



THE UNIVERSITY OF  
**SYDNEY**

# **Sydney Law School**

Legal Studies Research Paper  
No. 13/52

July 2013

## **Public and Private Bricolage – Challenges Balancing Law, Services & Civil Society in Advancing CRPD Supported Decision Making**

Terry Carney & Fleur Beupert

This paper can be downloaded without charge from the  
Social Science Research Network Electronic Library  
at: <http://ssrn.com/abstract=2284552>.

## PUBLIC AND PRIVATE BRICOLAGE – CHALLENGES BALANCING LAW, SERVICES AND CIVIL SOCIETY IN ADVANCING *CRPD* SUPPORTED DECISION-MAKING

TERRY CARNEY\* AND FLEUR BEAUPERT\*\*

### I INTRODUCTION

The balance between public law, private law and civil society has long attracted interest. As state or public functions have contracted in recent decades, much recent scholarly attention has been devoted to the erosion of public accountability associated with neoliberal ‘contracting-out’ of formerly government delivered services or responsibilities (often termed new public management or ‘NPM’).<sup>1</sup> The resultant exclusion of access to public law remedies to correct abuses of services or functions now discharged by so-called ‘third-party’ providers is one such long-standing concern,<sup>2</sup> but even basic data collection of key performance indicators was found to be problematic in a public mental health study conducted in Western Australia, due to undue devolution and fragmentation of administration.<sup>3</sup> Another illustrative concern in the literature is the trade-off between expansion of individual autonomy at the price of having sufficiently robust individual capacity to exercise and enjoy meaningful choices

---

\* Emeritus Professor of Law, University of Sydney Law School.

\*\* Independent Researcher, Sydney. The authors acknowledge the constructive contributions of three anonymous referees.

- 1 Peter Vincent-Jones, ‘Contractual Governance: Institutional and Organizational Analysis’ (2000) 20 *Oxford Journal of Legal Studies* 317. For its application to labour market matching services for the unemployed, see Terry Carney and Gaby Ramia, *From Rights to Management: Contract, New Public Management and Employment Services* (Kluwer Law International, 2002); for its application in social security, see Terry Carney, ‘Neoliberal Welfare Reform and “Rights” Compliance Under Australian Social Security Law’ (2006) 12(1) *Australian Journal of Human Rights* 223.
- 2 Avishai Benish and David Levi-Faur, ‘New Forms of Administrative Law in the Age of Third-Party Government’ (2012) 90 *Public Administration* 886; Rachel Bacon, ‘Rewriting the Social Contract? The SSAT, the AAT and the Contracting Out of Employment Services’ (2002) 30 *Federal Law Review* 39; Felix Hoehn, ‘Privatization and the Boundaries of Judicial Review’ (2011) 54(1) *Canadian Public Administration* 73; Michele Gilman, ‘Legal Accountability in an Era of Privatized Welfare’ (2001) 89 *California Law Review* 569; Matthew Diller, ‘The Revolution in Welfare Administration: Rules, Discretion and Entrepreneurial Government’ (2000) 75 *New York University Law Review* 1121.
- 3 Donnel Holloway et al, ‘Performance Management in Australia’s Public Mental Health Service: A State Based Perspective’ (2012) 71 *Australian Journal of Public Administration* 20.

as the presumed ‘prudential citizen’,<sup>4</sup> where paradoxically the expanded space for exercise of autonomous citizenship rights may also increase the risk of state intervention, such as in adult protection.<sup>5</sup>

Without diminishing the importance of these well-established scholarly debates, there is another less-studied phenomenon which uncomfortably straddles the macro level of governance and the micro level of individual citizen relations. ‘Supported decision-making’, as a novel legal institutional form, raises important new questions about the ‘boundaries’ between public and private law.<sup>6</sup> The peculiar features of the diverse range of options currently considered to fall within this category, however, are arguably best captured in their entirety by the messier conception of institutional ‘bricolage’ – where whatever is at hand is drawn on to create hybrid legal and normative forms from otherwise *incompatible* or ill-fitting elements.<sup>7</sup> The construction of supported decision-making arrangements to relieve or replace traditional forms of adult guardianship is, it will be suggested, illustrative of these new challenges about what type of law or normative arrangement is optimal, because strange assortments of familiar forms of public and private law are being joined with soft law, purely ‘educative’ law, facilitated ‘private-arranging’ and a spectrum of extra-legal normative influences. These are being combined in various ways in different jurisdictions across the world in order to promote a much-lauded goal enshrined in the *United Nations Convention on the Rights of Persons with Disabilities* (‘CRPD’).<sup>8</sup> But like a young child’s pocketful of melted lollies on a hot summer’s day, the

---

4 For a discussion of these issues in the context of differences between Scottish and English mental health law, see Kathryn Mackay, ‘Compounding Conditional Citizenship: To What Extent Does Scottish and English Mental Health Law Increase or Diminish Citizenship?’ (2011) 41 *British Journal of Social Work* 931, where it was concluded that the Scottish legislation ‘can be seen as supporting a model of citizenship that achieves a better balance between the ethic of care and the ethic of justice by holding practitioners to greater account and providing more individual rights. As a result, it should lead to less compounding of conditional citizenship’: at 944.

