

Office of the Public Advocate (Queensland) Systems Advocacy

Submission to the Australian Law Reform Commission

For the Investigation into Equality,
Capacity and Disability in
Commonwealth Laws

December 2013

Interest of the Public Advocate (Queensland)

The Public Advocate was established by the *Guardianship and Administration Act 2000* (Qld) to undertake systems advocacy on behalf of adults with impaired decision-making capacity in Queensland. The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity (the adults) in all aspects of community life.

More specifically, the functions of the Public Advocate are:

- promoting and protecting the rights of the adults with impaired capacity;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach their greatest practicable degree of autonomy;
- promoting the provision of services and facilities for the adults; and
- monitoring and reviewing the delivery of services and facilities to the adults.¹

In 2013, there are approximately 114,000 Queensland adults with impaired decision-making capacity.² Of these vulnerable people, most have a mental illness (54 per cent) or intellectual disability (26 per cent).

Queensland adults with impaired decision-making capacity are among the most disadvantaged people in the community. An unacceptably high level of disadvantage is experienced across a range of social and economic indicators. This disadvantage significantly reduces quality of life and increases the risk of abuse, neglect and exploitation. The disadvantage experienced by adults with impaired decision-making capacity is by no means unique to Queensland.

Despite accessing multiple service systems across multiple sectors (government, non-government, community and private organisations), people with impaired decision-making capacity have a high level of unmet need and their autonomy is regularly compromised by the way in which these systems are structured and operationalised.

As a result, there is a critical and immediate need for all levels of government, across all sectors, to invest in a sustainable social system that ensures access to social, economic, civic and specialist resources for people with impaired decision-making capacity, their families and support networks. This is a primary way to promote inclusion, protect rights and interests, and reduce risks of abuse, neglect and exploitation.

While not all of these issues are within the scope of the current inquiry, they are still relevant and must be considered within the context of any potential reform to Commonwealth laws and legal frameworks.

Position of the Public Advocate (Queensland)

I commend the Australian Government, the Honourable Mark Dreyfus QC MP, Attorney-General of Australia, and the Australian Law Reform Committee for its commitment to pursuing ways in which Australia can better uphold equal recognition before the law and ensure legal capacity for people with disability in Australia.

Given Australia's obligations as a signatory to the United Nations *Convention on the Rights of Persons with Disabilities*, as well as reforms currently being undertaken in various human service systems (for example those associated with the introduction of the National Disability Insurance Scheme), it is timely to consider the extent to which individual autonomy is protected and supported within Australia. In particular, this presents an opportunity to look at legislative and other systems through a human rights lens, and to offer solutions to improve those areas where people's rights are compromised as a result of a fragmented and inequitable approach to the application of basic human rights principles.

While the position I will present in this submission focuses primarily on people with impaired decision-making capacity, many of the themes are just as applicable to people with disability more generally.

¹ *Guardianship and Administration Act 2000* (Qld) s 209.

² Office of the Public Advocate, 'The Potential Population for Systems Advocacy' (Fact Sheet, Office of the Public Advocate (Queensland), February 2013).

1 Introduction

In according people with disability the same rights as others in society, it is incumbent upon society to ensure that there are appropriate mechanisms in place to enable people who have a disability that affects their capacity to make decisions about themselves the right and ability to make informed decisions about issues impacting their lives, and to ensure that the systems that are in place to protect those with impaired decision-making capacity operate in a manner that upholds these rights while still offering appropriate protections.

From a legal point of view, Australia arguably does not have strong legally enforceable human rights protections. While Australia is a signatory to the United Nations *Convention on the Rights of Persons with Disabilities*, this in and of itself is a relatively weak approach to human rights protection compared to formal enactment of human rights legislation in Australia.

In many cases, legislative regulation in relation to specific issues can encroach on individual liberty. Liberty includes both negative freedom (i.e. freedom from state interference) and positive freedom (i.e. freedom to develop your human potential). Broader human rights legislation may arguably provide a stronger foundation from which to promote and pursue change across the many systems with which people with disability interact.

The development of stronger human rights legislation that could potentially overrule the *parens patriae* jurisdiction (as exercised by Courts or Tribunals) by mandating decision-making approaches that better support the engagement of the person with disability may arguably provide better protection for the rights of such Australians. However that argument needs to be considered in the context of the much broader argument as to whether Australia needs to constitutionally protect Human Rights, how such Rights can be agreed to and the implementation in domestic law of rights that are reflected in International Treaties and Conventions.

It should be noted that many people have various forms of disability that in no way impact upon their capacity to exercise their legal rights or make decisions about themselves. It is only where an individual lacks 'capacity' to exercise those rights and make those decisions that there is any justification for intervention in their lives.

However, it is often argued that the 'true wishes' of the individual may be in conflict with their 'best interests'. This inherent conflict is evident in many if not all guardianship regimes in Australia. From a human rights perspective, it is incumbent upon the system to view the 'adult's wishes' as paramount. As is the case for people without disability, people with disability have the same right to make poor decisions and/or decisions on grounds such as religion even where, for example, these decisions contradict sound legal or medical advice.

People with impaired decision-making capacity have needs that extend across many different service systems, including (but not limited to) education, housing, health and disability. Some people with impaired decision-making capacity may also come into contact with the criminal justice system. In many cases, however, the needs of these individuals are not met and/or are met in a limited way with little consistency or cohesion across the different service systems.

The systems with which people with disability interact are fragmented and inequitable. People are channelled into different service systems according to defined target groups or the service parameters of those systems, with many of these systems lacking the sophistication to determine and provide an appropriate mix of services to adequately respond to the holistic needs of the person. The services that are available differ from system to system and are often premised on historical service types that do not map to contemporary understandings. In many cases, they are also provided according to rigid models of service delivery that do not give sufficient consideration for the outcomes being sought by the person nor how to create an effective network of support and services to assist the person to achieve their goals and maximise autonomy.

Evidence suggests that the fragmented and complex human services system often results in high levels of anxiety, frustration, and burn-out for adults with impaired decision-making capacity and their families as they attempt to identify, secure and manage supports.³ Systems change that focuses on integrated and collaborative approaches to service delivery is urgently required so that the adequacy of such services, both individually and collectively, to generate improved outcomes for adults with impaired decision-making capacity and their families is enhanced.

³ The Parliament of the Commonwealth of Australia, *'Who Cares...? Report on the Inquiry into Better Support for Carers'*, House of Representatives Standing Committee on Family Community Housing and Youth, April 2009, Commonwealth of Australia.

The focus of any reform should be to ensure that it allows for effective and individualised approaches that enable appropriate decision-making while protecting the rights and interests of the person with decision-making disability. Demonstrated and proven effectiveness in decision-making ultimately increases people's willingness to use the system rather than find ways to work around it.

A system that appropriately, effectively and equitably responds to people with impaired decision-making capacity is the shared responsibility of multiple government agencies and requires a coordinated and integrated approach.

2 Underlying philosophy of this submission

Convention on the Rights of Persons with Disabilities

The overarching principles that inform this submission are those reflected in the *United Nations Convention on the Rights of Persons with Disabilities* (the Convention)⁴.

The Convention has heralded a recent paradigm shift; that is, a new way of thinking about disability.

