



# Conclusions on the Use of Restrictive Practices for People with an Intellectual or Cognitive Impairment

## How to Return Respect and Control to Marginalised People

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## Summary of QAI's conclusions on the use of Restrictive Practices

QAI believes that all human beings are equally important, unique and of intrinsic value. Everyone should be seen and valued as a whole person, first and foremost. The human condition is such that societies tend to devalue those who do not fit within their models of perfection.

In keeping with these values and beliefs QAI will not perpetuate complicit use of language that detracts from the worth and status of people with disability. The exhibition of behaviour of concern to others is not an attribute of the person but rather a communication method that can be relied upon in times of duress or when other methods have failed. We will refer throughout this paper to exhibitions of behaviours of concern rather than the commonly used negative stereotype descriptor for people with disabilities ('people with challenging behaviour').

With this caveat, we make the following conclusions about the use of Restrictive Practices:

- 1) The use of Restrictive Practices on people with an intellectual or cognitive impairment is an issue of vital importance that touches on notions of human rights, equality, autonomy, choice, dignity and respect and pertains to a highly vulnerable, marginalised and disempowered group in our society. As such, this is a matter of paramount importance, the management of which must be approached with sensitivity and an appreciation and understanding of all of the relevant factors, including systemic issues.
- 2) Restrictive Practices are imposed upon vulnerable people by those who abuse their power and exert domination over the person. While this can occur in the family context, this paper addresses the legislation as it applies to service providers and pursuant to the guardianship regime, and the impact this has upon vulnerable people with disability.
- 3) QAI considers that a holistic approach should be taken to any consideration of the use of Restrictive Practices, situating this issue within an understanding of the many relevant issues, including the statutory framework, policies and resources impacting upon service providers, the history of treatment of the person with disability, the communicative strategies used by the person with disability and the relative power and vulnerability of those applying and subject to RPs. These factors must be considered, along with the behaviour purported to result in the application of the Restrictive Practice, as they are

highly relevant to the outcome. Experience has shown that the adoption of a narrow perspective that focusses only on the behaviour at hand predominantly results in the inappropriate, disproportionately high and ineffective use of Restrictive Practices.

- 4) QAI considers that, in attempting to understand a person's behaviour, it is imperative to start by understanding their life experiences, any difficulties they may face in communicating and the situations in which they may feel unsafe, threatened or disempowered. In many circumstances, behaviour can be interpreted out of context and can be incorrectly labelled as unprovoked aggression or lack of cooperation justifying seclusion, containment or mechanical or chemical restraint when in fact, the use of Restrictive Practices is associated with an escalation in the manifestation of behaviours of concern, rather than a reduction.
- 5) QAI endorses a supported decision-making approach for people with an intellectual or cognitive disability. By this approach, the role of the supporter is to assist in scaffolding or *maintaining* the adult's capacity for longer than would otherwise be the case. This decision-making approach, by helping to develop decision-making capacity and respecting autonomous choice, decreases the incidence of communicative behaviours that may lead to the application of a Restrictive Practice.
- 6) QAI is firmly committed to the values of autonomy and self-determination for people with a disability and considers that, for people with an intellectual or cognitive disability, true informed consent requires that they are presented with real choices, enabled to express their views and preferences and have their autonomy and right to make decisions respected (irrespective of whether their choices may be objectively considered to be 'good' or 'bad'). It is critical that those who care for or assist people with disability take all reasonable steps to identify and understand possible catalysts for communicative behaviours, including historical and current life experiences, environmental, relationship, sensory, mental health and physical factors that may be relevant.
- 7) QAI acknowledges the significant value of informal supports for a person with a disability and calls for informal supporters to be accorded greater respect and status, as well as formal recognition within bureaucratic guardianship processes.
- 8) Statutory safeguards, such as the need for the implementation of a positive behaviour support plan and approval of the Restrictive Practice by the relevant decision-maker, have been implemented to regulate the use of Restrictive Practices on people with a disability who exhibit behaviours of concern. However, the legislation focuses on procedural, rather

than substantive, safeguards and fails to examine issues of power and inadequate supports or provide tangible protection.

- 9) The anti-discrimination legislative framework also offers theoretical safeguards against the inappropriate use of Restrictive Practices, as the use of Restrictive Practices is potentially in contravention of the statutory prohibitions against discrimination in state, federal and international law, constituting practices and treatments that would be unlawful if done to others without the disability. While it is difficult to argue that there exist grounds that justify such adverse, differential treatment, the anti-discrimination jurisdiction has not provided an effective cause of action to date in this context, primarily as a consequence of endemic problems inherent in that jurisdiction.
- 10) The conclusions reached in this paper are pertinent in the context of the development of the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector by the Commonwealth Department of Social Services, in the bridging period to full implementation of the NDIS. It is QAI's hope and expectation that the conclusions of this paper will help to shape the practical approach taken to the use of Restrictive Practices in a way that will herald positive change in the lives of people with disability. To date, such change is yet to be seen despite theoretical shifts in law and policy.
- 11) There is a significant and concerning disparity between the theoretical position which mandates minimisation of the use of Restrictive Practices and the practice of excessive use of Restrictive Practices on people with a disability who exhibit behaviours of concern.
- 12) Mindsets and preconceptions about people with a disability and their behaviour have a significant impact on their treatment. This is an issue that is relevant to the entire trajectory, from the initial interaction between a person with a disability and a service provider to the application of a Restrictive Practice. A change in mindset is required to deconstruct not only the relevant legislative scheme, but just as importantly the mindsets of the service provision system.
- 13) When an approach of respect, autonomy and enablement is integrated with practical supports and safeguards, relationships are correctly balanced. We return control and respect to formerly marginalised people and reduce or remove the use of Restrictive Practices.

## Introduction

It is time to change the language commonly used as a descriptor for people with disabilities. There is a preponderance about the use of the term 'challenging behaviours' that has evolved into labelling and stereotyping of people who may, at times, communicate by using the only means available to them in times of duress. The exhibition of behaviours of concern to others is not an attribute of the person. When we address our language we can mitigate a tendency to prejudicial reactions that are reflected in our own behaviours. When actively and attentively listening to the person we can avoid adding to the angst experienced by the person and we can respond appropriately.

This research paper considers the use of Restrictive Practices on people with a disability who exhibit behaviours of concern.<sup>1</sup> Current practices in the use and imposition of Restrictive Practices in the disability services culture do not appear to have arisen from the need to manage acute crisis within a short timeframe. Rather, in practice the culture of approach seems to be a self-fulfilling prophecy. The person viewed as exhibiting the behaviours of concern is restricted, thus exacerbating the problem. Therefore the perceived solution is to apply more or longer use of the particular restrictive practice or practices, entrenching and sanitising this approach as acceptable for the long term. The person gains an ill-deserved reputation that is difficult to shed.

To effectively enable such persons, a more contemporary response is required that operationalises the notion of autonomy. This is especially true in the context of the multiple and long-term processes that impact upon people with an intellectual or cognitive disability.

This paper is structured as follows:

1. Part A – Setting the scene: The present Australian approach to autonomy in the context of people with an intellectual/cognitive impairment who exhibit behaviours of concern;

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<sup>1</sup> At the outset, it must be noted that the term “behaviours of concern” is used preferentially to the phrase “challenging behaviours”. Note that Philip French and associates define “behaviours of concern” as those that pose a risk of serious harm to self and others **and** that challenge the capacity of the service system to provide positive support: Phillip French, Jeffrey Chan and Rod Carracher, “Realizing Human Rights in Clinical Practice and Service Delivery to Persons with Cognitive Impairment who Engage in Behaviours of Concern” (2010) 17(2) *Psychiatry, Psychology and Law* 245.

2. Part B – From ideology to lived experience: The use of Restrictive Practices for persons exhibiting behaviours of concern;
3. Part C – Moving forwards: Operationalising autonomy in the real world of disability in a way that returns respect and control to marginalised people.

This paper will commence with a brief description of the different types of Restrictive Practices and the manner in which they are applied in the State of Queensland, Australia.

## Restrictive Practices Overview

Restrictive Practices are those practices used by funded disability service providers to respond to the behaviour of an adult with an intellectual or cognitive disability that causes harm to the adult or others. Restrictive Practices include mechanical, physical and chemical restraint, seclusion, containment and restricting access to objects.

Each of these practices will now be briefly discussed.

### Containment

Containment is the practice of physically preventing an adult from freely exiting the premises where they receive disability services (other than by seclusion), for example by locking doors or gates.<sup>2</sup> However an adult is not contained if they have a skills deficit<sup>3</sup> and the service provider locks gates, windows or doors to prevent the adult from leaving the premises without supervision. An example of a skills deficit is lack of road safety skills.

*QAI has concerns that this exemption can be misused for the ease of staff management or that risk aversion is an excuse rather than best practice of support to the person.*

### Seclusion

Seclusion is the practice of physically confining an adult alone, at any time of the day or night in an area or room from which they cannot exit freely.<sup>4</sup> That is, the door is unlockable from the outside only.

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<sup>2</sup> *Disability Services Act 2006* (Qld), s 146.

<sup>3</sup> *Ibid*, s 217 (definition of 'adult with a skills deficit').

<sup>4</sup> *Ibid* s 144 (definition of 'seclude').

*QAI has concerns that if a person chooses to be alone and closes such a door, that this can be construed as an instance of the use of this restrictive practice.*

## **Chemical, Mechanical or Physical Restraint**

### ***Chemical restraint***

Chemical restraint is using medication on an adult for the primary purpose of controlling behaviour that may cause harm to themselves or others.<sup>5</sup> An example is using diazepam to sedate an adult when there is no medical reason for using the medication. Medication given to enable an adult to receive a single instance of healthcare, such as a dental check-up, is not considered a chemical restraint.

*QAI has concerns about the overuse or misuse of medication, for example, where the person has not been included in discussions and decision-making about their healthcare nor been provided with education and coping skills. It would appear that there is still confusion in the service sector about appropriate support to assist people in order to avoid the use of this practice.*

### ***Mechanical restraint***

A mechanical restraint involves using a device for the primary purpose of controlling an adult's behaviour that causes harm to themselves or others.<sup>6</sup>

*The device restricts the adult from being able to move freely. Placing the adult in a chair with shackles would be a mechanical restraint. Using seat belts or a bed with side guards for safety reasons is not mechanical restraint.*

### ***Physical restraint***

A physical restraint involves using any part of another person's body to restrict an adult's free movement for the primary purposes of controlling their behaviour to prevent harm to themselves or others.<sup>7</sup>

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<sup>5</sup> Ibid s 145.

<sup>6</sup> Ibid s 147.

<sup>7</sup> Ibid s 147.

*Placing a hand on an adult (for safety/guidance) when crossing a road is not physical restraint. However, holding an adult's arm to prevent them from striking another is physical restraint.*

### **Restricting Access of an Adult**

Restricting access means restricting an adult's access to an object to prevent the adult using the object to cause harm to themselves or others.<sup>8</sup>

*For example, if an adult has a history of using a knife to cause harm, the knives may be locked in a drawer to prevent access. There are concerns that some people are restricted access to their own rooms and possessions, particularly when living in shared care arrangements or for punitive measures.*

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<sup>8</sup> Ibid s 144 (definition of 'restricting access').

## **Part A – Setting the scene: The present Australian approach to people with an intellectual or cognitive impairment who exhibit behaviours of concern**

Many people with disability experience a lifetime of devaluation from birth, through their school years and beyond. The imprint left upon people by the multiple layers of discrimination, exclusion and rejection is often a terrible burden of loneliness, pain or anger. When any, and at times the only, interaction they have with another person is in the form of a direction or instruction, a ‘do this, don’t do that’ chorus echoed throughout the years, it is not unexpected, having regard to normal human behaviour, that some people will retreat into themselves while others will attempt to exert some will and determination. Social isolation, a lack of status or esteem and an undeserved reputation is exacerbated by the proliferation of negative stereotyping which occurs within the disability sector and throughout the broader community.