5 Writing about Scottish powers of intervention based on the risk of harm to a vulnerable adult, Stewart and Atkinson suggest:

Therefore, those individuals who are citizens, in a legal sense, but who fail to act as citizens, are more likely to be subject to statutory interventions focused on protection. Is it the limited or fragile citizenship, or the overall vulnerability/requirement for protection, which makes their citizenship fragile and that consequently compromises their ability to meet the conditions of active citizenship, which makes intervention more likely?

Ailsa Stewart and Jacqueline Atkinson, ‘Citizenship and Adult Protection in the UK: An Exploration of the Conceptual Links’ (2012) 14 *Journal of Adult Protection* 163, 171.

6 The use of the terms public and private is for convenience, rather than as an endorsement of a much criticised heuristic distinction. See also Anna Grear, ‘Theorising the Rainbow? The Puzzle of the Public-Private Divide’ (2003) 9 *Res Publica* 169. For a recent treatment of the way private law doctrine might be invoked to provide redress for informal carers, see especially Brian Sloan, *Informal Carers and Private Law* (Hart Publishing, 2012) ch 1.

7 See, eg, Kanishka Jayasuriya, ‘Institutional Hybrids and the Rule of Law as a Regulatory Project’ in Brian Tamanaha, Caroline Sage and Michael Woolcock (eds), *Legal Pluralism and Development: Dialogues for Success* (Cambridge University Press, 2011) 145; Christopher Skelcher, ‘What Do We Mean When We Talk About “Hybrids” and “Hybridity” in Public Management and Governance?’ (Working Paper, Institute of Local Government Studies, University of Birmingham, 2012).

8 Opened for signature 30 March 1997, [2008] ATS 12 (entered into force 3 May 2008)

bricolage of remnant delights presents both taxonomic and culinary challenges. For example, law may be infiltrating relationships better left outside its sphere, or conversely its contribution may be being overlooked; and the innovative private, public and hybrid forms of law deployed may or may not be being correctly entertained or critically reviewed. Such questions do not lend themselves well to normative analysis alone, since they involve assessing what ‘works’, whether intended goals are achieved and to what degree, and at what anticipated or unanticipated cost to other interests. This is the evidence-based focus and larger canvas on which the present exploratory article is painted.

The article explores some of the issues involved in developing supported decision-making and other measures to replace or work alongside Australia’s current system of adult guardianship under state and territory laws; a system which has valiantly sought to shake off its paternalist philosophy from Roman law and 13<sup>th</sup> century prerogatives of chancery,<sup>9</sup> but which is disfavoured under the *CRPD*. Even so, views about the new institution of supported decision-making are mixed. Kohn, Blumenthal and Campbell observe that:

Supported decision-making holds promise both as an alternative to guardianship and as an element of the guardian–ward relationship. If it empowers persons with cognitive and intellectual disabilities to make decisions for themselves, as advocates of supported decision-making claim, it has the potential to advance the interests and human rights of persons with disabilities. However, without more evidence as to how supported decision-making functions in practice, *it is too early to rule out the possibility that it may frequently have the opposite effect.*<sup>10</sup>

And as the South Australian Public Advocate John Brayley explains, it is not only law which needs to be considered, since:

The minimisation of guardianship not only depends on supported decision-making reform, but reform to our service systems, so that they are based on true personalisation and choice, reform to our adult protection systems so that they provide a right to safety rather than a welfare response, and a commitment to overcome inequity and discrimination.<sup>11</sup>

All laws and other normative or distributive policies have disadvantages as well as advantages, however. And no law or policy can properly be assessed in isolation from its social context or place within formal and informal systems of governance and social interaction. So we should not be surprised by the remarks in these two quotations. Yet, under the *CRPD*, supported decision-making is now

9 Terry Carney, ‘Civil and Social Guardianship for Intellectually Handicapped People’ (1982) 8 *Monash University Law Review* 199. On the issue of neoliberal governance implications see Terry Carney, ‘Challenges to the Australian Guardianship & Administration Model?’ (2003) 2 *Elder Law Review* 1; Terry Carney, ‘Abuse of Enduring Powers of Attorney: Lessons from the Australian Tribunal Experiment?’ (1999) 18 *New Zealand Universities Law Review* 481; and Terry Carney, ‘The Mental Health Service Crisis of Neoliberalism – An Antipodean Perspective’ (2008) 31 *International Journal of Law and Psychiatry* 101.