Underpinned by what is known as the 'social model of disability', the Convention incorporates a contemporary approach to disability and emphasises the importance of:

- recognising that disability is an evolving concept and that disability results from the interaction between people with impairments and their surroundings as a result of attitudinal and environmental barriers;
- the right and capacity of people with disability to make valued contributions to their communities; and
- recognising that all categories of rights apply to people with disability, who should therefore be supported to exercise those rights.

Within the Convention there are numerous specific obligations on state parties relevant to many of the aspects of this submission, including the right to legal capacity, to act with autonomy and make their own decisions;⁵ the right to effective participation in the justice system;⁶ the right to live independently and be included in the community;⁷ the right to access information in accessible formats and accessible technologies;⁸ the right to freedom from unjustified physical and chemical interventions in accordance with their right to integrity of the person;⁹ and the right to access information about family planning, to retain their fertility on an equal basis to others and to be afforded respect in relation to their family life.¹⁰

An important overarching principle in the Convention, particularly relevant to the Australian Law Reform Commission's inquiry, is that of 'reasonable accommodation'. This refers to the support, modifications and adjustments that must be made so that people with disability can exercise their rights on the same basis as others. Importantly, discrimination is now defined by article 5 of the Convention to also mean the failure to provide adequate accommodation. This broadens the concept of discrimination from the traditionally 'reactive' approach to providing a variety of remedies to discrimination in particular areas of life on the basis of disability, towards a positive obligation on state parties to ensure that people with disability have the information, assistance and support they need to exercise their legal rights.

Arguably, disability is exacerbated by the lack of reasonable accommodation by the broader community to the range and nature of differing impairments; impairments that a person may be born with or those they may acquire in the course of their life. Reasonable accommodation is not just about physical modifications to environment but also includes attitudinal considerations. The social and economic disadvantages experienced by many people with impairment, and the lack of reasonable accommodation by community mean that people with disability and/or impaired decision-making capacity are not empowered or supported to develop and/or maintain

⁴ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, [2008] ATS 12 (entered into force 3 May 2008) ('*Convention on the Rights of Persons with Disabilities*').

⁵ *Convention on the Rights of Persons with Disabilities*, art 12.

⁶ *Ibid* art 13.

⁷ *Ibid* art 19.

⁸ *Ibid* art 21.

⁹ *Ibid* art 17.

¹⁰ *Ibid* art 23.

autonomy and independence. Rather, they are disempowered by a lack of support and, as a result, the practical effects of their disability and/or impaired decision-making capacity are not addressed and are often exacerbated.

The Convention has also been a significant influence in the movement away from what is seen as paternalistic substitute decision-making towards supporting people with disability to exercise their rights including their legal capacity.

A general principle of the Convention includes “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”.¹¹ Article 12 imposes an obligation on state parties to recognise that people with disability enjoy legal capacity on an equal basis with others. That is, the right to be recognised as a person before the law and the subsequent right to have one’s decisions and choices legally validated and recognised.¹² Read with article 5, an overarching principle of equality and non-discrimination, there is an obligation on State parties to ensure support is provided to people with disability to enable them to exercise their legal capacity, so as to avoid discrimination. Discrimination includes the failure to ensure the provision of reasonable accommodation.¹³

Three ‘planks’ of the Commonwealth’s legal and policy framework for people with disability

While there are innumerable Commonwealth laws that are relevant to people with disability, there are three key ‘planks’ of the Commonwealth’s legal and policy framework for people with disability that must provide a coherent platform for ensuring Australia is well positioned to deliver on its obligations under the Convention. These include the *Disability Discrimination Act 1992* (Cth); the *National Disability Insurance Scheme Act 2013* (Cth); and the National Disability Strategy.

The ideological and philosophical landscape has changed significantly since the commencement of the *Disability Discrimination Act 1992* (Cth), particularly heralded by the adoption by Australia of the Convention in 2008. The philosophy underpinning the Convention moves away from a social welfare to a rights-based approach, shifting from the idea of people with disability as objects of social protection to that of being rights bearers.

The key principles that underpin the Convention must also be reflected in these three legislative and policy instruments.

An underlying theme throughout this submission is that the legal and policy framework for people with disability must incorporate this new approach, in particular the notion of ‘reasonable accommodation’, and the importance of ensuring support is provided so that people with disability can exercise their legal capacity and are proactively empowered to exercise their rights.

3 Anti-Discrimination Legislation¹⁴

Ambit of Legislation

There are ongoing calls for people with disability to be treated equally or, as is more appropriate in some cases, equitably with their non-disabled counterparts and to be properly recognised and accommodated within Australian society. This is a call that continues to be acknowledged and addressed by State and Federal governments, both through legislation and policy. To a large part, anti-discrimination laws such as the *Anti-Discrimination Act 1991* (Qld) and the *Disability Discrimination Act 1992* (Cth) operate to protect the rights of people with disability.

The *Disability Discrimination Act 1992* (Cth) has three primary objectives. These are to: eliminate discrimination on the grounds of disability in particular areas of life; ensure that persons with disabilities have the same rights to equality before the law as the general community; and promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the general community.¹⁵

¹¹ Ibid art 3.

¹² E Flynn and A Arstein-Kerlake, ‘Legislation Personhood: Realising the Right to Support in Exercising Legal Capacity’ (conference proceedings at the Australian Guardianship and Administration Council World Conference, Melbourne, 2012) 1.

¹³ *Convention on the Rights of Persons with Disabilities*, art 5.

¹⁴ This relates to question 6 of the issues paper.

¹⁵ *Disability Discrimination Act 1992* (Cth) s 3.

The *Disability Discrimination Act 1992* (Cth) prohibits discrimination against a person on the ground of that person's disability in areas such as employment, education, access to premises, the provision of goods, existing laws, and the administration of Commonwealth laws and programs. Arguably, the Act primarily takes a 'protective' approach to the rights of persons with disability. The Act is also largely reactive in that it sets out conduct that is prohibited, thereby providing grounds on which a person can make a complaint of discrimination. While it is important that these remedies exist, I would respectfully suggest that something more is now needed.

In light of the paradigm shift heralded by the Convention and the move away from the idea of people with disability as objects of social protection to being that of rights bearers, the *Disability Discrimination Act 1992* (Cth) should be updated to take a positive and proactive approach to the rights of persons with disability. The Act could, for example, establish a positive onus to provide 'reasonable accommodation' or support, assistance and information in different areas of public life to ensure that people with disability can exercise their rights.

Further, the Act does not articulate the positive rights of people with disability, including those in the Convention. One option that could be considered by the ALRC is incorporating a 'charter' of rights, consistent with the Convention, as a schedule to the Act.

The modernisation of the *Disability Discrimination Act 1992* (Cth) should also align with the National Disability Strategy. In particular, there should be a coherent policy framework to guide government activity across mainstream and disability-specific areas of public policy; improve the performance of services; ensure that disability-related issues are included and addressed in the development and implementation of relevant public policy; and provide a means of national leadership toward the greater inclusion of people with disability.¹⁶

Vilification

As discussed, the *Anti-Discrimination Act 1991* (Qld) and the *Disability Discrimination Act 1992* (Cth) primarily operate in relation to specific areas of life and often do not apply in more general instances, such as interactions occurring in a public place. This represents a gap in the current legislation.