### **Behaviour and communication**

QAI takes the position that, in attempting to understand a person’s behaviour, it is imperative to start by understanding their experiences and history, including the quality of previous support arrangements and instances of abuse and neglect. People with intellectual impairments often face significant difficulties communicating, and this can be aggravated in situations in which they feel unsafe, threatened or disempowered. Behaviour is usually part of a process of attempted communication that has escalated as a consequence of a failure by the service provider to respect the rights of the person to autonomous choice and respect. It is not always easy to get this right – even family members with all the best intentions can make mistakes no matter how well they know the person. This does not mean, however, that they or any service provider should merely resort to the use of Restrictive Practices and abandon earnest endeavours to understand the person and to elevate their capacities and status. In many circumstances, behaviour is interpreted out of context and can be incorrectly labelled as unprovoked aggression or lack of cooperation justifying seclusion, containment or mechanical or chemical restraint.

## Factors that calm and factors that escalate behaviours of concern

The use of RPs has been identified as a factor that escalates behaviours of concern. A meta-analysis of the literature regarding the use of physical restraint in child protective services in South Australia concluded that there was no robust evidence to show that physical restraint reduces either the frequency or intensity of 'challenging behaviour'.<sup>9</sup> To the contrary, the use of RPs has been recognised to escalate behaviours of concern. Research by scholars including Carr<sup>10</sup> and McLean and Grey<sup>11</sup> establishes that there is a parallel reduction in behaviours of concern associated with a reduction in the use of physical restraint.

Recent research by Tyrer and associates has shown not only a lack of evidence-based efficacy of chemical restraints for people with an intellectual disability, but that a placebo group, rather than a group on antipsychotics, showed the greatest positive change in behaviour.<sup>12</sup> Webber and associates similarly note: 'overall, the evidence in favour of chemical restraint for controlling behaviours of concern such as aggression is weak'.<sup>13</sup> This is concerning, given the widespread use of chemical restraint for people with a disability over extended periods, with little or no data collected to determine treatment efficacy.<sup>14</sup> They conclude:<sup>15</sup>

Our available data to date suggest that restrictive interventions do not lead to reduction in the occurrence of behaviours of concern except in the short term (ie while applied) and that what is needed is a better understanding of the functions of behaviours of concern and the individual needs of the person and interventions that address those functions and needs.

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<sup>9</sup> Andrew Day, Michael Daffern and Pam Simmons, 'Use of Restraint in Residential Care Settings for Children and Young People' (2010) 17(2) *Psychiatry, Psychology and Law* 230, 922.

<sup>10</sup> Carr, EG, RH Horner, AP Turnbull, et al, *Positive behaviour support for people with developmental disabilities: A research synthesis*, American Association on Mental Retardation, Washington DC, 1999.

<sup>11</sup> Grey, IM, RP Hastings and B McLean, 'Staff training and challenging behaviour' (2007) 20 *Journal of Applied Research in Intellectual Disabilities* 1; Grey, IM and B McLean, 'Service user outcomes of staff training in positive behaviour support using person-focused training: A control group study' (2007) 20 *Journal of Applied Research in Intellectual Disabilities* 6.

<sup>12</sup> P Tyrer, PC Oliver-Africano, Z Ahmed et al., 'Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: A randomised controlled trial' (2008) 371 *The Lancet* 57; Lynne Webber, Frank Lambrick, Mandy Donley et al., 'Restraint and Seclusion of People on Compulsory Treatment Orders in Victoria, Australia in 2008-2009' (2010) 17(4) *Psychiatry, Psychology and Law* 562, 564.

<sup>13</sup> Webber, Lambrick, Donley et al., note 12, 564.

<sup>14</sup> Ibid 565.

<sup>15</sup> Ibid 572.

A summary of the relevant literature on the use of RPs on children in respite services in Australia found:<sup>16</sup>

The use of restrictive interventions to manage challenging behaviour may impact adversely on their psycho-social adjustment, and re-traumatize a very vulnerable group of children and young people, thus increasing a family's need for further respite over time and increasing both the psychological and economic burden for the community.

The serious adverse consequences of the use of RPs for both adults and children include serious physical injury, such as asphyxia and cardiac complications and death, as well as significant adverse psychological effects on quality of life and well-being.<sup>17</sup>

This evidence of the effects of the use of RPs is unsurprising, if we consider the likely response of any person, whether they have a disability or not, to the imposition of a Restrictive Practice, which is tantamount to abduction, imprisonment, bondage, solitary confinement, chemical sedation or sterilisation. This is exacerbated in the case of persons with increased vulnerability and diminished legal autonomy.

As French notes, the current Queensland legislative regime is founded upon the assumption that people with disability 'can and ought to change their behaviour', rather than locating the problems encountered by persons with behaviours of concern in the environment in which they are placed – it incorrectly focuses on the individual, rather than the environment.<sup>18</sup>

The research shows that even a person who does use verbal communication may rely upon the manifestation of unique behaviours as their reflex communication when under duress, anger, fear or emotional upheaval.<sup>19</sup> In the context of people with a disability, this behaviour can be aggravated as the inevitable result of the exacerbation of this situation by the disempowerment, isolation and decreased ability to communicate their experience. This situation, as the limited empirical research on this point clearly shows, is exacerbated by the use of RPs.

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<sup>16</sup> Jeffrey Chan, Lynne Webber & Brent Hayward, 'Examining the Use of Restrictive Interventions in Respite Services in an Australian Jurisdiction' (2013) 20(6) *Psychiatry, Psychology and Law* 921, 922-3.

<sup>17</sup> The Australian Psychological Society Ltd, *Evidence-Based Guidelines to Reduce the Need for Restrictive Practices in the Disability Sector*, 2001.

<sup>18</sup> Phillip French, 'Human Rights and Human Wrongs: A Human Rights Analysis of Queensland Restrictive Practices Legislation', Presentation to Queensland Advocacy Incorporated's Restrictive Practices Forum, 24 August 2010, 2, 13.

<sup>19</sup> Peter Andersen, *Nonverbal Communication: Forms and Functions* (Mayfield, 1999), 18.

Michael Kendrick's work on exploring the ethics of 'right relationships' for people with disability, as a protective safeguard in the face of the contemporary dominance of human service organisations, emphasises the importance of identifying and internalizing an appropriate ethical framework in both interpersonal and impersonal relationships.<sup>20</sup> Kendrick identifies the following features as integral to this process, with the end goal of creating a fundamentally ethical and respectful relationship between the person and the service delivery provider:<sup>21</sup>

1. Creating service delivery arrangements that permit service users sufficient powers to be able to meaningfully shape how service is rendered;
2. Helping individuals to recognise that they can personally embody 'right relationship' ethics in how they relate to the people they assist, irrespective of the bureaucratic structures in which they work, and by prepared to uphold the cost of 'right relationship' ethics;
3. Keeping services as small, 'grass roots' and non-bureaucratized as possible;
4. Favouring flexible and personalised approaches over standardised ones;
5. Relating 'with' people, not 'at', 'on', or 'down' to them;
6. Negotiating with people, rather than imposing answers;
7. Creating mutual and shared ideals of what the 'right relationship' is;
8. Rejecting the theory of professional or managerial ultimacy over service;
9. Relating to each person as unique in the design and operation of services; and
10. Leaving core decisions of a personal nature to the person concerned.

There is evidence in the literature that an approach to people with disability that supports their choices and understands and responds to the recognised 'triggers' for behaviours of concern are more effective responses to behaviours of concern than the imposition of RPs.<sup>22</sup> Positive

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<sup>20</sup> Michael Kendrick, 'Some Initial Thoughts On Establishing "Right Relationship" Between Staff, Professionals, Service Organisations and the People They Assist' *QAI Newsletter*, April 2000; Michael Kendrick, 'The Role of Personal Integrity in Upholding 'Right Relationship' in Organisations' (2003) 28 *CRUCial Times* 4.

<sup>21</sup> Ibid.

<sup>22</sup> Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, *Challenging behaviour: a unified approach*, 2007.

Behaviour Support is identified as reducing behaviours of concern<sup>23</sup> and therefore the use of restrictive interventions.<sup>24</sup>

A factor that has been identified as having a significant impact on the psychological well-being and behaviour of many people with an intellectual or cognitive impairment relates to the person's accommodation arrangements. This is an issue that has previously been accorded significant attention as a consequence of reported atrocities committed in institutions in which people with mental illness or intellectual and cognitive impairments were accommodated.<sup>25</sup>

There has been a strong emphasis on deinstitutionalisation and reformation of social and housing policy framework in Australia over the past few decades.<sup>26</sup> Since the early 1990s, theories of normalisation and Social Role Valorisation<sup>27</sup> have created the impetus for a substantial focus on deinstitutionalising people with an intellectual or cognitive impairment – that is, moving people from large state institutions into a home of their own. The case for deinstitutionalisation has been compelling, and has been supported by inquiries and commissions into malpractices and abuses that have occurred at state institutions and were in fact unlawful use of Restrictive Practices.<sup>28</sup> Consequently, deinstitutionalisation in the disabilities context now receives mainstream support as an accepted practice in most Western countries.<sup>29</sup> Unsurprisingly, the favourable outcomes of the residential service model as compared with institutionalisation for adults with an intellectual disability are noted.<sup>30</sup>

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<sup>23</sup> Carr, Horner, Turnbull, et al, note 10.

<sup>24</sup> Lynne Webber, Ben Richardson, Frank Lambrick and Tarryn Fester, 'The impact of the quality of behaviour support plans on the use of restraint and seclusion in disability services' (2012) 2(2) *International Journal of Positive Behavioural Support* 3.

<sup>25</sup> Refer, for example to the Basil Stafford Judicial Inquiry, which documented the ongoing abuse mistreatment and some killings of people with intellectual disability living there (1994, <http://www.cmc.qld.gov.au/data/portal/00000005/content/30013001200355733952.pdf>).

<sup>26</sup> Lisa Bostock, Brendan Gleeson, Ailsa McPherson and Lillian Pang, deinstitutionalisation and housing futures: final report (Australian Housing and Urban Research Institute UNSW-UWS Research Centre, 2001).

<sup>27</sup> Social Role Valorisation theory is discussed below.

<sup>28</sup> See, for example, The Hon WJ Carter QC, *Challenging Behaviour and Disability: A Targeted Response*, Report to Honourable Warren Pitt MP, Minister for Communities, Disability Services and Seniors, July 2006 (the 'Carter Report'). See also Criminal Justice Commission, *Report of an Inquiry Conducted by the Honourable DG Stewart into Allegations of Official Misconduct at the Basil Stafford Centre*, 1995 (the Stewart Inquiry).

<sup>29</sup> Janet Louise Young, *Deinstitutionalisation and Changes in Life Circumstances of Adults with Intellectual Disability in Queensland*, Unpublished doctoral thesis, University of Queensland, 2001.

<sup>30</sup> See, for example, doctoral research by Young, which reports on Australia's largest deinstitutionalisation research project, whereby residents from Challinor, a government-run institution located in Ipswich, Queensland, were relocated after the centre was closed. The residents of Challinor was predominantly classified as a most problematic group to deinstitutionalise, as the demographics of this group were mostly older (aged over 40 years), had been institutionalised for an extremely lengthy period (over 20 years), many had severe and profound levels of intellectual disability and many had behaviour problems. However, the deinstitutionalisation of this group resulted in favourable outcomes: Young, note 29.