10 Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?* (2013) 117 *Penn State Law Review* 1111, 1157 (emphasis added).

11 John Brayley, ‘The Future of Supported and Substitute Decision Making’ (Paper presented at the World Congress of Adult Guardianship, Melbourne, 16 October 2012) 2 <[http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//11\\_Supported%20Decision%20Making](http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//11_Supported%20Decision%20Making)>.

strongly favoured over substitute decision-making models traditionally adopted by adult guardianship laws, principally because it gives effect to the equality principle in article 12.<sup>12</sup> Article 12(3) embodies the notion of supported decision-making in providing that ‘States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.’ This is one of a multiplicity of measures and principles designed to advance rights of equal participation and dignity of people with disabilities by securing individual choice and control over their lives as ‘active citizens’, in recognition of the roles played by social institutions and cultural values in the ‘social construction’ of their disability.<sup>13</sup>

Supported decision-making, however, is conceptually ill-defined,<sup>14</sup> and has been interpreted as spanning everything from targeted legal powers and authorities through to facilitation of the normal interactions of daily family or social intercourse. Systemic perspectives regarding where supported decision-making fits within the overall mix of services, laws and civil society arrangements are also rare: holistic overviews appear as the lonely poor orphans among a plethora of unduly narrow investigations concentrating on particular legislative or social measures assessed in isolation; and discussions of both legal and social measures of supported decision-making tend to be abstracted from their social or operational context. Power, Lord and deFranco echo Brayley by eloquently demonstrating that participation of people with a disability as active citizens necessarily relies on ‘supply side’ reforms (public sector, non-government and civil society ‘responsiveness’ to consumer agency and choice) as well as ‘demand side’ measures (informal supports, supported decision-making, advocacy and other measures). As they write in the conclusion of their groundbreaking study:

Demand-side options ... are designed to restore more choice and control to people with disabilities over the types of support they may need or require. They involve embedding important facilitation mechanisms such as *independent planning* and *supported decision making* to enable people to take advantage of the opportunities of personalisation.<sup>15</sup>

---

12 Article 12(2) provides that ‘States Parties shall recognize that persons with disabilities *enjoy legal capacity on an equal basis with others in all aspects of life*’ (emphasis added). Article 12(4), however, stipulates that ‘all measures that relate to the exercise of legal capacity’ shall provide for ‘appropriate and effective safeguards to prevent abuse in accordance with international human rights law’, before going on to expressly refer to ‘respect[ing] the rights, will and preferences of the person’, freedom from ‘conflict of interest and undue influence’, and being ‘proportional and tailored to the person’s circumstances, apply[ing] for the shortest time possible, and ... subject to regular review’.

13 See especially Andrew Power, Janet Lord and Allison deFranco, *Active Citizenship and Disability: Implementing the Personalisation of Support* (Cambridge University Press, 2013) ch 2. This is their recently published detailed comparative study of ‘personalisation’ and empowerment reforms in the United States, Canada, England, Northern Ireland, Sweden, France and the Irish Republic.

14 Thus supported decision-making laws in European and Canadian jurisdictions adopt an array of terms including ‘assistants’, ‘support people’ and ‘advocates’: Robert M Gordon, ‘The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making’ (2000) 23 *International Journal of Law and Psychiatry* 61, 63; Power, Lord and deFranco, above n 13, 171–4 (Canada), 255, 281–2 (Sweden), 320–2 (France).

15 Power, Lord and deFranco, above n 13, 441–2 (emphasis added).

Yet the first of these two italicised clusters of options, the ‘independent planning measures’ (such as arrangements to provide a ‘facilitator’<sup>16</sup> or an ‘advocate’<sup>17</sup>), usually lies *outside* the sphere of new supported decision-making arrangements, as often also do a number of the ways of *subsequently* supporting people in their daily lives. In short, the *form* and the *social* contribution of supported decision-making, and its very design and connection to other social supports, remains very much a work in progress.