In Queensland, the *Anti-Discrimination Act 1991* (Qld) prohibits vilification of another person. Specifically, section 124A provides that a person must not, by a public act, incite hatred towards, serious contempt for, or severe ridicule of a person or a group of persons on the grounds of race, religion, sexuality or gender identity. Section 131A is worded in similar terms but includes the additional requirement that the person must 'knowingly or recklessly' incite such feelings and includes the aggravating circumstance that a person threatens or incites others to threaten physical harm towards persons or property.

Sections 124A and 131A of the *Anti-Discrimination Act 1991* (Qld) should be amended to include 'impairment'¹⁷ as another ground upon which a person is prohibited from inciting hatred, serious contempt or severe ridicule. No person or group of persons should be vilified because they have any form of impairment. People with impairment are vulnerable to abuse, and it should be made clear that vilification on the grounds of impairment is socially unacceptable and is damaging to both the person/s vilified and to society as a whole. This Act should also be amended to make clear that instances where a public act has the capacity or potential to incite hatred, serious contempt or severe ridicule are prohibited by the Act.¹⁸ Finally, an amendment of this nature should ensure that instances of discrimination that do not fall into a specified category, such as interactions in a public place, are similarly prohibited and given redress by law.

For the same reasons as detailed above, provisions equivalent to sections 124A and 131A of the *Anti-Discrimination Act 1991* (Qld) should be included in the *Disability Discrimination Act 1992* (Cth). Such amendments are particularly important in light of the introduction of the National Disability Insurance Scheme (NDIS), which will further encourage the social and economic participation of people with impairment and increase opportunities for participation in the community as a result of people who receive funding being able to exercise greater choice and control over how that funding is utilised. While offering many positive benefits, this may also increase opportunities for people with impairment to be targeted and made subject to discrimination or vilification. Ahead of the introduction of the NDIS in Queensland and its progressive implementation elsewhere in

¹⁶ Australian Government, *National Disability Strategy 2010-2020*, 9.

¹⁷ As defined in the schedule to the *Anti-Discrimination Act 1991* (Qld).

¹⁸ The decisions of *Burns v Dye* [2002] NSWADT 32 and *Peters v Constance* [2005] QADT 9, referencing *Burns v Radio 2UE Sydney* [2004] NSWADT 267 have reached the conclusion that this provision (or the NSW equivalent) covers instances where an act has the potential or capacity to incite vilification.

Australia, legislative amendments to prohibit the vilification of people with impairment provide an opportunity for the Queensland and Commonwealth governments to mitigate against one of the potential risks associated with increasing opportunities for social and economic participation by people with impairment in the community.

It is not proposed that provisions equivalent to section 18C of the *Racial Discrimination Act 1975* (Cth), which pertains to racial vilification,¹⁹ and which are currently the subject of criticism and potential amendment, should be enacted. Rather, it is proposed that the narrower approach to vilification taken by sections 124A and 131A of the *Anti-Discrimination Act 1991* (Qld) should be broadened at the State level to apply to people with impairment and adopted, in this broadened format, at the Federal level.

4 Decision-Making Support²⁰

The Convention on the Rights of Persons with Disabilities and Support

As a signatory to the Convention, Australia is obliged to take appropriate measures to ensure that the requirements of the Convention are supported and applied in legislation and in practice. In particular, Australia is obliged to provide people with disability with access to adequate and appropriate support to enable them to exercise their right of legal capacity and to provide ‘reasonable accommodation’ for people with disability in the way that legislative and other systems operate in practice.

Article 12 of the Convention recognises that people with disability have the right to recognition everywhere as persons before the law and that they enjoy legal capacity on an equal basis to those without disability. Article 12 requires that appropriate measures be taken to provide people with disability access to the support that they may require when exercising their legal capacity.²¹ This requirement is strengthened by article 5, which requires that, in order to promote the equality and eliminate discrimination, reasonable accommodation must be provided to people with disability.²² The provision of support to people with disability in order to improve their ability to exercise their legal capacity reflects the Preamble of the Convention, which affirms that disability arises from a person’s interactions with their surrounding environment, not solely from their impairment.²³

Article 21 of the Convention provides for the right to freedom of expression and opinion. Notably, this article provides people with disability with the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication.²⁴ This article charges Australia with the responsibility to ensure people with disability have sufficient information in appropriate and accessible formats.²⁵ Arguably, the effect of this article is that Australia is also charged with the responsibility to ensure people with disability have adequate and appropriate opportunities to be involved in, and the freedom to make, decisions affecting their own lives.²⁶

Supported Decision-Making

Supported decision-making embraces a wide range of models in theory, practice and legislation that have different degrees of alignment with the concepts of maximising autonomy, retaining legal capacity, and exercising self-determination. The potential to develop and enhance the overall physical and psychological wellbeing of people with disability is also recognised through the process of supported decision-making.²⁷

A handbook on the Convention produced by the United Nations describes supported decision-making in the following terms:

¹⁹ Section 18C Offensive behaviour because of race, colour or national or ethnic origin

(1) It is unlawful for a person to do an act, otherwise than in private, if:

(a) the act is reasonably likely, in all the circumstances, to offend, insult, humiliate or intimidate another person or a group of people; and
(b) the act is done because of the race, colour or national or ethnic origin of the other person or of some or all of the people in the group.

²⁰ This part broadly relates to question 1 of the issues paper.

²¹ *Convention on the Rights of Persons with Disabilities*, art 12.

²² *Ibid* art 5.

²³ *Ibid* preamble.

²⁴ *Ibid* art 21.

²⁵ *Ibid*.

²⁶ *Ibid*.

²⁷ N A Kohn, J A Blumenthal and A T Campbell, ‘Supported Decision-Making: A Viable Alternative to Guardianship?’ (2013) 117 *Penn State Law Review* 1111, 1127.

“With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision-maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when the person with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual.”²⁸

Supported decision-making also reflects efforts to provide better ways of recognising and meeting the needs of adults who have difficulty with certain areas of decision-making but who could make their own decisions “with a little friendly help”.²⁹ In the absence of appropriate support, these adults could be inappropriately subjected to guardianship.

In contrast to the practice of guardianship and substitute decision-making, supported decision-making often involves the person retaining their legal powers of decision-making,³⁰ although a third party may provide decision-making support. This arrangement can be authorised by law, but can also occur informally. Importantly, and particularly where it can occur informally, the use of supported decision-making can enable a person to retain their autonomy and agency to make decisions.

There should be much greater emphasis in policy and legislation on ensuring that people with disability get the support, assistance and information they need to exercise their legal capacity and make their own decisions.

Supported Decision-Making and Guardianship

Ongoing debate surrounds the issue of whether guardianship is in conflict with the intent of article 12 of the Convention. This is because guardianship requires a determination that a person lacks capacity to make their own decisions and involves the appointment of a person to make decisions on that person’s behalf. In some circumstances, this may limit the extent to which the person may exercise their legal capacity. This debate also involves concerns that substitute decision-making reflects a traditional paternalistic model towards decision-making, rather than supporting the participation and autonomy of people with disability.

Regardless of views about the compatibility of guardianship laws with the Convention, there is general recognition that the focus must now move from the challenges facing a person with disability to the supports that should be provided to enable them to make decisions and exercise their legal capacity. This means that the appointment of a substitute decision-maker should not preclude efforts to support a person to make their own decisions.