A guiding principle in making accommodation arrangements is that of normalization, whereby people with intellectual disability are given socially valued roles and treated equally to those without disability, with the goal of improving their quality of life.<sup>31</sup> Research has shown that, even for adults with severe and profound intellectual disability, there are improvements in adaptive behaviour associated with the move from institutional accommodation to community housing.<sup>32</sup>

However, there remains a significant disparity between the preferences and reality of accommodation for many people with an intellectual or cognitive impairment. For many people with disability, their choice is not to be accommodated in a group home, but rather to live in an ordinary home in the community, either alone or with housemates chosen by them, in the manner that most Australians are able to choose their accommodation arrangements. Recent Australian research has recognised the desirability of taking an individualistic approach to housing for people with a disability.<sup>33</sup> Any arrangements must recognise the importance of self-determination and autonomy and the consequent need to ensure accommodation arrangements are tailored to suit the relevant person, with appropriate tailored funding available to support independent living arrangements with services provided in the community.

An external evaluation of the delivery and outcomes of the Queensland Government's Housing and Support Program conducted in 2010 found that people with intellectual and cognitive disability or mental illness can successfully reside and participate in their community of choice, with adequate community support, stable housing and appropriate clinical case management.<sup>34</sup>

Queensland researchers Chenoweth and Dorsett<sup>35</sup> are presently conducting qualitative research into the experience of self-direction for people with a disability who have been self-directing, with a view to informing the development of NDIS.<sup>36</sup> It is anticipated that the findings of this research will provide important insight into the experiences and desires of a subset of

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<sup>31</sup> Young, note 29.

<sup>32</sup> Young, note 29.

<sup>33</sup> Lesley Chenoweth, Natalie Clements and School of Human Services and Social Work, *Funding and service options for people with disabilities: Final Report*, Griffith University, June 2009, reporting on the 2008 meta-analysis by Parmenter and Arnold for the Victorian Department of Human Services.

<sup>34</sup> The evaluation was conducted by the Department of Psychiatry, University of Queensland, in conjunction with the Queensland Centre for Mental Health Research (known as 'The Park').

<sup>35</sup> This study is being conducted by academics of Griffith University.

<sup>36</sup> Chenoweth, Clements and School of Human Services and Social Work, note 33.

people with a disability who have been supported to exercise their autonomy as regards their living arrangements, and inform further development in the area of accommodation vis-à-vis people with an intellectual or cognitive impairment.

## **Case studies**

There are a number of case studies that demonstrate the link between the use of Restrictive Practices and the repetition or escalation of behaviours of concern. The following case studies are provided to provide practical examples of some of the issues discussed in this paper. There are many similar stories.

### ***Case Study 1 – Tina, a 23 year old female***

Tina was being supported by a service provider who regularly sought to increase the range of Restrictive Practices they could use around Tina. As a baseline, Tina was contained for 16 hours per day and secluded for eight hours overnight. During the day she would also be placed in seclusion or have chemical restraint applied in order to control her behaviour.

Tina's behaviour arose because neither she nor her family were listened to. Tina was bored, had little meaningful activity in her life and had been isolated from the community in which she lived. The service provider showed little interest in addressing these issues when they were raised by the family. Instead, they attempted to restrict Tina's access to her family and on several occasions applied to QCAT to have the public guardian appointed, as opposed to the family member. The service provider refused to acknowledge that Tina's behaviour was a form of communication (expressing dissatisfaction) and labelled Tina as difficult and prone to 'challenging behaviours'.

Tina really wanted to move to her own place and be closer to her family. The service provider discouraged this dream. Rather, they made application to QCAT submitting that Tina could never live on her own, was unsafe to be in the community and needed high level use of Restrictive Practices. The family continued their strong advocacy for Tina and contacted QAI for assistance.

Eventually Tina was moved into her own residence, closer to her family and to a service provider who has never used any form of Restrictive Practices. Tina now has a part-time job

and has become part of her local community. The 'challenging behaviours' have drastically reduced, as has the level of funding required to provide her support.

*(CRPD Breaches: Articles 3, 14, 15, 16, 17, 18, 19, 20, 22, 23, 25, 26, 27, 28 and 30)*

### ***Case Study 2 – Frances, a 22 year old female***

Frances was living in the community, however due to inadequate funding and inappropriate supports Frances' needs were unmet. As a result she started to display behaviours which were seen by the service provider as challenging, so much so that they withdrew from providing support. A decision was made by Disability Services to place Frances in a secure facility, contrary to the appointed guardian's requests. This meant that Frances was contained 24 hours per day, seven days a week.

Subsequent to the move all activities that Frances had previously enjoyed were ceased, as was her personal mobility and freedom. Due to boredom and an inability to move around freely, Frances began to self-harm and strike out at staff. Additional Restrictive Practices such as seclusion and chemical restraint were applied yet, unfortunately, positive strategies were not as rigorously applied. Frances began to spend large amounts of time in seclusion.

It was 18 months before activities pleasurable to Frances were re-introduced into her daily routine. This was only achieved through the strong advocacy of her family and QAI's involvement. Some 12 months later Frances remains at this facility and continues to have Restrictive Practices applied, albeit the frequency of use is decreasing.

The question to be pondered is: would any of this have occurred if appropriate funding and supports were available to Frances in the first instance?

*(CRPD Breaches: Articles 3, 4, 14, 15, 17, 18, 19, 22, 23, 26, 28 and 30)*

### ***Case study 3 – Michael, a 50 year old male***

Michael was living happily with his sister in a Department of Housing house. However due to a bureaucratic policy around department of housing tenancies a third person was moved in with them. This occurred without discussion or consultation with either Michael or his sister.

The co-tenant became abusive to Michael's sister. This naturally resulted in Michael becoming protective of her and beginning to hit out at the co-tenant. Eventually Michael became subject to Restrictive Practices, in particular physical restraint. Michael's 'behaviour' was not explored and he was labelled an aggressor. By placing this label on Michael, no additional support was provided to prevent the escalation, nor was any consideration given to removal of the co-tenant. Rather, there was a reliance on using Restrictive Practices to manage the situation.

Michael's advocate contacted QAI for assistance when the service provider requested ongoing approval to use Restrictive Practices. The Restrictive Practice order was revoked and additional supports were placed in the house to manage the situation. However, the co-tenant remains and the situation remains conflictual.

*(CRPD Breaches: Articles 3, 4, 5, 15, 17, 19, 22, 23 and 28)*

### ***Empirical research from Winchester, United States***

Looking to other jurisdictions, empirical research from Winchester, United States, highlights the success of strategies aimed at minimising the use of physical restraints on people with disability, in terms of the resulting reduction in 'challenging behaviour' exhibited.

Information was gathered to obtain a clear understanding of the employees' feelings about the initiative to minimize physical restraint. Training was provided regarding philosophical issues as well as how to utilize a new tool/procedure to keep everyone safe during aggressive outbursts. Presence by the management team was increased to support employees and encourage newly trained techniques. Finally, a formal system of processing was put in place to learn from each restraint in order to prevent the situation in the future.

The Winchester Region reduced the use of physical restraint by 99.4% and client-induced employee injuries by 37.7%.<sup>37</sup>

### **Contemporary sociological approaches to decision-making**

There are four different primary models of decision-making:

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<sup>37</sup> Kim Sanders, 'The Effects of an Action Plan, Staff Training, Management Support and Monitoring on Restraint Use and Costs of Work-Related Injuries', (2009) 22(2) *Journal of Applied Research in Intellectual Disabilities* 216.

1. Substituted decision-making;<sup>38</sup>
2. Best interests decision-making;<sup>39</sup>
3. Supported decision-making;<sup>40</sup> and
4. Co-decision-making.<sup>41</sup>

In Australia, the normative model for decision-making by people with an intellectual or cognitive impairment or dementia is currently substituted decision-making,<sup>42</sup> although scholars such as French, Kayess and Kanter<sup>43</sup> have argued that there has been an ideological shift towards supported decision-making in recent years.

The salient features of supported decision-making are that the person with a disability is empowered to make their own decisions, with appropriate assistance provided by a supporter to understand and communicate their decision. Rather than using the notion of incapacity as a threshold concept, which is a key feature of guardianship regimes, the supported decision-making model is grounded on the assumption that the role of the supporter is to assist in *developing and or maintaining* the adult's capacity and takes a more nuanced approach to the issue of capacity aimed at enhancing autonomy. This position is consistent with international humanitarian law and with contemporary sociological approaches to autonomy. We consider that this decision-making approach, by helping to develop decision-making capacity and respecting autonomous choice, decreases the incidence of communicative behaviours that may lead to the application of a Restrictive Practice.

In the context of the use of Restrictive Practices, we consider that all people have the right to self-determination without limitation, including the right to make important decisions about their own lives. The legal right of people with disability to make their own decisions should only ever be interrupted in extraordinary circumstances, with persons with impaired decision-making provided with supports to enable them to exercise capacity like any other.

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<sup>38</sup> Where a decision is made based on what the decision-maker believes the person themselves would have decided if they still had capacity: Queensland Advocacy Incorporated, *Position Statement*.

<sup>39</sup> Where a supporter or guardian makes a decision in the best interests of the person: Queensland Advocacy Incorporated, *Position Statement*.

<sup>40</sup> Where the person makes their own decision, with a supporter explaining and helping the person to understand and communicate the decision: Queensland Advocacy Incorporated, *Position Statement*.

<sup>41</sup> A recently developed approach, where decisions are jointly made by the person and their supporter, although legal ownership of the decision rests with the person: Then, note 9.

<sup>42</sup> Then, note 38, 135

<sup>43</sup> Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2009) 8 *Human Rights Law Review* 1, 5-6; Kanter, note 69, 560.

Commencing with the ratification of the CRPD, which was adopted by the United Nations in 2006,<sup>44</sup> Australia has taken tentative steps towards a supported decision-making model. Rather than purporting to recognise new human rights, the CRPD seeks to apply established human rights to persons with disability.<sup>45</sup> The human rights recognised by the CRPD that are of present relevance include the right to equality before the law, the right to liberty and security of person, the right to freedom of movement and to live independently and be included in the community, the right to privacy, the right to be treated non-discriminately, the right to freedom from torture and cruel, inhuman and degrading treatment, the right to physical and mental integrity and the right to habilitation and rehabilitation.<sup>46</sup> These broad human rights are tailored specifically for situations where persons with a disability may experience a violation of these general human rights.<sup>47</sup>

The CRPD favours supported decision-making approach,<sup>48</sup> with Article 12 in particular notable for creating a presumption of legal capacity, enshrining the right of persons with disabilities to enjoy equal legal capacity to persons without disabilities.<sup>49</sup> Scholars consider that the CRPD generally,<sup>50</sup> and Article 12 of the CRPD particularly,<sup>51</sup> marks a 'paradigm shift' from the traditional guardianship approach of appointing a substitute decision-maker to a more nuanced approach to capacity that promotes autonomy of decision-making to the greatest extent possible.<sup>52</sup>

As Kayess and Fogarty argue, the CRPD has been instrumental in shaping the perspective that *difficulty* in making or communicating a decision is not the same as an *inability* to do so.<sup>53</sup> Caivano notes:<sup>54</sup>

My contention is that the drafters of the CRPD intended the text of Article 12 [of the CRPD] to set out a strong presumption of capacity and to permit substituted decision-

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<sup>44</sup> Australia signed the CRPD on 30 March 2007 and formally ratified it on 17 July 2008.

<sup>45</sup> French, note 18, 2.

<sup>46</sup> These human rights are recognised more generally in the International Covenant on Civil and Political Rights and the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment and Punishment.

<sup>47</sup> For example, the right of a person with a disability to live independently and be included in the community is rooted in the rights to liberty and freedom of movement: Article 19 of the CRPD.

<sup>48</sup> See Art 12(3) of the CRPD; Carney and Beaupert, note 55, 177-8.

<sup>49</sup> <http://www.un.org/disabilities/convention/conventionfull.shtml>.

<sup>50</sup> Kayess and French, note 91, 5-6.

<sup>51</sup> Kanter, note 69, 560.

<sup>52</sup> Leslie Salzman, 'Guardianship for Persons with Mental Illness – A Legal and Appropriate Alternative?' (2010-2011) 4 *St Louis University Journal of Health Law & Policy* 279, 285.

