carers wear out or are otherwise unable to continue providing care or if they can't access sufficient financial support.

4.1 Medical Aids & Equipment (*current issue*)

Medical aids and equipment are vital to people with high care needs. Often the nature of their disabilities means that they have highly specific requirements from such aids and equipment and this necessarily means greater cost.

Youngcare has advocated for a revision of medical aids and equipment subsidy schemes, particularly in Queensland in terms of both expanding the catalogue of items covered to remove key gaps and in terms of re-examining the levels of subsidy funding provided. Whilst this is important there are also issues of market failure that effect the choice and price of aids and equipment available to consumers.

Youngcare has previously made a submission to the Queensland Competition Authority's (QCA) investigation into medical aids and equipment pricing both in Queensland and across Australia. The QCA has released its draft report which found that prices for aids and equipment were higher in Australia than comparable overseas markets.

The Object of the *Competition and Consumer Act* is to "enhance the welfare of Australians through the promotion of competition and fair trading and provision for consumer protection." Whilst the QCA's Draft Report did not find significant market power issues in the Queensland or Australian markets for medical and disability aids and equipment, it did find that information asymmetries, exclusive dealing arrangements and the size of the Australian market for highly specialised aids and equipment as well as Australia's status as a high-cost country in general, did have the effect of driving up prices.

Whilst it is true that Australian prices in a range of markets are higher, the disparities uncovered in the area of medical aids and equipment were often much greater, whilst the would-be consumers of these products are much poorer. The coming of the National Disability Insurance Scheme will increase the purchasing power of these consumers somewhat, but if the market remains small and inefficient and prices remain unreasonably high a great deal of taxpayer money provided through the NDIS will be wasted and some products may well remain out of reach.

Additionally, though the Australian Consumer Law, laid out in Schedule 2 of the *Competition and Consumer Act* does offer protections for people with disability where 'unconscionable conduct' is involved, many of the information asymmetries do not reflect particularly malicious conduct on the part of suppliers and retailers, yet still involve trade practices that disadvantage consumers.

One example of this that Youngcare has become aware of is in the role of prescribers within the medical aids and equipment market. Many prescribers are employed by suppliers and this inevitably means that the advice given to consumers is marred by the potential for a conflict of interest. Consumers in this market need independent and complete advice as to their options. Not only does this have a direct benefit for individual consumers, but removing these asymmetries will likely have the further effect of driving down prices in the market.

KEY OBSERVATION:

When considered in connection with the medical aids and equipment market the stated object of the *Competition and Consumer Act 2010* (Cth) does not seem to have been achieved. In light of the peculiarities of the medical aids and equipment market and the need to pave the way for the NDIS, it may be worth investigating legislating specific protections for people with disability, including those aimed at addressing key information asymmetries within the medical aids and equipment market.

4.2 Government Support (*current issue*)

People with disability are eligible in Australia for a disability support pension. Likewise carers can receive support through Centrelink in the form of the Carers Support Payment or Carers' Support Allowance. The minimum full-time weekly wage in Australia is \$622.20 whilst the *maximum* disability support pension amounts to just \$375.85 for singles or \$283.30 per person for couples. Support for carers is even less, even when they are effectively barred from full-time or sufficient part-time work by their caring commitments.

From these supports both people with disability and carers need to find the money to pay for all the usual array of expenses people face and as well as those specifically tied to their disability such as medical aids and equipment.

Perhaps the chief issue in this area however is the labyrinth people – especially couples – must navigate in order to access those government services that are available. Family members, often spouses or partners, are in many cases primary care providers. However when young people with disability are forced into aged care their spouse may immediately be transferred from the Carer's Payment to Newstart with its attendant requirement to actively seek paid employment. However, because of the fundamental inappropriateness of aged care for young people, this same spouse may still be required to attend the nursing home to conduct personal care such as hand feeding for an individual with a neurologically derived swallowing disorder claiming up to six hours of their time each working day. This makes meeting the job seeking requirements of Newstart impossible to meet.

KEY OBSERVATION

Policies deriving from administrative law are failing to protect the families of young people living in nursing homes from unreasonable bureaucratic burdens, further amplifying the misery these young Australians' families endure on a day to day basis.

Information asymmetries afflict people with disability in many areas and in few is the issue highlighted more than in the challenges that face them in navigating government support options. In order to better serve people with disability Centrelink and other services need to be made more accessible, more transparent and better information needs to be made available to service users.

4.3 Choice and Control (*emerging issue*)

All of the above factors frequently conspire to deny people many of the basic choices that the broader population take for granted. Accommodation for young people is a profoundly disturbing example of this. This morning approximately 7,500 young people woke up in residential aged care, a form of housing exclusively designed and delivered for older Australians. This national tragedy is due not to natural factors such as bushfires or floods. It arises purely from a system which turns a blind eye to natural justice.

With 'choice and control' enshrined at the centre of the NDIS progress is being made to ensuring people with disability are empowered to take control of their own destinies. However in order for the NDIS to be maximally effective a great deal of preparatory work needs to be done. The states have begun the process of introducing such preparatory legislation (for example the *National Disability Insurance Scheme (NSW Enabling) Bill 2013* (NSW), with Queensland set to follow course), but this principally deals with the transfer of accommodation support and respite services from governments to NGOs and the private sector. With guarantees of continuation of service being tied to these transitions, they do not provide for any increases in disability housing stock. Choice is not choice without any options to choose from.

KEY OBSERVATION

Whilst the NDIS is full of promise for people with disabilities the progress towards and of its implementation needs to be watched carefully. In order to maximise its effectiveness and ensure that it meets its objectives of choice and control the proper groundwork needs to be laid. Within the next few years it will be apparent whether or not the NDIS stands to achieve its objectives or whether it requires reform.

5.0 Conclusion

In Australia we do provide for older Australians to be cared for in aged appropriate accommodation, but not for young people. This means we are falling short of our efforts to implement Australia's international obligations.

Whilst significant progress has been made in recent times with the introduction of the National Disability Insurance Scheme there still remain many unresolved issues affecting the status of people with disability as equal before the law.

The key areas that Youngcare believes merit closer examination are:

1. The opportunity to reform the *DDA* to the benefit of young people at risk of premature entry into residential aged care.
2. The effectiveness of the *Competition and Consumer Act* in protecting consumers of medical aids and equipment.
3. The implementation fidelity of the protections embedded in administrative law to assist the carers of young people with high care needs.



4. The emerging effectiveness of the *NDIS Act* to avoid future premature admissions to aged care.

Overall Youngcare recommends further investigation of all areas with the aim of:

1. Improving the legal protection of young people living in residential aged care; and
2. Using the law as a powerful tool to avoid new admissions.