Even though guardianship is supposed to be an intervention of last resort, there are concerns that it is excessively used and misapplied.³¹ The accessibility and low cost of Australian guardianship systems have resulted in guardianship applications being sought in preference to other options that are less restrictive and do not infringe on people’s rights.³² Arguably, it has also resulted in some guardianship orders being broader than is necessary.³³

The excessive use and misapplication of guardianship orders is particularly concerning because a determination of a lack of capacity and the appointment of a substitute decision-maker can have a significant impact on a person’s civil rights.³⁴ Similarly, guardianship can disempower people, meaning those subject to guardianship are not involved in the process of making decisions about their lives. It is therefore arguable that guardianship may have anti-therapeutic effects, undermining a person’s physical and psychological wellbeing by reducing their sense of control over their lives.³⁵

²⁸ United Nations, Handbook for Parliamentarians – From Exclusion to Equality: Realising the Rights of Persons with Disabilities (United Nations Department of Economic and Social Affairs, Office of the United Nations High Commissioner for Human Rights and Inter-Parliamentary Union, 2007) 89-90.

²⁹ R M Gordon, ‘The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making’ (2000) 31(1) *International Journal of Law and Psychiatry* 61, 71.

³⁰ T Carney, ‘Participation and Service Access Rights for People with Intellectual Disability: A Role for Law?’ (2013) 38(1) *Journal of Intellectual and Developmental Disability* 59, 60.

³¹ Kohn, Blumenthal and Campbell, above n 27, 1118.

³² D Tait and T Carney ‘Too Much Access: The Case for Intermediate Options for Guardianship’ (1995) 30(4) *Australian Journal of Social Issues* 445.

³³ Kohn, Blumenthal and Campbell, above n 27, 1118.

³⁴ *Ibid* 1117.

³⁵ *Ibid* 1120.

5 Approaches to Legal Capacity³⁶

Capacity has traditionally been legally viewed as a deterministic and absolute concept. A person either has capacity or they do not, and if they do not, they are disqualified from making decisions or even engaging in a range of activities.³⁷ Australian guardianship laws operate on a threshold of capacity;³⁸ that is, the appointment of a substitute decision-maker upon determination that a person lacks capacity for a matter (even if it is only for one type of matter). Such a determination can have a radical effect on the person's autonomy, as they can no longer make decisions with legal effect in relation to the matters subject to the guardianship order.

The dominant approach to assessing capacity for guardianship purposes is premised on a person's functional ability. However, there is a growing emphasis on strength-based assessments for capacity, where capacity should be related less to the level of a person's cognitive capacity or functional ability and more to the level of support that is available to, or that could be built around, a person to make the decision.

The way in which people make decisions and the degree of guidance or support that they seek from others differs between people and situations, regardless of whether a person is deemed to lack decision-making capacity. People commonly seek information from, and/or the views of, other people when faced with a decision that they have not encountered before or where the situation in which they need to make the decision includes variables that have not been present in the past. People with disability depend upon their social networks to assist them to make decisions at different times and to varying degrees, and to thereby achieve independence.³⁹

Key elements of an appropriate assessment of legal capacity should include:

- A presumption of capacity and acknowledgement of the right of people to make decisions (including decisions that other people may not agree);
- The right to decision-making support and the availability of informal support to a person;
- Underlying principles to maximise rights, autonomy, independence, consideration of a person's views and prioritise the least restrictive decision-making intervention;
- Recognition that legal capacity is not an absolute concept;
- Incapacity to be restricted to specific matters wherever possible (a person may lack capacity for a type of matter, but not others).

Central to any approach to capacity is that, where there are several systems in which a person may have an appointed decision-maker, those systems must integrate and, where appropriate, allow the same decision-maker to act in all systems. Most relevantly (as discussed above) the *National Disability Insurance Scheme Act 2013* (Cth), the NDIS Rules and state-based guardianship and administration legislation must interact and work in a cohesive manner, so that a state-appointed guardian is also recognised by the NDIS.

Further, approaches to legal capacity must not result in abuse of a guardianship system. For example, there is evidence to suggest that guardianship orders are sometimes used to facilitate access to services or for other case management responses, for example to facilitate the hospital discharge process or a change in accommodation.⁴⁰

6 National Disability Insurance Scheme⁴¹

The National Disability Insurance Scheme (NDIS) represents a significant step toward addressing the deficiencies of the current disability service systems that exist across Australia, and to advancing cultural change and genuine social inclusion. Experiences in other countries, such as Sweden, have shown that with inclusive systems of

³⁶ This relates to question 4 of the issues paper.

³⁷ For example entering into a binding contract, disposing of property by will or gift, voting, becoming a member of parliament, holding various public offices, having sexual relations with another person, marrying, authorising many forms of medical treatment, engaging in various occupations as discussed by the Victorian Law Reform Commission published *Guardianship: Final Report*, which was tabled in Parliament on 18 April 2012 (<http://www.lawreform.vic.gov.au/projects/guardianship-final-report>), [100].

³⁸ Shih-Ning Then, 'Evolution and Innovation in Guardianship Laws: Assisted Decision-Making' (2013) 35 *Sydney Law Review* 133, 144; Kohn, Blumenthal and Campbell, above n 27, 1120.

³⁹ Carney, above n 30, 59.

⁴⁰ Office of the Public Advocate, 'The Adult Guardian Client Profile Project: An Independent Analysis of Guardianship Client and Orders made to the Adult Guardian 2000-2010' (Report, Office of the Public Advocate (Queensland), February 2013) 50.

⁴¹ This part of the submission broadly addresses questions 12, 13 and 14.

entitlement to social support for people with disability, including the provision of personal assistance, the need for guardianship and other forms of substitute decision-making, which deny people their legal rights to exercise capacity, can be reduced. For example, in Sweden, the law⁴² makes a personal assistant a mandated support service for people with disability covered by the scope of the legislation.⁴³

In Australia, there is a similar potential for the NDIS to facilitate and enable a less restrictive alternative than the guardianship system to navigate the array of social, medical, financial and other services that people with disability might need. These were issues that were once taken care of by institutional staff, by way of access to assistance and case management, but with deinstitutionalisation there has been an unfortunate trend toward using the guardianship system to fill this gap.⁴⁴

To realise the potential of a less restrictive alternative, the NDIS legislation and policy framework must ensure that there are not barriers in the way to becoming a participant and developing, managing and reviewing a plan. Whilst the *National Disability Insurance Scheme Act 2013* (Cth) provides a requirement for the National Disability Insurance Agency (the Agency) to provide support and assistance to prospective participants and to eligible participants,⁴⁵ this requirement must be strengthened.

There are a number of points in the process of becoming and being a participant that may prompt the appointment of a guardian or other substitute decision-maker if appropriate support and assistance is not provided. For example, the application to become a participant occurs prior to the appointment of either a nominee or a plan manager. Given the application may be quite complex, with a discretionary power for the CEO of the Agency to order the person undergo an assessment, this is a key point where carers, social workers or family members may seek the appointment of a guardian to facilitate the process. This phenomenon currently occurs with older people accessing aged care, and a similar situation must be strongly guarded against in relation to the NDIS. Appointments of guardians should be a last resort and not sought in lieu of appropriate support, assistance, information or case-management.