<sup>53</sup> Rosemary Kayess and Ben Fogarty, 'The Rights and Dignity of Persons with Disabilities – A United Nations Convention' (2007) 32 *Alternative Law Journal* 22, 25.

<sup>54</sup> Caivano, note 59, 4.

making only in rare circumstances, such as when the use of supported decision-making fails to reveal the will of the person with disabilities.

## Understanding autonomy

In understanding the origins of the right to self-determination and respect for personhood, we must appreciate the importance of autonomy. Originally, it was thought that the individual was the focus of decision-making – this was a philosophically-based view which emphasised that the outcome of any individual's life was based almost solely around the decisions and actions of that individual. A more progressive view is based on the sociological understanding that there are many issues that impact upon autonomy and that individual choice cannot be understood in isolation from the context in which it is exercised (or curtailed). QAI prefers this latter approach, as it acknowledges the many issues outside an individual's control that are relevant to their life experiences.

Adopting a sociological approach to the issue of choice in the context of disability, it is important to recognise that autonomous choice is highly dependent upon the dominant framework (comprised of the relevant laws, policies and systemic issues) within which the person is seeking to exercise their right to choose. Put simply, an understanding of choice for disempowered and marginalised members of our society is not simply about recognising the considerations that may be relevant to their individual decision-making, but about adopting a broader perspective which encompasses an understanding of power, disempowerment and systemic issues.

As Then states:<sup>55</sup>

Autonomy in [the disabilities] context does not simply mean leaving adults in question alone to do what they want, but includes support for them to maximise the options available. The promotion of autonomy was the primary rationale behind guardianship regimes statutorily recognising legally binding advance planning documents, and it remains a primary driver for enacting assisted decision-making mechanisms.

In a different context, but of present relevance, Petchesky supports both the individual right to choose and the resulting decisions, acknowledging that this is so notwithstanding that individuals cannot control the social framework within which they make their choices or their 'moral capacity to make them'. For Petchesky, this means that rather than emphasising the

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<sup>55</sup> Shih-Ning Then, 'Evolution and Innovation in Guardianship Laws: Assisted Decision-Making' (2013) 35 *Sydney Law Review* 133, 142.

relevance of individual choice, we should turn our attention to the way in which choices are shaped, and limited, by the social conditions in which they are made.<sup>56</sup>

Jennifer Nedelsky, adopting a relational approach, argues that autonomy is not equated with independence, but rather: '[a]utonomy is made possible by constructive relationships'.<sup>57</sup> From this perspective, autonomy is not static, a quality which one has (or does not have) but rather, a 'capacity whose realization is ever shifting'.<sup>58</sup>

Similarly, Cannold notes:<sup>59</sup>

Choice requires more than legal freedom – the removal of a prohibitive law is the start of freedom, but on its own does not guarantee it – it is the social and material conditions in which people make choices that determine whether they have empty rights or rights that are real.

In the context of people with an intellectual or cognitive disability that limits their autonomy, this concept of ensuring that the choices able to be exercised are 'real' requires that the person's supporter scaffold the development of their ability to make choices, irrespective of whether each resulting decision is objectively considered to be a 'good choice'. What is important is the autonomous ability to exercise the right to choose.

Where possible, the person is supported to exercise their decision-making capabilities to the greatest extent, from the earliest opportunity. This develops their decision-making capacity and confidence. QAI believes that practice in making decisions in daily life provides important opportunities to develop skills, starting with small decisions and building to more complex decisions with time. This experience is essential with the introduction of the NDIS, to ensure that as many people as possible are able to exercise choice and control under the new system.

Furthermore, as Cannold notes, the choices offered to a person must be real – a person is not empowered where the only choices available to them are inadequate and there is a

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<sup>56</sup> R Petchesky, *Abortion and Woman's Choice: The State, Sexuality and Reproductive Freedom* (Northeastern University Press, 1985), 11.

<sup>57</sup> Jennifer Nedelsky, *Law's Relations: A Relational Theory of Self Autonomy, and Law* (Oxford University Press, 2011), 118.

<sup>58</sup> Mary Donnelley and Claire Murray, 'The role of family in mental health law: a framework for transformation' (2013) 25(4) *Child & Family Law Quarterly* 380, 398-9.

<sup>59</sup> Lesley Cannold, *What, No Baby? Why Women are Losing the Freedom to Mother, and How They Can Get it Back* (Curtin University Books, 2005), 286-7.

dearth of appropriate supports in place to foster the translation of the theoretical choice into reality.

The Australian legal system, like those of other neoliberal societies, remains committed to the values of autonomous choice and individual responsibility. However, in many areas, including disability services and mental health, the law fails to address the broader socio-legal context. This discussion thus considers the role of the law in translating the neo-liberal concepts of autonomous choice and equality into practice at the coalface of disability care provision.

Immanuel Kant is credited with giving voice to the idea of personal autonomy as an ethical value in its own right, and thereby deserving of moral respect. At the heart of personal autonomy is freedom of choice, the capacity for self-determination. This is valued in a neoliberal society as an ends in itself; that is, even if the choice itself is objectively considered to be a 'bad' choice, the act of choosing is considered a moral good in that it is a free and autonomous, rather than coerced, act.<sup>60</sup> In the disabilities rights context, concern with protecting people with a disability from making potentially 'bad' choices on their own behalf historically provided the platform of support for best interests decision-making. However, a concern with autonomy has recently developed to challenge the paternalistic approach that has traditionally dominated this area. As Pare notes, 'autonomy has emerged as a new value that casts into doubt the value of protectionist regimes'.<sup>61</sup> She explains the pragmatic implications of the tension between autonomy and protectionism as follows.<sup>62</sup>

[D]ecision-makers often return to a protectionist paradigm, stripping individuals of their autonomy rights if their choices are deemed to lead to a socially unacceptable outcome. Tension between protection and autonomy has caused conceptual confusion and negatively influenced the lives of those who remain affected by the protection-autonomy dichotomy. New ways must thus be sought to approach health care related decision-making in a way that is respectful of both protection and autonomy rights of children and persons with mental illness.

This shift has heralded the beginnings of recognition that objectively 'bad' choices are also acceptable in the disabilities context, as Mr Justice Quinn stated in the Canadian case of *Re Koch*.<sup>63</sup>

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<sup>60</sup> Ibid 13.

<sup>61</sup> Mona Pare, 'Of Minors and the Mentally Ill: Repositioning Perspectives on Consent to Health Care' (2011) 29 *Windsor Year Book Access to Justice* 107, 108.

<sup>62</sup> Ibid 108.

<sup>63</sup> *Koch (Re)*, 33 OR (35) 485, [1997] OJ No. 1487 [*Re Koch*], [58], [89].

The right to be foolish is an incident of living in a free and democratic society. The right to voluntarily assume risks is to be respected... The dignity of the individual is at stake.

This statement resonates with QAI's position on the issue of choice. As part of our core values, we are firmly committed to self-determination for people with a disability. Accordingly, it is our belief that everyone, whether they have a disability or not, should be enabled to express their views and preferences (however ill or well-developed) and to have their right to make decisions respected. Individual preferences are an important facet of identity and QAI considers that permitting all people opportunities to express their preferences is fundamental to enabling human dignity. This is the case even in circumstances where a person may wish to make a decision that may not be considered to be in their best interests. Of fundamental importance is ownership of the decision-making process by the person with a disability – the person, and not their supporter, should be the one to make the decision. In balancing the fundamental respect and care for a person's wellbeing and 'best interests' it is important that there is sufficient time, dedication and support devoted to providing the person with all the information they need, and ensuring that they have the life experiences to contextualise and understand the consequences of their decisions. This concerted 'affirmative action' is part of the interdependence that most of us experience in our daily lives but with necessary emphasis where and when required.

## **Informed consent**

The doctrine of informed consent is founded on the principles of autonomy and respect for person. While informed consent traditionally solely focussed on the individual, it is now recognised that true informed consent cannot be given where the person required to give the consent is presented with a single, inadequate option. To increase the potential for proper informed consent to be provided, choice and autonomy must be improved. This is a particularly important issue in the context of our most vulnerable and disempowered members of society.

A core requirement of informed consent is capacity, or competence,<sup>64</sup> which can become contentious in the context of persons with a disability that can, or can be alleged to, affect competence. This issue will now be considered.

### The continuum from legal capacity to incapacity

Legal capacity has been contemplated at length by many different disciplines. While competence was initially the subject of consideration in the biomedical setting, we focus here on the relevance of competence for people with an intellectual or cognitive disability who may be subject to Restrictive Practices.<sup>65</sup>

A functional approach to the assessment of legal capacity has been the dominant approach since the mid-1950s.<sup>66</sup> In contrast to the traditional approach of viewing capacity as an all-or-nothing assessment,<sup>67</sup> this approach recognises the shifting nature of competency and its subjectivity according to both time and to the requirements of the specific decision to be made.<sup>68</sup>

It must be emphasised that legal capacity or competence is distinct from mental capacity and while assessments of mental capacity have been utilised when determining legal capacity, this approach has been criticised in recent times.<sup>69</sup> Those opposed to the use of capacity tests argue that it is artificial and unhelpful<sup>70</sup> and that a more appropriate approach would be to recognise the shifting nature of capacity for all people.<sup>71</sup>

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<sup>64</sup> The other core requirements are full disclosure of relevant information; comprehension and understanding of that information; and freedom or voluntariness: T. Lovat & K Mitchell. *Bioethics for medical and health professionals* (Social Science Press, 1991); P. McGrath, 'Informed consent to peripheral blood stem cell transplantation' (2000) 2 *Cancer Strategy* 44.

<sup>65</sup> Roth and associates note that there is no 'magical definition' of competency and that it is not only a psychiatric or medical concept, but also a social and legal one: LH Roth, A Meisel and C Lidz, 'Tests of competency to consent to treatment', in S Gorovitz, R Macklin, AL Jameton, JM O'Connor and A Sherwin (eds), *Moral Problems in medicine*, 2<sup>nd</sup> ed (Prentice-Hall, 1983), 182.

<sup>66</sup> Kristen Booth Glen, 'Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond' (2012-2013) 44 *Columbia Human Rights Law Review* 93, 94.

<sup>67</sup> Then, note 38, 144.

<sup>68</sup> Glen, note 49, 94.

<sup>69</sup> For example, Hall argues that mental capacity, while appropriate and functional in the health-treatment or property-law context, is a 'source of dysfunction' and deeply problematic in the context of guardianship and should be removed as the criteria for intervention: Margaret Isabel Hall, 'Mental Capacity in the (Civil) Law: Capacity, Autonomy, and Vulnerability' (2012-2013) 58 *McGill Law Journal* 61.

<sup>70</sup> For Hall, the concept of mental capacity is neither 'natural, compelling or necessary' and is deeply enmeshed with a traditional-liberal theory of autonomy. She considers that a more appropriate framework for the disabilities context is the 'vulnerability construct', which she develops from theories of equity and relational autonomy: *Ibid.* Two leading scholars writing in the area of guardianship law, Sabatino and Wood, have recently highlighted the artificiality and socially constructed nature of capacity and incapacity norms: Charles Sabatino and Erica Wood,

There has also been a recent appreciation of the close interrelationship between concepts of legal capacity, legal existence and equal recognition as a person.<sup>72</sup> This flows directly from the Convention on the Rights of Persons with Disabilities (CRPD).<sup>73</sup> Legal capacity has a different meaning in international human rights law and international conventions and within the discourse of the disability rights movement, as a person's capacity to have rights that are equal to those of other citizens and also to have the capacity to have their actions recognised by law.<sup>74</sup> Glen states:<sup>75</sup>

This paradigm sees incapacity as socially constructed, insists on the full legal capacity of every person with intellectual disabilities, and does away with substituted decision-making in favour of society's obligation to provide appropriate supports to permit everyone to make his or her own decisions.