The provision of advice, personal assistance and other alternatives should be further explored in legislation, policy and procedures prior to the appointment of a plan nominee. Such an appointment currently has the effect, similarly to the appointment of a guardian, of removing the person's legal rights to make decisions under the scheme. While the principles of the NDIS Rules express the importance of support for participants to exercise choice and control and to participate in decision-making, which are most welcome, ultimately the nominee is a *de facto* substitute decision-maker for the person. Given this position of nominees as '*de facto* substitute decision-makers' it is also important that the interaction between the *National Disability Insurance Scheme Act 2013* (Cth), the NDIS Rules and the state-based guardianship and administration legislation is further clarified. While there is currently a 'presumption' that an existing guardian would also be appointed as a nominee for a participant, this is not sufficient.

Finally, the success of the NDIS will be dependent on the accessibility and inclusiveness of the systems complementary to the NDIS, for example education, transport, health, employment and other relevant systems. The current lack of accessibility and coordination between these broader systems has the potential to both undermine the effectiveness of the NDIS for people with disability and may also lead to further appointments of guardians and other substitute decision-makers. This is something that should be addressed creatively and in a coordinated manner across the three important 'planks' of the Commonwealth policy and legislation framework for people with disability – the National Disability Strategy, the *Disability Discrimination Act 1992* (Cth) and the *National Disability Insurance Scheme Act 2013* (Cth).

⁴² *Lag om stöd och service till vissa funktionshindrade* (which came into effect in 1994 and gives people with disability the right to ten different kinds of support and services)

⁴³ Stanley S Herr, *Self Determination, Autonomy and Alternatives for Guardianship* <<http://ruralinstitute.umn.edu/transition/Handouts/Self-Determination.Herr.pdf>>.

⁴⁴ Office of the Public Advocate, above n 40, 49-50.

⁴⁵ *National Disability Insurance Scheme Act 2013* (Cth) s 6.

7 Health Care and Aged Care

Institutionalisation of people with disability⁴⁶

Up until the 1980s in Australia, it was common for people with disability to reside in large institutions on the outskirts of cities, supported predominately under a medical model of care. While there was a large-scale movement of people with disability to community-based living, known as deinstitutionalisation, during the 1980s and 1990s, many people with disability continue to live in institutional-type environments including hospitals, mental health hospitals, residential aged care services and other types of health facilities.

I recently released a report detailing the findings of a research project undertaken by my Office into people with intellectual disability or cognitive impairment residing in long-stay health care facilities in Queensland.⁴⁷ As at May 2013, it was reported by Queensland Health that there were 271 people with intellectual disability or cognitive impairment who continue to reside in long-stay health facilities in Queensland. These people include:

- many people with intellectual disability, notably those who ‘missed out’ on earlier deinstitutionalisation and have remained living in institutions for up to 65 years. Many were initially placed in these institutions as babies or small children but, for various reasons, were denied the opportunities that were given to other people with similar levels of disability to live in the community. Others came to these facilities later in life following a breakdown in supports and/or the inability to access the necessary services to be supported in the community; and
- people with acquired brain injuries (ABI) residing in hospitals and other health facilities who are unable to access crucial opportunities for rehabilitation and reintegration back into the community. Some residents have lived in these ‘bed-blocked’ facilities for up to 35 years.

In many cases, the models of care provided in these health facilities do not meet contemporary standards of care and support. In particular, support is often not available to develop the functional skills and capability of people with disability. Neither do they receive adequate support to ensure the best outcomes regarding their physical, social and emotional well-being. Furthermore, there are few opportunities for choice, or participation in the community.

People currently residing in these facilities are living in inappropriate accommodation, are not receiving support services congruent with contemporary standards of disability support or Australia’s human rights obligations, and are exposed to a significant risk of deterioration in their health and wellbeing. As such, all people with intellectual disability or cognitive impairment currently living in health care facilities must be prioritised for the phased approach into the NDIS.

There must also be a commitment under the three planks of the Commonwealth Government’s legislative and policy framework for disability services (the NDIS legislative and policy framework, the National Disability Strategy and the *Disability Discrimination Act 1992* (Cth)) to finally ending the institutionalisation of people with disability in Australia.

The *Disability Discrimination Act 1992* (Cth) should prohibit the practice of people with disability residing in large-scale health facilities such as hospitals and mental health hospitals on a long-term basis if it is not required to treat a mental illness or medical condition. The Act should also establish a positive obligation, consistent with Article 26 of the Convention, to ensure the provision of habilitation and rehabilitation services and programs that will enable people with a disability to attain and maintain maximum independence and full physical, mental, social and vocational ability.

Fertility, Reproduction and Human Rights⁴⁸

It is a fundamental human right to control your own body, including your fertility, and to be able to make choices about whether or not to have children. The Convention creates an obligation on state parties to ensure that

⁴⁶ This relates to question 34 of the issues paper.

⁴⁷ Office of the Public Advocate, ‘People with Intellectual Disability or Cognitive Impairment Residing Long-Term in Health Care Facilities: Addressing the Barriers to Deinstitutionalisation’ (Report, Office of the Public Advocate (Queensland), October 2013).

⁴⁸ This broadly addresses question 34 and question 39 of the issues paper.

people with disability are protected from discrimination in any matter concerning marriage, family, parenthood and relationships, so that they can enjoy these on an equal basis with others.⁴⁹

Recognition of the sexual identity of people with disability and their right to be educated about and engage in sexual activities, should they so choose, is an issue that has not been well promoted or acknowledged in Queensland or indeed Australia for many years. It is timely that this inquiry has commenced in that it offers the opportunity to pursue a shift in values, practices and resources to enable this recognition and provide for appropriate educational opportunities and the availability of information to assist people with disability to make informed choices.

There is a concerning lack of emphasis in the National Disability Strategy in relation to access to family planning, sex education and information and support for people with disability, in particular those with impaired decision-making capacity. An adult's right to choose, and their right to have adequate and appropriate support available in making that choice, could also be enshrined in the *Disability Discrimination Act 1992* (Cth).

Furthermore, people with disability, including people with impaired decision-making capacity, have personal values and beliefs, religious and other ideological views that will inform their decisions in relation to health care, including issues of fertility and reproduction. The right to make decisions to accept or refuse medical treatment on these grounds is an important right afforded to all other Australians, and should be similarly afforded to people with disability.

People with impaired decision-making capacity should be enabled to exercise health care decisions, including issues pertaining to their fertility, and to choose between the same range of options that are available to people who do not have a disability. Whilst it is crucial that our laws enshrine safeguards in relation to the sterilisation of people with impaired decision-making capacity, it is also important that people with impaired decision-making have equal treatment in relation to access to a range of fertility choices.

Adults without any impairment of their decision-making capacity have the right to make their own choices about contraception and fertility, including whether or not to undergo sterilisation. Adults who possess the relevant capacity to consent to medical treatment may undergo a sterilisation procedure by a medical practitioner without any intervention by government or society. Such procedures are conducted in accordance with the general law regulating the delivery of health services and the general criminal law.

The importance of ready access to appropriate family planning services, information and support for people with impaired decision-making capacity cannot be underestimated. It is only once people with impaired decision-making capacity are truly engaged in the process of making decisions about their health care, including their fertility, and every effort is made to ascertain their wishes and preferences, that equality can be achieved.

Ultimately, regardless of the extent to which a person's wishes and preferences can be truly ascertained, the approach to sterilisation, or other such fertility or health care decisions, should not be discriminatory. For example, it should not be assumed that because a person has a decision-making disability they either would or would not choose sterilisation.

All such decisions must be considered on an individual basis and with regard to the options that a person would be offered if they did not have a disability. If the same range of options is not made available to a person with disability, then it constitutes unequal treatment.

Aged Care⁵⁰

Dementia is forecast to become the leading cause of disability in Australia, with nearly one million Australians predicted to experience dementia by 2050.⁵¹ A dementia diagnosis does not automatically imply that a person does not have capacity to make decisions or manage their affairs. However, it may prompt a person to consider making enduring documents and otherwise plan for their future, whilst they retain their capacity. People living with dementia should be supported to plan for their future, including the organisation of their personal, health, financial and legal affairs, and the preparation of authoritative instruments to ensure their views and directions are known to relevant parties in the future.

⁴⁹ *Convention on the Rights of Persons with Disabilities*, art 23.

⁵⁰ This broadly addresses question 35 of the issues paper.

⁵¹ Department of Health and Ageing 2012, *Living Longer, Living Better*, Commonwealth of Australia, Canberra.

As mentioned previously, the delivery of human services, including those provided to older Australians and people living with dementia, can lack cohesion and be inequitable. Improved access to appropriate services and support is needed to improve social inclusion and enable people living with dementia, and older Australians more broadly, to live independently and participate meaningfully in their community for as long as practicable.

Adaptive equipment and assistive technologies are an important inclusion in any individualised, needs-based approach to supporting a person's inclusion and participation in community life. They can, amongst other benefits, assist a person experiencing dementia to remain living in their home for longer and reduce the need for early entry into supported accommodation or hospital.⁵² However, the increasing advances in and focus on technology brings with it a risk that it will be used to replace human contact or restrict, rather than enhance, a person's freedom. Therefore, it is important to involve the person experiencing dementia in the decision-making process about whether to use particular equipment and/or technologies and obtain their consent. A person should not be forced into using equipment or technology that they do not feel comfortable using or that is not appropriate for their needs.⁵³

Particularly relevant to adults with dementia are the rights to: have access to the physical environment and to information; live independently and within the community for as long as possible; have access to mobility aids, assistive technologies and live assistance; enjoy the highest attainable standard of health and health care; have access to habilitation and rehabilitation programs; enjoy an adequate standard of living; participate in society; and have access to adequate and appropriate support to enable understanding, participation and decision-making. These rights (along with other in the Convention that are relevant to other groups) should be included in the *Disability Discrimination Act 1992* (Cth), and there should be an obligation to uphold and further those rights.

Restrictive Practices – restraint and chemical restraint in aged care⁵⁴

Dementia can commonly result in behavioural changes such as aggression and wandering that can pose a risk of harm to the person and others. While there are alternative and less restrictive ways to manage some of the behavioural symptoms of dementia,⁵⁵ unfortunately it seems that a range of restraints, including physical, mechanical and chemical restraint are commonly used in aged care settings, particularly with people with dementia.⁵⁶

The use of restraint is a significant infringement on a person's human rights, in particular the right to liberty and security of the person, the right not to be deprived of their liberty or to be subject to cruel, inhuman or degrading treatment or punishment. It is also potentially unlawful and may give rise to criminal or civil liability. The Commonwealth's *Aged Care Act 1997* currently does not regulate the use of restraints in residential aged care. Rather the issue is dealt with by way of policies and procedures including a handbook, poster and leaflet.⁵⁷

Given the serious impact on a person's rights and the risk of serious harm or death as a result of the use of such practices, it is imperative that the ethical, practice and legal issues are comprehensively explored and addressed in relation to the use of restraints in aged care. A review of the *Aged Care Act 1997* (Cth) should be undertaken with a view to regulating the use of restraints in aged care facilities.

⁵² Alzheimer's Society, *Assistive Technology - Devices to Help with Everyday Living* (2013) <http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=109>.

⁵³ Ibid.

⁵⁴ This broadly addresses question 35 of the issues paper.

⁵⁵ H Qureshi, *Restraint in Care Homes for Older People: A Review of Selected Literature* (Report No 26, Social Care Institute for Excellence, October 2009); Joanna Briggs Institute (2002) *Physical Restraint – Pt 2: Minimisation in Acute and Residential Care Facilities*, quoted in Australian Government (2012) *Decision Making Tool: Supporting a Restraint Free Environment in Residential Aged Care*, Department of Health and Ageing, Canberra.

⁵⁶ D V Jeste et al, 'ACNP White Paper: Update on Use of Antipsychotic Drugs in Elderly Persons with Dementia' (2007) 33 *Neuropsychopharmacology* 957-70, Department of Psychiatry and Neurosciences, University of California, San Diego; Alzheimer's Australia, *Quality of Residential Aged Care the Consumer Perspective* (Paper 37, November 2013).

⁵⁷ Department of Health, *Supporting a Restraint Free Environment in Residential Aged Care* (4 December 2012) Australian Government Department of Health <www.health.gov.au/internet/main/publishing.nsf/Content/ageing-decision-restraint-residential.htm>.

8 Restrictive Practices⁵⁸

Australia is in the early stages of exploring policy, program and regulatory responses to the use of restrictive practices, with inconsistent approaches being applied across different jurisdictions.

The use of restrictive practices is a significant infringement on a person's human rights, in particular the right to liberty and security of the person and the right not to be subject to cruel, inhuman or degrading treatment or punishment. It is also potentially unlawful and may give rise to civil or criminal liability. It is therefore imperative that ethical and legal issues are comprehensively explored and addressed before using restrictive practices. It is also imperative that, where restrictive practices are used, this is only ever as a last resort and with a focus on ensuring that the least restrictive approach is taken.

Support for people subject to restrictive practices to make choices and exercise rights

At common law, there is a presumption of capacity that must be applied across all aspects of daily decision-making as well as more complex matters and decisions.⁵⁹ It is concerning that the proposed national framework for restrictive practices does not emphasise the importance of protecting and maintaining a person's autonomy or the presumption of decision-making capacity.

A person's autonomy must be respected and upheld both in legislation as well as in practice. The presumption of capacity for decision-making must be recognised and a person's consent and participation in decision-making sought, with support provided where necessary. Furthermore, where decisions about restrictive practices are made on behalf of the person because they are deemed to lack capacity, the appropriate decision-maker must be involved as early as possible, and must engage with the person to ensure their views inform the decision-making process.

In addition to regular reviews, a person subject to restrictive practices should have the right to request a review at any time; noting that for this to be an effective right, people with disability need support to exercise it.

Strategies, resources and tools must be developed to assist people with disability to understand their rights, exercise choice and control, assess whether they get good outcomes from the services and supports they purchase, and protect themselves from abuse, neglect and exploitation.

Safeguards under the NDIS

As we progress towards the NDIS, disability services are increasingly focused on the importance of a person-centred approach, including the use of individualised or self-directed funding models. These changes to the way funding is provided and services purchased will not only provide more choice and control for people with disability, but will potentially lead to significant changes in the way disability services are delivered.

While these reforms are welcome and integral to a person-centred approach to disability support, the potential for new services to enter the market poses new challenges for maintaining quality standards and safeguards, particularly in relation to the use of restrictive practices. People with disability who are subject to restrictive interventions are often highly vulnerable and there is significant potential for their human rights to be violated and for abuse to occur. This potential will only increase under the NDIS, where challenges may arise in safeguarding vulnerable people's rights in a market-based approach to the provision of disability services.