The principles of inclusion, non-discrimination and equality prescribed by the CRPD require that laws and policies for people with a disability must be based on presumed legal competence, rather than incompetence.<sup>76</sup> This shift in perspective requires that supported decision-making becomes embedded as normative practice, with substituted decision-making limited to the exceptional cases (and even of these cases, all efforts should be made to ascertain the will of the person).<sup>77</sup> As Quinn explains:<sup>78</sup>

Take the person for whom there is no-or at least no obvious-will or preference. Bad substitute-decision-making is no longer acceptable. Or put another way, the necessity of making some decisions "for" rather than "with" the person has to be accompanied by a parallel and serious commitment to put in place the necessary ingredients to help spark the will and preference .... [T]hat means connecting the individual with social capital, with community. This is especially important with respect to those who have

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'The Conceptualization of Capacity of Older Persons in Western Law', in Isreal Doron & Ann Snoden (eds), *Beyond Elder Law: New Directions in Law and Aging* (2012) 35, 36.

<sup>71</sup> See for example Margulies, who contends that capacity is 'a shifting network of values and circumstances': Peter Margulies, 'Access, Correction and Voice: A Contextual Approach to Representing Senior Citizens of Questionable Capacity' (1994) 62 *Fordham Law Review* 1073, 1083.

<sup>72</sup> Pare, note 44, 108.

<sup>73</sup> *Ibid* 108-9.

<sup>74</sup> Glen, note 49, 96.

<sup>75</sup> *Ibid* 98.

<sup>76</sup> Nicholas Caivano, 'Conceptualizing Capacity: Interpreting Canada's Qualified Ratification of Article 12 of the UN Disability Rights Convention' (2014) 4(1) *Western Journal of Legal Studies* 1, 23-4; Glen, note 49, 93.

<sup>77</sup> As Quinn notes – even in the truly 'hard' cases (which he quantifies as 5% of cases), there 'should be an added obligation to divine the will if at all possible and create social embeddedness that allows some flash of the will to emerge': Gerard Quinn, *European Foundation Centre: Consortium on Human Rights and Disabilities*, An Ideas Paper 18 (June 4, 2009) available at [www.nuigalway.ie/cdlp/documents/events/EFCGQfinal.doc](http://www.nuigalway.ie/cdlp/documents/events/EFCGQfinal.doc).

<sup>78</sup> Gerard Quinn, *Rethinking Personhood: New Directions in Legal Capacity Law & Policy or How to Put the 'Shift' Back into 'Paradigm Shift'*, Paper Presented at the University of British Columbia, April 29, 2011, reprinted in NIU Galway Ctr. for Disability Law & Policy, Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence & Equality app. 5, at 44, available at [http://www.nuigalway.ie/cdlp/documents/cdlp\\_submission-on-legal-capacity-the-oireachtascommittee-onjusticedefenceand-equality\\_.pdf](http://www.nuigalway.ie/cdlp/documents/cdlp_submission-on-legal-capacity-the-oireachtascommittee-onjusticedefenceand-equality_.pdf).

been institutionalized and for whom the "mystic chords of memory" that connect them with family and acquaintances are shattered...

The issue of decision-making in the context of people with a disability must not be approached with the assumption that a person who lacks full capacity is not cognisant of their diminished capacity or choice as compared with other ordinary citizens. Rather, it is important to understand that increasing autonomy and control can increase capacity, capability and dignity, with the obvious corollary that reducing autonomy and control can result in an increased sense of helplessness, marginalisation, isolation and loss of control. It is recognised that the experience of sustained disempowerment and lack of autonomy can result in learned helplessness, or may translate into other behaviours such as outrage or physical violence. However, as noted above, learning decision-making processes and practicing exercising autonomy is a process, and one that is optimised where the person is supported to make decisions from the earliest opportunity. This is the case for all citizens, and while those with a disability may require support to understand and communicate their decisions, QAI's position is that the same process must be applied.

## Guardianship

The legal guardianship regime in most Western societies, including Australia, provides decision-making mechanisms for adults with intellectual disabilities.<sup>79</sup> In Queensland, the *Guardianship and Administration Act 2000* (Qld) (GAA) contains a comprehensive regime governing the appointment of guardians for persons with impaired capacity.<sup>80</sup> In Queensland, approximately 2,000 people are subject to guardianship and administration orders at any time.<sup>81</sup> The purpose of the GAA, as expressly stipulated by the Act, is to achieve balance between the right of an adult with impaired capacity to the 'greatest possible degree of autonomy in decision-making' and their right to 'adequate and appropriate support for decision-making'.<sup>82</sup> This is consistent with the sociological approach to autonomy discussed above.

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<sup>79</sup> Then, note 38, 133.

<sup>80</sup> See *Guardianship and Administration Act 2000* (Qld), Ch 3.

<sup>81</sup> As at 30 June 2012, there were 2,041 guardianship clients of the Adult Guardian: *Office of the Adult Guardian (Queensland) Annual Report 2012-2013*.

<sup>82</sup> *Guardianship and Administration Act 2000* (Qld), s 6.

However, there is a significant and concerning divergence between the contemporary sociological approach to decision-making, the legislative position and the policies and practices applied by those working within this area. A significant humanitarian concern is that the theoretical regime established by the GAA to achieve its stated purpose is not authentically translated into practice, both in terms of the circumstances in which guardians are appointed pursuant to the GAA and in the actions of those guardians to the persons then subject to their control. This can obviously have significant adverse consequences, including infringing the autonomy of, and determining or otherwise restricting the choices available to, people with a disability.

The disability rights movement, which has been a significant force in Australia and internationally, was responsible for the cognitive shift from the 'medical' to the 'social' model of disability.<sup>83</sup> Implicit in this shift was the understanding that restrictions experienced by people with disabilities were not necessarily innate or inevitable; rather, they were often socially or politically constructed and therefore subject to change.<sup>84</sup> Another relevant realisation brought about by the disability rights movement was the understanding that mental impairment was not necessarily static and unchangeable but that capabilities, such as decision-making capacity, could be developed with appropriate support and utilisation.<sup>85</sup> An associated development was the perspective that removing choice from an adult with impaired capacity (by placing the person under the guardianship regime where a substitute decision-maker was appointed) could lead to a 'vicious cycle of decline', where the individual, as a consequence of losing the opportunity to test his/her abilities and practice his/her decision-making powers, ultimately became more isolated and experienced a further decline in their capabilities and sense of competence.<sup>86</sup> As such, in theory at least, the appointment

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<sup>83</sup> Blanck, Peter David and Michael Millender, 'Before Disability Civil Rights: Civil War Pensions and the Politics of Disability in America' (2000) 52 *Alabama Law Review* 1, 3; Sarah Burningham, 'Adult Guardianship and Co-Decision-Making Law' (2009) 18 *Dalhousie Journal of Legal Studies* 119, 4.

<sup>84</sup> Luke Clements and Janet Read, 'Introduction: Life, Disability and the Pursuit of Human Rights' in Luke Clements and Janet Read (eds), *Disabled People and the Right to Life: The Protection and Violation of Disabled People's Most Basic Human Rights* (Routledge, 2008); Anna Lawson, 'The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?' (2007) 34 *Syracuse Journal of International Law & Commerce* 563; Then, note 9, 137;

<sup>85</sup> Robin Creyke, 'Who Can Decide? Legal Decision-Making for Others' (No 19, Department of Human Services and Health Aged and Community Care Division, September 1995), 38.

<sup>86</sup> Leslie Salzman, 'Rethinking Guardianship (Again): Substituted Decision-making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act' (2010) 81 *University of Colorado Law Review* 157, 168-70; A Kanter, 'The United Nations Convention on the Rights of Persons with Disabilities and its Implications for the Rights of Elderly People under International Law' (2008) 25 *Georgia State University Law Review* 527, 561; Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar of the Future' (2007) 34 *Syracuse Journal of International Law and Commerce* 429, 436-7; Then, note 38, 140.

of statutory officials, or adult guardians, is considered a measure of last resort.<sup>87</sup> This is a stance taken by disability rights advocates, including Bach, who likens a declaration of guardianship to a '[s]tate-sanctioned removal of personhood from an individual with respect to one or more or all areas of personal decision-making',<sup>88</sup> and Perlin, who characterises the imposition of guardianship as a form of 'civil death'.<sup>89</sup>

With respect to the small minority of people for whom guardianship orders are appropriate, QAI considers that the rights, will and preferences of the person should be the starting point and not just a consideration in the decision-making process of a substitute decision-maker.

## The NDIS

The introduction of the National Disability Insurance Scheme has been widely optimistically received as potentially bolstering autonomous choice for persons with an intellectual or cognitive impairment in all areas of life. When coupled with the guiding principles articulated by the CRPD, the intent and purpose of the NDIS is to proactively elevate a person with disability to full citizenship in all respects. Accordingly, while the NDIS facilitates a comprehensive program for the management of services available to people with a disability, it is intended as more than a mere funding stream to enable disabled people as consumers in a marketplace. Duffy and Williams assert that the NDIS must develop and maintain the following two things:<sup>90</sup>

1. A clear public account of what it means to be a citizen. It is only if we know what we mean by, and expect from, citizens that we can have any sensible conversation or research process to determine whether the NDIS is successful in its first goal: ensuring people get what they need to advance their life chances in support of citizenship.
2. Work hand in hand with people living with disability and their families to make sure the process feels respectful, effective and enabling at every stage. The NDIS process must be co-designed with people living with disability; but even more importantly for the future it must be accountable to them.

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<sup>87</sup> Then, note 38, 141; Lawrence Frolik, 'Plenary Guardianship: An Analysis, a Critique and a Proposal for Reform' (1981) 23 *Arizona Law Review* 599, 642-3..

<sup>88</sup> Michael Bach, Legal Capacity, *Personhood and Supported Decision-Making*, Canadian Association for Community Living (UN Enable Working Group, Jan 2006), <http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7ii3.ppt>.

<sup>89</sup> Michael L Perlin, "'Striking for the Guardians and Protectors of the Mind": The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law' (2013) 117 *Penn State Law Review* 1159, 1162.

<sup>90</sup> Simon Duffy and Robbi Williams, *The Road to NDIS: Lessons from England about Assessment and Planning* (JFA Purple Orange, 2012).

However, scholars such as Carney and Beaupert have raised concerns about the mechanisms associated with the appointment of a 'plan nominee', who is vested under the recently enacted *National Disability Insurance Scheme Act 2013* (Cth) with responsibility for representing the interests of the person with disability in drawing up their 'personal plan' - the crucial document serving to set down the very basis of their entitlements to support. They point to the concerns outlined in submissions to the Senate Committee which considered the draft Bill, which revolve around the fact that appointments will ultimately be made by the agency responsible for resourcing and realising the plan, which gives rise to the potential for a serious conflict of interest and also to the risk of 'undue paternalism in exercising the power of appointment', which is a discretionary power and involves understanding and articulating the preferences of the person they are representing.<sup>91</sup>

A purported rationale underpinning the introduction of the NDIS is to increase autonomy. As noted above, when considered in the context of the explicit purpose of the CRPD, a clear objective of the NDIS is to proactively elevate a person with disability to full citizenship in all respects. QAI's concern is that there are significant obstacles to increasing autonomy for people who exhibit behaviours of concern in circumstances where, under the current system, the autonomy of people without such behaviour is so severely curtailed. If we respond appropriately to the communications made by adults with a disability, we can potentially fulfil the stated objectives of the NDIS and also meet our obligations under the CRPD.

As will be discussed below, the Australian Government has developed the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector as an interim measure pending the development and implementation of a quality assurance and safeguards system for the use of Restrictive Practices by service providers under the NDIS. Accordingly, the future of Restrictive Practices under the NDIS remains to be seen.