Ensuring continuing and appropriate safeguards must be a priority, particularly for those who are most vulnerable. Should the regulation of restrictive practices be pursued, protections must have broad application regardless of how, and from whom, a person purchases services and support. There must be stringent reporting requirements, and associated monitoring, with a focus on demonstrating clear quality of life outcomes and a reduction in restrictive practice use.

In accordance with the right of people with disability to integrity of their person, the Convention places an obligation on state parties to ensure that people with disability are protected from unwanted and unjustified

⁵⁸ This broadly addresses questions 36 and 37 of the issues paper.

⁵⁹ *Re Bridges* [2001] 1 Qd R 574; *Re T* [1992] 4 All ER 649, 664 (Lord Donaldson MR).

physical and chemical interventions.⁶⁰ The *Disability Discrimination Act 1992* (Cth) should prohibit actions that inflict physical restraint, chemical restraint or deprive a person of their liberty simply because of disability.

9 Access to Justice⁶¹

Adults with disability or impaired capacity are over-represented in the criminal justice system as both defendants and victims of crime.⁶² Many adults with disability or impaired decision-making capacity experience disadvantages such as difficulties with education, issues within their family, difficulty obtaining or maintaining employment and a lack of permanent accommodation.⁶³ It has been concluded that “having a cognitive impairment predisposes persons who also experience other disadvantageous social circumstances to a greater enmeshment with the criminal justice system early in life...”⁶⁴

In order to address this over-representation, Australia must take steps to improve early intervention strategies targeted both at addressing the disadvantages experienced by adults with disability or impaired decision-making capacity and increasing opportunities for meaningful participation in the community, as well as addressing ‘challenging’ behaviours that may heighten the risk of contact with the criminal justice system. These strategies may include:

- improving access to education and training for both adults and their families;
- increasing the numbers and accessibility of youth diversion programmes;
- increasing, enhancing and improving the targeting of employment services;
- increasing access to ‘positive behaviour support’ to address challenging behaviours;⁶⁵
- improving education for adults regarding their personal safety and protection;⁶⁶ and
- utilisation of alternative responses by police who encounter an adult at risk of committing or becoming victim to an offence, such as referring any adult to services using SupportLink;⁶⁷ preventing and resolving mental health crisis situations through the Mental Health Intervention Project,⁶⁸ and the use of cautioning.⁶⁹

Consistent with the obligations by state parties to the Convention to ensure effective access to justice for people with disability, Australia must seek to ensure that, where adults with disability or impaired decision-making capacity are exposed to the criminal justice system, the system makes reasonable accommodations to facilitate their effective participation in the justice system. The Queensland Police Service, which is often the first point of contact for both defendants and victims, has made commendable efforts to accommodate adults with impaired decision-making capacity, particularly through the implementation of the Vulnerable Persons Policy⁷⁰ and the recognition of persons with a special need in the Operations Procedures Manual.⁷¹ However, there is a need for

⁶⁰ *Convention on the Rights of Persons with Disabilities*, art 17.

⁶¹ This broadly addresses questions 23, 24 and 25 of the issues paper.

⁶² P French, ‘Disabled Justice: The Barriers to Justice for Persons with Disability in Queensland’ (Report, Disability Studies and Research Institute, May 2007) 27; Office of the Public Advocate (Victoria), Submission No 29 to Victorian Law Reform Committee, *Inquiry into Access to and Interaction with the Justice System by People with an Intellectual Disability and the Families and Carers*, 13 September 2011, 7; Department of Corrective Services, ‘*Intellectual Disability Survey 2002*’ (Report, Queensland Department of Corrective Services 2002) 17-18.

⁶³ J Simpson, ‘Participants or Policed: Guide to the Role of DisabilityCare Australia with People with Intellectual Disability who have Contact with the Criminal Justice System’ (Practical Design Fund Project, NSW Council for Intellectual Disability, May 2013) 28-35.

⁶⁴ Simpson, above n 63, 6 citing E Baldry, L Dowse and M Clarence *People with Intellectual and Other Cognitive Disability in the Criminal Justice System* (2012) University of New South Wales <www.adhc.nsw.gov.au/about_us/research/completed_research>.

⁶⁵ E G Carr et al, ‘Positive Behaviour Support: Evolution of an Applied Science’ (2002) 4(1) *Journal of Positive Behaviour Support Interventions* 4, 4-5.

⁶⁶ S Robinson, ‘Safe at Home? Factors Influencing the Safety Strategies Used by People with Intellectual Disability’ (2013) *Scandinavian Journal of Disability Research* 1.

⁶⁷ Queensland Police Service, *QPS Makes 50,000th SupportLink Referral* (24 January 2013) Queensland Police Service News <<http://mypolice.qld.gov.au/blog/2013/01/24/qps-makes-50000th-supportlink-referral/>>.

⁶⁸ Queensland Police Service, *Operational Procedures Manual* (18 January 2013) Queensland Police Service Operational Procedures Manual (Public Copy) <<http://archive.sclqld.org.au/qps-manuals/opm/current-issue/>>, 6.6.20.

⁶⁹ *Ibid*.

⁷⁰ Queensland Police Service, *Vulnerable Persons Policy* (30 July 2013) Queensland Police Service – Our Policies <<http://www.police.qld.gov.au/Resources/Internet/rti/policies/documents/QPSVulnerablePersonsPolicy.pdf>>.

⁷¹ Queensland Police Service, above n 68, 6.3.1.

greater training of police officers throughout Australia to enable them to readily identify⁷² and better engage with⁷³ people with a disability or impaired decision-making capacity. Further, it would also be of benefit for adults to have access to skilled independent persons who understand the system and are able to truly assist the person, as opposed to simply having a support person.⁷⁴

Reasonable accommodations must also be made within the legal system, particularly in interactions with professionals and in the courtroom setting. It is important that lawyers, magistrates, judges and other courtroom personnel be appropriately trained to identify and communicate with people with disability or impaired decision-making capacity, to an extent appropriate to their roles. As the issues paper has identified, there have been accommodations made regarding the way in which people with disability can give evidence. To better facilitate their participation, both Commonwealth and State government should consider adopting and fully utilising practices such as those in the UK,⁷⁵ NSW⁷⁶ and Western Australia⁷⁷ whereby a third party can facilitate the giving of evidence by a person with disability, including by explaining the questions being asked and the answers given by the person with disability.

The use of court diversion options must also be considered. Where a person has committed a summary or indictable offence and is unfit for trial, suffering from a mental illness, or suffering from an intellectual disability, there is provision for them to be diverted away from traditional responses and made subject to programs or treatments.⁷⁸ To facilitate the use of these diversions it must be ensured that professionals such as police, lawyers, judges and magistrates are able to competently identify those with impaired decision-making capacity so that they can be afforded the response that is most appropriate to their needs. It must also be ensured that such diversionary options are sufficiently funded to provide the requisite assistance.

Finally, reasonable accommodations must be made by correctional centres in instances where adults with impaired decision-making capacity are sentenced to imprisonment. This includes providing a process by which a disability or impairment is identified immediately upon entry and is made known to staff at the correctional centre. People with a disability or impairment must also be given assistance throughout their term of imprisonment to ensure both that they understand the rules and procedures to be followed and to enable them to participate in appropriate rehabilitative programs. Finally, adults with disability or impairment must be given support when they are released from imprisonment. This support must be in the form of a coordinated response that takes into account a person's needs across all areas of life and must continue beyond the immediate release period to ensure that people remain in a stable situation with the aim of reducing their risk of re-offending.