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<sup>91</sup> Terry Carney and Fleur Beaupert, "Public and Private Bricolage – Challenges balancing law, services and civil society in advancing CRPD supported decision-making" (2013) 36 *University of New South Wales Law Journal* 175, 188-9.

## The value of informal supports

The importance of informal supports has been widely noted in the literature and documented as a critical consideration in discussions pertaining to law reform in this area.<sup>92</sup> A significant majority of Queenslanders who have impaired decision-making already have supporters who assist them in the decision-making process. Part of QAI's vision for normalising supported decision-making is to encourage informal supports and acknowledge the importance of this relationship, and to support informal supporters to conduct their support with morality that respects the dignity of risk and allows people with disability to make mistakes, to learn and to truly make their own decisions.

Due to the importance of informal supports in giving adults with diminished capacity a voice and supporting their autonomy, a core concern held by those concerned with disability welfare has been the practice, in jurisdictions such as Queensland, for informal support networks to be excluded by formal bureaucratic processes. French has noted that the Queensland Civil and Administrative Tribunal have a tendency to remove family members as formal guardians where there is reported conflict between the family member and service providers over service quality issues.<sup>93</sup> This is acutely concerning when the conflict concerns the use of Restrictive Practices and the Tribunal silences the informal advocate.

Article 19 of the CRPD, which recognises the equal right of all persons with disability to live independently and to be included in the community, has been described by the Council of Europe Commissioner for Human Rights as embodying 'a positive philosophy, which is about enabling people to live their lives to their fullest, within society'.<sup>94</sup> As Bach and Kerzner point out, it is difficult to see how a state can deliver on this right without engaging with the role of family (as well as the other people) insofar as this makes it possible for people with mental illness to live in the community.<sup>95</sup> Lemay argues that people with cognitive impairment, irrespective of their degree of disability, "are apt to do better in the community on most measures and do no worse when it comes to challenging behaviours" and that there are

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<sup>92</sup> See for example Carter Report, note 28, Victorian Law Reform Commission, *Guardianship Final Report*, Report No 24 (2012), ch 6; Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws*, Report No 49 (1996), 201.

<sup>93</sup> French, note 18.

<sup>94</sup> Commissioner for Human Rights, *The Right of Persons with Disabilities to Live Independently and be Included in the Community*, CommDH/Issue Paper (2012), 3 available at [www.commissionercoe.int](http://www.commissionercoe.int)

<sup>95</sup> Michael Bach and Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Law Commission of Ontario, 2010), 40.

many opportunities for individuals to build relationships and develop valued roles within the community. However, Lemay emphasises that for social integration to be achieved, it must be driven by a “deliberate and well-thought-out strategy”, with strong support from well-trained community-based services, as regards individuals with cognitive impairments.<sup>96</sup>

The CRPD recognises that people with disability operate in a relational context, with Article 12 requiring States Parties to recognise that people with disability enjoy legal capacity on an equal basis with others and to take appropriate measures to provide access by people with disability to the support they may require in exercising their legal capacity. Related rights, prescribed by Article 22 and 23 of the CRPD, protect the right to privacy and home and family of people with disabilities. Thus, the CRPD mandates a new approach based on supported decision-making, which recognises the importance of informal support networks. While the CRPD is yet to be given substantive weight in Australia, similar rights to respect for privacy and family life designated by the European Convention on Human Rights<sup>97</sup> have been instrumental in enhancing protections for individual rights, including the right of autonomy<sup>98</sup> and the right to physical and psychological integrity,<sup>99</sup> in member states and have contributed to the development of a more rights-based mental health law, as well as affording greater recognition to the role of family, both as a source of support and in its own right.<sup>100</sup>

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<sup>96</sup> Raymond LeMay, “Deinstitutionalization of People With Developmental Disabilities: A Review of the Literature” (2009) 28(1) *Canadian Journal of Community Mental Health* 181, 190.

<sup>97</sup> Article 8.

<sup>98</sup> In *Pretty v United Kingdom* (2002) 35 EHRR 1, para 61, the ECtHR found that ‘the notion of personal autonomy is an important principle underlying the interpretation of [ECHR] guarantees’.

<sup>99</sup> See *X and Y v the Netherlands* (1986) 8 EHRR 235; *Bensaid v United Kingdom* (2001) 33 EHRR 205; *YF v Turkey* (2004) 39 EHRR 34; *Storck v Germany* (2005) 42 EHRR 96.

<sup>100</sup> The European Court of Human Rights has recognised that the individual's right of privacy includes the individual's right to foster and develop relationships: *Niemietz v Germany* (1993) 16 EHRR 97; *Botta v Italy* (1998) 26 EHRR 241. In *Glass v United Kingdom*, the European Court of Human Rights found a breach of the right to physical integrity of a severely physically and mentally disabled 14-year-old boy by the implementation of medical decisions made about him without his mother's knowledge: (2004) 29 EHRR 341, at para 70. These included the provision of diomorphine and the placing of a do-not-resuscitate (DNR) order without parental consent/consultation. The European Court of Human Rights did not find that the mother's views should have determined the matter but rather, that she should have been consulted and that, given that objections had been raised by the mother, the authorisation of the court should have been obtained: Donnelley and Murray, note 79, 401-2.

## Part B – From ideology to lived experience: The use of restrictive practices for persons exhibiting behaviours of concern

### Legislative/policy position

The 2006 Carter Report, *Challenging Behaviour and Disability: A Targeted Response*, is considered the founding document for the present Restrictive Practices regime. The investigation culminating in this report was triggered by significant human rights abuses at Queensland centres.<sup>101</sup> Justice Carter was briefed to consider options for a targeted service response and to make recommendations for legislative reform designed to meet the needs of people with an intellectual or cognitive disability who exhibit behaviours of concern. The Carter Report noted the heavy reliance on RPs by many service providers, as well as the harm that can be caused by RPs, including human rights violations and physical and emotional harm, notwithstanding evidence of the efficacy of a positive behaviour support approach to address behaviours of concern. The Carter Report called for, among other things, the prohibition of practices recognised to result in inadequate outcomes for people with disability who exhibit behaviours of concern, including accommodation arrangements that are not chosen by the person with the disability and the grouping of people with behaviours of concern together.<sup>102</sup>

The Australian Government Department of Social Services has recently developed the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector*. Akin to the purported rationale for legislative amendments in Queensland, the Framework is theoretically designed to reduce the use of Restrictive Practices in disability services as an interim step in the transition to the regulation of RPs under the NDIS. While the introduction of the Framework, and a unified national approach to minimising the use of Restrictive Practices, is laudable, to date there has been no apparent change in the Restrictive Practices usage of many disability services providers. The translation of Framework policy into practice remains to be seen. The release of the Framework has not been accompanied by decisive practical measures, rigorous safeguards

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<sup>101</sup> Carter Report, note 28. See also Stewart Inquiry, note 28.

<sup>102</sup> Research has established the desirability of accommodating a person with behaviours of concern with tenants who do not exhibit such behaviours, rather than grouping persons with behaviours of concern together: Professor Eric Emerson, Professor of Disability of Health Research, Lancaster University, UK, cited by Carter, note 28.

or enforceable fetters on the powers of service providers to apply Restrictive Practices to those in their care. As such, without further development, its practical impact is questionable.

### **The Disability Services Act 2006 (Qld)**

In response to the Carter Report, the Queensland Government introduced the *Disability Services and Other Legislation Amendment Act 2008* (Qld), which amended the *Disability Services Act 2006* (Qld), and the *Guardianship and Administration Act 2000* (Qld). The enactment of the *Disability Services and Other Legislation Amendment Act 2008* (Qld) and the *Guardianship and Administration Act 2000* (Qld) raised the bar as regards the theoretical protection offered to those with a disability by providing greater regulation of the use of RPs for persons who exhibit behaviours of concern.

There have been two amendments pertaining to the use of RP's since the original legislation was drafted. The first extended the period for a short term approval – doubling its duration to six months. Most people would find the imposition of any restriction upon their person or life to be unendurable for one day, hence the extension of this period from three to six months is of significant concern. The other relevant amendment extends the immunity accorded to service providers, which is also of paramount concern, as discussed below.

The stated purpose of the most recent amendment legislation was to protect persons with an intellectual or cognitive impairment who are subject to the *Disability Services Act 2006* (Qld) by virtue of being a recipient of support services funded pursuant to the Act, by regulating the use of RPs on these adults by their Service Providers. However, the practical experience has been that this legislative framework has sanctioned the largely unfettered application of Restrictive Practices, providing immunity to service providers for actions that, but for the Restrictive Practices legislation, would be considered false imprisonment or assault in contravention of the criminal laws.

Part 6 of the *Disability Services Act 2006* (Qld), as amended, sets out the principles relevant to the use of Restrictive Practices on adults with impaired capacity. The legislation explicitly has as a core objective the reduction or elimination of the need for the use of RPs, as well as ensuring transparency and accountability in the use of RPs. Section 139 of the DSA provides as follows:

The purpose of this part is to protect the rights of adults with an intellectual or cognitive disability by –

- a) stating principles to be taken into account by funded service providers in providing disability services to those adults *who exhibit (our emphasis) behaviour that causes harm to themselves or others*; and
- b) regulating the use of restrictive practices by funded service providers in relation to those adults in a way that –
  - (i) has regard to the human rights of those adults; and
  - (ii) safeguards them and others from harm; and
  - (iii) maximises the opportunity for positive outcomes and aims to reduce or eliminate the need for use of the restrictive practices; and
  - (iv) ensures transparency and accountability in the use of the restrictive practices.

The procedures proscribed by the *Disability Services Act 2006* (Qld) to be followed before a RP is used include assessment of the adult, with the significant and concerning exceptions of short-term approvals<sup>103</sup> or where the RP is implemented in the course of providing respite services or community access services to the adult.<sup>104</sup>

The Act also requires establishment of a positive behaviour support plan and approval of the RP by the relevant decision-maker,<sup>105</sup> which is only to be provided where it is shown that, firstly, the RP is necessary to prevent the person causing harm to themselves or others; and secondly, that it is the least restrictive way of doing so.

Underpinning Part 6 (and the entire *Disability Services Act 2006* (Qld)) is the principle that people with a disability have the same human rights as others, and specific reference is made to this requirement in implementing any RPs.<sup>106</sup> However, as noted by commentators such as French, the drafting of the legislation insofar as human rights principles are concerned is declaratory only – there are no operative provisions that pragmatically translate this broad statement into practice, nor are any of the other human rights contained in the CRPD, or more generally in international law, recognised or incorporated.<sup>107</sup> This is significant when we understand that in Queensland, human rights are not formally recognised at law.<sup>108</sup>

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<sup>103</sup> Given the fundamental infringement of a person's human rights brought about by application of a RP, it is inappropriate to sanction waiver of the requirement for approval in the case of short-term approvals, which constitute significant periods of time having regard to the nature of RPs.

<sup>104</sup> See s 148 of the *Disability Services Act 2006* (Qld).

<sup>105</sup> See s 143 of the *Disability Services Act 2006* (Qld). This differs according to the type of RP.

<sup>106</sup> Sections 17 and 18 of the *Disability Services Act 2006* (Qld) promote and prescribes the human rights principle.

<sup>107</sup> French, note 18, 9.

<sup>108</sup> *Ibid* 15.

The stated objective of the Queensland legislative regime is to regulate the use of RPs and only sanction their application as a last resort and in the least restrictive manner, thus reducing and eliminating the use of RPs. However, as French points out, the legislation fails to prescribe any substantive safeguards against the use of RPs, leaving only procedural safeguards, which are akin to no tangible safeguards at all in this context.<sup>109</sup> French states:<sup>110</sup>

In my view, at the very least, the legislation ought to have prohibited any conduct or practice that causes pain or discomfort, or that intimidates or humiliates a person, or which is utilised to seclude a person, to physically restrain a person, or to punish a person in relation to their behaviour.

The new amendments also provide time-limited immunity from criminal and civil liability for services providers implementing Restrictive Practices, provided they acted honestly and without negligence, where there are delays in deciding an approval or consent.<sup>111</sup> This is a broad protection that essentially authorises actions that would otherwise amount to a contravention of the criminal law (for example, false imprisonment, assault). Prior to the introduction of the immunity provision, service providers were adequately protected by the common law doctrine of necessity and by workplace health and safety legislation.

QAI asserts that the amendments that extended the duration of a short term approval and extended immunity provisions to service providers have not only weakened the intended protections to vulnerable people with disability but have sanctioned the violation of human rights and exerted unreasonable domination, ownership and control over such people.

While the legislative amendments that came into effect on 1 July 2014 offer little promise of substantive improvement in this area, the requirement that disability service providers report to the Department on the use of Restrictive Practices is encouraging, as there has previously been a lack of accountability with respect to the use of RPs. The requirement that information on the use of RPs be provided to the Chief Executive extends the accountability of service providers beyond the pre-amendment threshold of simply requiring that records of the use of RPs be kept.<sup>112</sup> The prioritisation of the amendments pertaining to safeguards for people with disability who are subject to Restrictive Practices is a telling factor. There appears to be no impetus driving the development of strategies to ensure that the application of RP is avoided,

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<sup>109</sup> Ibid 12.

<sup>110</sup> Ibid 12.

<sup>111</sup> See s 189 *Disability Services Act 2006* (Qld).

<sup>112</sup> Section 123ZZE of the *Disability Services Act 2006* (Qld).

nor is there any mention of the implementation of monitoring or other conditions by which service providers can be held accountable for applying RPs.

The use of RPs is a fundamental infringement on the human rights of a person, and therefore it is critical that there are strong safeguards put in place to ensure any decisions taken with respect to the application of RPs are transparent and open to independent scrutiny and advocacy, as well as being reviewable by an independent body.

It is also important that the reporting and data collection obligations be accompanied by provision for mandatory training of service providers and staff who fail to meet the objective of reducing or eliminating the use of Restrictive Practices, and ultimately removal of those staff in the case of continued failure to comply with the targeted reduction.

The Department of Communities, Child Safety and Disability Services has advised:<sup>113</sup>

The Amendment Act... introduces a power for the Department to require reporting on the use of restrictive practices. However, the Department is undertaking a staged collaborative launch of reporting, and will work with a small number of service providers to test reporting process and framework before the larger roll out and communication of reporting to the sector. Service providers will not need to report until a Regulation under the Act has been made prescribing reporting requirements and timeframes.

The Department further advises that the likely timeframe for mandated reporting will be early 2015 which, in light of the immediacy of the introduction of other amendments, is perhaps indicative of the prioritisation of monitoring and minimising the use of RPs.

### **Anti-discrimination law**

Another area of the law that offers statutory protection to people with disabilities which is potentially enlivened by the use of RPs is the anti-discrimination jurisdiction.

The use of Restrictive Practices is potentially in contravention of the statutory prohibition of discrimination that exists in Queensland, federally and also as recognised under international law, as it authorises the application of practices and treatment on people with a disability that would be unlawful if done to others without the disability. As French notes, the Restrictive

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<sup>113</sup> Notification from Mary-Ellen Lane on behalf of Clare O'Connor of the Department of Communities, Child Safety and Disability Services, entitled: 'Commencement of Reforms to the Restrictive Practices Framework', 26 June 2014.

Practices regime essentially authorises the performance of acts and practices on people with a disability that are unlawful under criminal and civil law (for example, assault, battery and deprivation of liberty).<sup>114</sup>

However, critics have noted a number of endemic weaknesses of anti-discrimination law, chiefly the individualist approach taken; the focus on formal, rather than substantive equality; the focus on negative, as opposed to positive or affirmative, action; and the lack of effective remedies or sanctions.<sup>115</sup> It is often considered a blunt tool to assist those aggrieved by discriminatory treatment. In the context of this understanding of the present efficacy of the anti-discrimination law jurisdiction, it is perhaps unsurprising that anti-discrimination law has not been coveted as providing an effective defence against the use of Restrictive Practices, despite the arguable case that the use of RPs is in contravention of anti-discrimination law. This is particularly so in the context of an understanding of the vulnerability and disempowerment inherent in the experience of an intellectual or cognitive disability, both for the person and their family.

### International law – CRPD rights and requirements

The CRPD stipulates that people with disability are to be accorded the same rights and respect as persons without disability. Additionally, given the vulnerability of this group, it is important that additional safeguards are put into place to protect their rights, particularly in circumstances where they may be subject to practices that infringe their human rights. As noted above, in an endeavour to achieve these ends the CRPD recognises a number of core human rights that are particularly relevant for people with disability, and focusses them so that they are applicable to the situations in which the human rights of persons with a disability may be infringed.

The CRPD rights that are presently relevant include:

- Article 14, which concerns the rights to liberty and security – this requires both that people with disability have these positive rights and also that they are not deprived of their liberty unlawfully or arbitrarily;

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<sup>114</sup> French, note 18, 11.

<sup>115</sup> See Margaret Thornton, *The Liberal Promise: Anti-Discrimination Legislation in Australia* (Oxford University Press, 1990) for an excellent discussion of these issues that remains authoritative.

- Article 15, which pertains to the right to liberty and security of person, and requires that people with disability are not deprived of their liberty unlawfully or arbitrarily;
- Article 16, which relates to the rights to freedom from exploitation, violence and abuse, both within and outside the home;
- Article 17, which concerns protection of the physical and mental integrity of the person;
- Article 18, which relates to liberty of movement and encompasses freedom for people with disability to choose their place of residence;
- Article 19, which pertains to living independently and being included in the community – this requires that people with disability have the opportunity to choose their place of residence and where and with whom they live, and may not be forced into particular living arrangements;
- Article 22, which pertains to respect for privacy in relation to correspondence or other types of communication or to unlawful attacks on a person’s honour and reputation; and
- Article 23, which relates to discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships
- Article 26, which covers the habilitation and rehabilitation of people with disabilities with a view to ensuring persons with disabilities are able to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

As the CRPD is not itself incorporated into Australian law, it is not enforceable pursuant to its provisions.<sup>116</sup> However, the terms of the Convention relevant to a human right can be considered in interpreting the relevant legislation.<sup>117</sup> Accordingly, the CRPD has practical relevance as establishing the applicable human rights standards or benchmarks in interpreting the relevant Australian laws pertaining to the use of RPs for persons with disability who exhibit behaviours of concern.

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<sup>116</sup> It has been well established in Australia that ratification or accession to an international treaty does not, of itself incorporate the terms of the treaty into Australian law; this requires the Australian Parliament to specifically legislate to incorporate the obligation: *Minister of State for Immigration & Ethnic Affairs v Ah Hin Teoh* [1985] HCA 20.

<sup>117</sup> See s 32(2) of the Charter; *Minister of State for Immigration & Ethnic Affairs v Ah Hin Teoh* [1985] HCA 20.

A report to the UN General Assembly by the Special Rapporteur of the Human Rights Council on torture and other cruel, inhuman and degrading treatment or punishment that focusses extensively on violence and abuse of persons with disability, calls for its reframing as torture and ill-treatment (specifically referring to restraint and seclusion).<sup>118</sup>

French and associates note the important implications of the CRPD rights to equality and non-discrimination for the regulation of RPs and compulsory treatment, as follows:<sup>119</sup>

Essentially, they will not permit treatment of persons with disability differently to other persons, except where this treatment is a positive measure designed to overcome pre-existing disadvantage, or a reasonable accommodation designed to ensure that human rights and fundamental freedoms may be exercised on an equal basis with others. For persons who have behaviours of concern, this may require substantial positive measures, such as the provision of appropriate accommodation and adequate skilled support staff to assist the person to realize their positive development potential.

QAI asserts that proactive assistance should include habilitation, education, training and enriching life experiences.

Similarly, the CRPD rights to inclusion and participation, as well as the related rights to liberty and freedom of movement, provide a lawful basis for the state to ensure persons with disability are enabled to live independently in the community with choices equal to others with the supports they require to achieve this, and to enjoy personal mobility with the greatest possible independence.<sup>120</sup>

## The significant disparity between statutory position and normative practice

As noted above, the legislative framework for the use of RPs in Queensland provides some theoretical safeguards, although it is less than ideal for the reasons outlined. In this context, it is of significant concern that the present experience in Queensland is that the principles identified in the *Disability Services Act 2006* (Qld) and the *Guardianship and Administration*

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<sup>118</sup> United Nations General Assembly, *Torture and other cruel, inhuman or degrading treatment or punishment; Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/63/175, [37] – [76]; French, Chan and Carracher, note 1, 246.

<sup>119</sup> French, Chan and Carracher, note 1, 265.

<sup>120</sup> Article 19 and 20 of the CRPD; French, Chan and Carracher, note 1, 265.

*Act 2000* (Qld) with respect to RPs do not align with the practical reality of the use of RPs on adults with impaired capacity. As French and associates assert:<sup>121</sup>

Although human rights in their original formulation have always applied to persons with disability on the same basis as they have applied to others, in reality these rights have largely failed to penetrate to the principal sites of human rights violation experienced by persons with disability. Even where human rights discourse and practice have penetrated to some degree, it is strongly arguable that implementation efforts have not been sufficiently precise, or sufficiently potent, to enliven the full beneficial content of key human rights.

French and associates outline intersecting reasons that are typically proposed to account for this problem:<sup>122</sup>

1. The invisibility of persons with disability within human rights discourse (it is argued that there has been a failure to substantially recognize persons with disability as right-bearers, and a tendency to view the needs and concerns of persons with disability in terms of social development and population health rather than in terms of human rights);
2. The somewhat abstract and general nature of the traditional formulation of some key human rights has created difficulties in the application of these rights with certainty to specific violations more likely to be, or uniquely, experienced by persons with disability; and
3. A lack of disability-related experience and expertise in human rights protection and implementation agencies.

They note that these problems have been particularly acute in relation to persons with cognitive impairment who engage in behaviours of concern.<sup>123</sup>

There is also compelling anecdotal evidence of the use, and excessive use, of Restrictive Practices on people with an intellectual or cognitive impairment based on past stereotypes of the person's behaviour without any, or any adequate, assessment of the efficacy of the use of RPs (including the escalation of the behaviour following the use of RPs).

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<sup>121</sup> French, Chan and Carracher, note 1, 245.

<sup>122</sup> *Ibid* 245-6.

<sup>123</sup> *Ibid*.

There is also literature linking frequency of use of restraints with the practices of the care provider.<sup>124</sup> This is associated with the documented lack of disability-related experience and expertise on the part of human rights protection and implementation agencies, particularly in relation to persons with cognitive impairment who engage in behaviours of concern.<sup>125</sup> This issue is strongly associated with the lack of choice frequently experienced by people with intellectual disability in terms of their accommodation arrangements. As noted above, despite the deinstitutionalisation movement, many people with intellectual disabilities are not accorded respect and autonomy as regards their housing preferences. QAI considers any grouping of people with disability that is not clearly of their own choosing is in breach of the CRPD, as well as in defiance of cultural norms. Forced accommodation that is not in accordance with a person's preference can result in domestic violence and this is unsurprising, as choice with respect to whom we live with is a fundamental human right. This observation is applicable to all people denied their liberty to choose their accommodation arrangements, not only people with disability.

The significant disparity between legislative position and practice is not unique to Queensland; as Surtees notes in the context of Saskatchewan, Canada: 'The principles were never the problem. The inappropriate application of the blunt tool of guardianship was the problem.'<sup>126</sup>

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<sup>124</sup> Day, Daffern and Simmons, note 9, 242-3.

<sup>125</sup> French, Chan and Carracher, note 1, 246.