The use of diversionary systems and the provision of support when exiting prison are particular aspects of the criminal justice system that must be linked to the NDIS and the National Disability Strategy. The National Disability Strategy seeks to drive the improved performance of mainstream services in delivering outcomes for people with disability. In order to ensure that people with disability or impaired decision-making capacity receive adequate services and are properly supported upon their release from prison, there must be provision made for NDIS supports to be put into place before or simultaneously with a person's release. These supports must be individualised and take into account any post-prison needs, such as ongoing rehabilitation courses or risk-factors that need to be addressed. If a person is released without proper support, there is a greatly increased chance of re-offending. Similarly, where a person is placed into a diversionary program, there must be provision for the NDIS to take into account the person's present and future needs, in light of the diversionary program, and tailor the support provided to that person as necessary.

⁷² Victorian Law Reform Committee, *Report of the Law Reform Committee for the Inquiry into Access to and Interaction with the Justice System by People with an Intellectual Disability and the Families and Carers*, Parliamentary paper No 216 (2013) 115 citing New South Wales Police Force, Code of practice for CRIME (custody, rights, investigation, management and evidence) (2011) NSW Police Force, 144-145; L Douglas and M Cuskelly, 'A Focus Group Study of Police Officers' Recognition of Individuals with Intellectual Disability' (2012) 19(1) *Psychiatry, Psychology and Law* 35.

⁷³ Victorian Law Reform Committee, above n 72, 125-126; L Douglas and M Cuskelly, above n 72; B L Spivak and S D M Thomas, 'Police Contact with People with an Intellectual Disability: The Independent Third Person Perspective' (2013) 57(7) *Journal of Intellectual Disability Research* 635, 635.

⁷⁴ Victorian Law Reform Committee, above n 72, 138-139; French, above n 62, 69.

⁷⁵ Victorian Law Reform Committee, above n 72, 283.

⁷⁶ *Criminal Procedure Act 1986* (NSW) ss 275B, 306P(2), 306ZK(3).

⁷⁷ *Evidence Act 1906* (WA) ss 106F, 106R(4)(b).

⁷⁸ *Crimes Act 1914* (Cth) divs 6 – 9.

10 Privacy⁷⁹

Adults with disability or impaired decision-making capacity are particularly vulnerable in relation to invasions of privacy.⁸⁰ This vulnerability may arise particularly as a result of their living arrangements and the monitoring practices employed in supported accommodation environments.

Adults with impaired decision-making capacity are 70 times more likely to live in supported accommodation than the general population.⁸¹ Reports suggest that the use of electronic monitoring devices (including visual and audio monitors such as closed circuit cameras, mobile devices and baby monitors) at these facilities is increasing.⁸² Similar devices are also used in nursing homes.⁸³ The use of these devices presents a potential for serious invasions of privacy for these adults.

A study undertaken jointly by the Office of the Public Advocate and the Community Visitor Program in Queensland found that electronic monitoring is being used in 13% of disability accommodation sites, and a significant proportion of these (69%) appear to lack fundamental safeguards to ensure the protection of residents' privacy. Policies governing the use of electronic monitoring and procedures for seeking and gaining consent from those subject to electronic monitoring are not yet commonplace; nor is any form of regulation currently in operation.

Many adults with impaired decision-making capacity have a communication impairment (28%)⁸⁴ that may impact their ability to make complaints about serious breaches of their privacy and limit the capacity to take statutory action. Furthermore, the conditions that impair decision-making capacity, for example intellectual disability, dementia or mental illness, may also diminish an adult's capacity to understand the nature and effect of invasions of privacy, make complaints, or seek support to progress legal action in these situations.

While electronic monitoring can represent a serious invasion of a person's privacy, it also has the potential to improve the standard of support that services providers deliver. The majority of disability accommodation sites (83%) reported that the use of electronic monitoring improved the support provided to residents while others (20%) identified that the electronic monitors were simply replacing older, out-dated systems. However, electronic monitoring should never be used because of resource constraints or in lieu of appropriate support and services.

Considering these potential benefits, there must be allowances in any regulatory system to enable the use of electronic monitoring in appropriate circumstances while still ensuring sufficient safeguards are in place.

In order to give greater recognition to the right of adults with disability or impaired capacity to respect for their privacy, this should be stated in the *Disability Discrimination Act 1992* (Cth) together with an obligation to uphold and further this right. The right to privacy is also an important consideration related to the National Disability Strategy, particularly with regard to developing a policy framework to guide activity in public policy areas.

If Commonwealth laws and legal frameworks are amended to provide redress for such breaches of privacy, these must include necessary accommodations for adults with impaired decision-making capacity that:

- ensure recognition/accommodation for a litigation guardian to initiate and manage legal proceedings on behalf of an adult with impaired decision-making capacity;
- ensure that provisions similar to those relating to special witnesses in the *Evidence Act 1977* (Qld) are available to an adult with impaired decision-making capacity when giving evidence in Court; and
- ensure that any legal remedy available to an adult with impaired decision-making capacity includes protections from reprisal, continuation of support and allowances for the justifiable use of electronic monitoring.

⁷⁹ This relates to question 11 of the issues paper.

⁸⁰ The potential population for our systems advocacy is made up of the aforementioned 114,000 Queensland adults with impaired decision-making capacity, of which 54% have a mental illness and 26% have an intellectual disability. This group forms the potential population for our systems advocacy.

⁸¹ Australian Bureau of Statistics (ABS) 2011, *Microdata: Disability, Ageing and Carers, Australia, 2009*, cat no. 4430.0.30.002, ABS, Canberra.

⁸² R Viellaris, *Questions Raised over Baby Monitors in Queensland Nursing Homes* (28 December 2012) The Courier Mail <<http://www.couriermail.com.au/ipad/questions-raised-over-baby-monitors-in-queensland-nursing-homes/story-fn6ck51p-1226544338675>>.

⁸³ Ibid.

⁸⁴ ABS, above n 81.

11 Concluding Comments

Recognition for the inherent human rights that must be afforded to people with disability is at the core of my submission, and will continue to be central to my consideration of any reforms that may be proposed in the course of this inquiry.

People with disability, in particular those with impaired decision-making capacity are among the most disadvantaged people in the community, with an unacceptably high level of disadvantage experienced across a range of social and economic indicators.

There is a clear need to ensure appropriate support is provided through legislation and other means so as to uphold people's rights and promote and protect their autonomy and legal capacity.

There must be a focus on continually reviewing human services systems with a view to identifying further areas for improvement while ensuring that current approaches and procedures provide increasingly appropriate means of accommodation and inclusion. It is only if this ongoing commitment is pursued that Australia will demonstrate true compliance with its international obligations under the Convention.

While not a focal point for this submission, the success of any legislative reforms that may be pursued is contingent on the complementary human services systems operating in an integrated and cohesive way. Any consideration of, or recommendations for, reform must take into account the supporting systems such as disability services, housing, education and health, and what may be required from them to enable optimal responsiveness, and to promote and protect the autonomy of people with disability.

I am pleased to lend my support to the Commission as it progresses this important inquiry in the interests of ensuring the success of necessary reforms to Commonwealth law and legal frameworks in support of people with disability and their right to having their legal capacity upheld and to equal recognition before the law. I would be pleased to make myself available to the Commission should there be an opportunity to further discuss the points made in this submission and/or explore opportunities for collaboration.



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