<sup>126</sup> Doug Surtees, 'The Evolution of Co-Decision-Making in Saskatchewan' (2010) 73 *Saskatchewan Law Review* 75, 85.

## **Part C – Moving forwards: Operationalising autonomy in the real world of disability in a way that returns respect and control to marginalised people**

### **Changing mindsets**

#### **Mindsets and preconceptions as a barrier to progress**

A significant factor leading to sub-optimal treatment of people with a disability is that of mindsets and preconceptions. This is an issue that is relevant to the entire trajectory, from the initial interaction between a person with a disability and a service provider to the application of a Restrictive Practice. It is also a pertinent issue for those not subjected to RPs, as the mindsets of those with power to impact upon the lives of people with a disability have a significant impact upon the autonomy and citizenship of all of those subject to the disability services and guardianship statutory scheme. As the United Nations has noted, disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.<sup>127</sup>

The language used when describing people with disabilities is also problematic and in need of change. This is exemplified in the case of people with an intellectual or cognitive disability who exhibit what is commonly termed ‘challenging behaviours’, where the label itself can function as the basis for negative stereotyping and labelling, and a conflation of the person and their behaviour, rather than development of a sensitive response aimed at understanding the attempted communication. By addressing the language used in talking to and discussing people with disability, we can mitigate a tendency to prejudicial reactions that are reflected in our own behaviours. When actively and attentively listening to the person we can avoid adding to angst for the person and enable an appropriate response to be provided.

QAI comes from a Social Role Valorization perspective. This viewpoint was formulated by Wolf Wolfensberger in 1983 and was most recently defined by him as: ‘[t]he application of

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<sup>127</sup> Preamble to the *Convention on the Rights of Persons with Disabilities*, United Nations, 2006.

what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defence of valued social roles for people'.<sup>128</sup> Wolfensberger explains:<sup>129</sup>

Social roles dominate people's lives, and people largely perceive themselves and each other in terms of their roles. The value people attribute to various social roles tends to decisively shape their behaviour toward persons whom they see in valued or devalued roles. Those in valued roles tend to be treated well and those in devalued roles, ill... social role theory can be recruited for designing very powerful practical measures to pursue valued roles for mentally retarded and other persons or classes at risk of social or even societal devaluation, to upgrade the perceived value of the roles such persons already occupy, and/or to extricate such persons from devalued roles.

Osburn contends that the major goal of SRV is to create or support 'socially valued roles' for people within society, as this is considered to result in the opportunity to obtain the goods society has to offer.<sup>130</sup> Osburn explains:<sup>131</sup>

[A]ll sorts of good things that other people are able to convey are almost automatically apt to be accorded to a person who holds societally valued roles, at least within the resources and norms of his/her society.

There exists a high degree of consensus about what the good things in life are. To mention only a few major examples, they include home and family; friendship; being accorded dignity, respect, acceptance; a sense of belonging; an education, and the development and exercise of one's capacities; a voice in the affairs of one's community and society; opportunities to participate; a decent material standard of living; an at least normative place to live; and opportunities for work and self-support.

Social Role Valorization theory has had a significant impact in the development of policies and procedures that protect and advocate for those receiving disability services in Australia.<sup>132</sup>

## Stigma

Historically, there have been negative connotations associated with mental illness that have created a stigma about mental illness, and also generated a correlation between mental illness and a predisposition to violence.<sup>133</sup>

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<sup>128</sup> W Wolfensberger, *The SRV training package* (Unpublished manuscript, 1995).

<sup>129</sup> W Wolfensberger, 'A Brief Overview of Social Role Valorization' (2000) 38(2) *Mental Retardation* 105.

<sup>130</sup> Joe Osburn, 'Overview of Social Role Valorization Theory' (1998) 3(1) *The International Social Role Valorization Journal/La revue internationale de la Valorisation des roles sociaux* 7.

<sup>131</sup> Ibid.

<sup>132</sup> Ibid.

Similarly, there has also been significant stigma associated with intellectual disability, as Caivano notes:<sup>134</sup>

People with disabilities, particularly those with intellectual and psychosocial disabilities, have long been subject to limitations on their right to legal capacity. They have endured arbitrary detention and have been deprived of access to basic health interventions. They have faced cruel, inhumane, and degrading treatment, including physical abuse, confinement in squalid institutions, and subjection to restraint and seclusion. Due to stigma and discrimination, people with disabilities in many parts of the world continue to be deprived of legal capacity despite being able to make and communicate decisions, either by themselves or with support.

At times, mental illness and intellectual disability have been conflated, including by those in positions of power, with the unacceptable result that people with intellectual disability have been inappropriately institutionalised in mental health facilities.

While this stigma has been substantially overcome in recent decades, enduring effects of these stereotypes and prejudices remain and have a significant effect on the day-to-day lives of people with intellectual disability.

### **Power and disempowerment**

The difficulty of changing mindsets is enhanced by virtue of the fact that the group of persons concerned are vulnerable, marginalised and disempowered. They are side-lined, individually and collectively, from the legal, political and bureaucratic processes that have such a significant impact on their day-to-day lives.<sup>135</sup> They are not given a voice in many decisions that relate to their fundamental rights, including where and with whom they live.

### **The need for a shift in mindset**

Accordingly, QAI's perspective is that a change in mindset is required to deconstruct not only the relevant legislative scheme,<sup>136</sup> but just as importantly the mindset of Disability Services Queensland and service provision systems and thus enable the CRPD and NDIS to be given an authentic voice on behalf of people with an intellectual or cognitive disability. This cultural

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<sup>133</sup> Salzman, note 101, 286.

<sup>134</sup> Caivano, note 59, 2-3.

<sup>135</sup> The metaphor of regulatory space developed by Hancher and Moran, as developed by Freeman and Rossi, is a useful framework for understanding the complexity of the impact of the law and regulatory factors in the disabilities context: see Leigh Hancher and Michael Moran, 'Organizing Regulatory Space' in Leigh Hancher and Michael Moran (eds), *Capitalism, Culture, and Economic Regulation* (Clarendon Press, 1989), 276 and Jody Freeman and Jim Rossi, 'Agency Coordination in Shared Regulatory Space' (forthcoming 2012) *Harvard Law Review* 125.

<sup>136</sup> Relevantly, the GAA and DSA (RP legislation).

shift is not merely about consumerism and marketplace choices, but more fundamentally about elevating the status of those with a disability to citizenship and autonomy – a shift from a model of disempowerment to a model of enablement and positive rights. In this regard, QAI endorses the sentiments of Pare when she states:<sup>137</sup>

Vulnerability exists, but it does not have to be a label that enhances marginalization, ignores rights or demands paternalistic measures. Vulnerability can and should be addressed while still respecting dignity and autonomy.

Salzman notes that there is both a judicial and social tendency to ‘more readily provide accommodations needed to overcome barriers to physical disabilities than those needed to overcome barriers to mental disabilities’.<sup>138</sup> While this point is made in the American context, it is equally applicable to Australian society. She explains:<sup>139</sup>

While all persons with disabilities continue to confront barriers to integration and participation, as a society we seem better able to grasp the barriers affecting persons with physical and sensory impairments such as impassable stairs or printed materials and the accommodations needed to overcome them, such as ramps, elevators or talking computers. We are less adept at understanding the barriers affecting individuals with mental disabilities, such as the need for assistance with decision-making, and the precise nature and appropriate contours of the support needed to overcome these barriers. Unless we are going to exclude persons with mental disabilities from many of the benefits of our disability discrimination laws, however, it is necessary to reconsider the failure to provide accommodations such as support with decision making. Just as we don't carry a person up the stairs but provide assistance so that she can overcome that barrier on her own, we should not assign an individual with limitations in decision-making abilities a guardian to make decisions for her, but should provide decision-making support so that she can make her own decisions whenever possible.

Lord and Stein, drawing upon the well-known scholarship of Kuhn pertaining to paradigm shifts, note the power of changes in law to significantly impact upon mindsets in a particular area. In the context of the international humanitarian reforms brought about by the CRPD, they assert:<sup>140</sup>

Human rights norms have power to work change through non-legal mechanisms.... [They] trigger belief changes by providing information to societies about the human

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<sup>137</sup> Pare, note 44, 125.

<sup>138</sup> Ibid 285.

<sup>139</sup> Ibid.

<sup>140</sup> Janet E Lord & Michael Ashley Stein, ‘The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities’ (2008) 83 *Washington Law Review* 449, 474-75.

rights ideas with the attendant effect of serving as educational tools for altering social mores.

As Glen notes, paradigmatic shifts are typically accompanied by disbelief and resistance.<sup>141</sup>

## Conclusion

French and associates enthusiastically welcomed the ratification by Australia of the CRPD in 2008 and the enactment of progressive legislation, stating:<sup>142</sup>

The normative basis for clinical practice and service delivery in relation to persons with disability who engage in behaviours of concern is set to change substantially as human rights standards are more vigorously and more intelligently applied in this area. This will require clinicians and providers to develop the knowledge, skills, and tools necessary to recognize the human rights implications of their work, and to interpret and effectively apply human rights.

French and associates made this optimistic statement in 2010. While the progressive theoretical paradigm shift cannot be questioned, we are yet to see the shift in practice (which is the move that will affect the reality of the lives of those persons with a disability who are subject to Restrictive Practices). It is discouraging that the human rights of those who do not exhibit behaviours of concern are not adequately protected; this presently leaves little hope for improvement in the treatment of those who are reputed to exhibit behaviours of concern. However, with the introduction of the NDIS, we can only hope that French and associates' expectation for significant, positive change in the disabilities context will be realised.

It is important that support for vulnerable people with disability (including those purported to communicate at times in unique and possibly challenging ways) is viewed in the same context as the interdependency of societal norms. In the words of Cox:

In a civil society, we need to recognise the supreme importance of social connections which include plenty of robust goodwill to sustain difference and debate. This possibility exists within Australia today, but we risk squandering it in our search for illusory economic development...

I want to question some too common assumptions, challenge many beliefs seen as truths, and recast some old ideas which have fallen out of fashion. I want to persuade those in high places to recognise that we are social beings.<sup>143</sup>

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<sup>141</sup> Glen, note 49, 99.

<sup>142</sup> In Victoria, the Victorian Charter of Human Rights and Responsibilities as well as amendments to the *Disability Services Act 2006* (Vic), in Queensland the *Disability Services and Other Legislation Amendment Act 2008* (Qld) and the *Guardianship and Administration Act 2000* (Qld): French, Chan and Carracher, note 1, 265.

By the present status quo, people who exhibit behaviours of concern are cast into a negative stereotype, as 'deviant', 'uncontrollable', 'difficult', 'unmanageable' people who need to be subject to restraint. The unconscious perpetuation of such adverse stereotypes results in lower expectations of and for people with disability and therefore inhibits the potential of such people.

The evidence indicates that the application of chemical restraint is ineffective in managing the perceived behaviours of concern and that the use of physical restraint is equally ineffective and can indeed act as a catalyst for escalation of behaviours indicating distress, aversion and or duress.

When the approach is changed, by empowerment, enablement and ensuring a person with a disability is scaffolded by support from the right relationships, the perspective on that person can change from a negative to a positive one and their status can be elevated to equal citizenship. When perceptions and expectations are changed, our approaches, behaviours and responses also implicitly change. When we remove the burdens we place upon people, they can flourish and respond accordingly.

When an approach of respect, autonomy and enablement is integrated with the practical safeguards required by people with a disability, in terms of their supports and assistance from right relationships, we return control and respect to marginalised people and reduce or remove the use of Restrictive Practices.

QAI asserts that the use of Restrictive Practices is a violation of human rights on the grounds that such treatment, if applied as a societal norm would not be tolerated and would be viewed as criminal conduct. It is discriminatory, cruel, inhuman and degrading treatment that must be ceased.

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<sup>143</sup> Eva Cox, *Broadening the Views*, The 1995 Boyer Lectures: A Truly Civil Society.

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