This article considers some of the more fundamental conceptual and practical questions which arise as governments and service providers rethink laws, services and civil society roles in advancing the objective of ‘supported decision-making’ enshrined by the *CRPD*. To illustrate the analysis it draws on, but does not definitively or comprehensively expound, some of the recent experiences in Canada, Australia and elsewhere, including proposals by the Victorian Law Reform Commission (‘VLRC’), the development of personal budget models of service delivery (including for the pending National Disability Insurance Scheme (‘NDIS’) and in possible aged care reforms), notions of ‘family’ decision-making, and various pilot programs of innovative new models of delivery of support or services to different disability groups.

The first section maps the concept of supported decision-making, positioning it within a spectrum from autonomous decision-making to substitute decision-making, and analyses a number of arrangements which fall under the supported decision-making banner. The second section considers the implications of research findings related to supported decision-making and cognate reforms and highlights some of the risks associated with a shift towards this paradigm. This section also discusses community service programs and policies which may interact with supported decision-making arrangements.

It is argued that the social benefits (and unintended costs or risks) of supported decision-making to people with cognitive disabilities (such as people with dementia, acquired brain injury and developmental disability), psychosocial disability (including some severe episodes of mental illness), and the public at large, are too significant to be based solely in abstract normative analysis. Instead, supported decision-making, in all its different social and legal forms, should first be empirically tested through research and pilot programs before an optimal approach is selected.

---

16 As in the Canadian province of British Columbia, where it lies outside the expansive and highly praised new supported decision-making machinery of ‘representation agreements’, or France, which maintains high levels of institutionalisation, paternalism and older ‘substitute decision-making’ forms of guardianship: Power, Lord and deFranco, above n 13, 442.

17 Examples include Sweden, with its ‘personal ombudsman’ advocates, serving an average of about 22 people each, or Ireland, where once again other aspects of the social and service matrix are skewed towards paternalist settings: Power, Lord and deFranco, above n 13, 255–6, 444 (Sweden), 405–7, 444 (Ireland).

## II WHAT 'IS' SUPPORTED DECISION-MAKING: CONCEPTUAL MAPPING

Despite some significant recent contributions by the Ontario Law Reform Commission and others, there is surprisingly little settled understanding of what supported decision-making entails.

### A Supported Decision-Making in Principle

A common starting point is the observation by Rob Gordon that supported decision-making 'simply recognizes the way in which most adults function in their everyday lives'<sup>18</sup> through *interdependent* decision-making which marshals available advice and support. These *social networks* of family members, friends and others assist in various degrees at different times. As Bigby, Webber and Bowers write, 'people with disabilities are part of complex family systems which play multiple, diverse and changing functions in the lives of all family members',<sup>19</sup> forming 'circles of support' which constitute the social capital to perfect the capacity for decision-making in the face of any barriers or limitations.<sup>20</sup>

Many such processes do not require legislative provision for their implementation but rather are contingent on the policies and practices of services, agencies and institutions that interact with the needs of people with impaired decision-making ability – including rather diverse needs of groups such as the aged, those with mental illness, people with an acquired brain injury and those with a developmental disability<sup>21</sup> – and their social networks. The organic development of relationships of trust and interdependence that can fruitfully emerge between people are especially critical to the success of such processes. In short, analysis of supported decision-making calls for consideration of the complex character of social intercourse at a localised family or community level.

One of the reasons the conceptual map is fuzzy (encouraging peculiar bricolage combinations) is that there are multiple dimensions in play: between legal measures and informal ones; between state action and that of civil society; between measures directed at altering legal and social environments and those

---

18 Gordon, above n 14, 65.

19 Christine Bigby, Ruth Webber and Barbara Bowers, 'Relationships in Later Life Between Group Home Residents with Intellectual Disability, Their Siblings and Staff' (Paper presented at the Proceedings of the Sixth Roundtable on Intellectual Disability Policy: Services and Families Working Together to Support Adults with Intellectual Disability, La Trobe University, Bundoora, 29 November 2011) 23, 23.

20 David W Leake, 'Self-Determination Requires Social Capital, Not Just Skills and Knowledge' (2012) 8(1) *Review of Disability Studies: An International Journal* 34, 35. For the stepped options in the legally-grounded segment of supported decision-making, see John Brayley, 'Supported Decision Making in Australia' (Paper presented to the Victoria Office of the Public Advocate, 14 December 2009) 16 <[http://www.opa.sa.gov.au/documents/11\\_Supported%20Decision%20Making/4-Supported%20Decision%20Making%20in%20Australian%20-%202009%20Presentation.pdf](http://www.opa.sa.gov.au/documents/11_Supported%20Decision%20Making/4-Supported%20Decision%20Making%20in%20Australian%20-%202009%20Presentation.pdf)>.

21 Terry Carney and Patrick Keyzer, 'Planning for the Future: Arrangements for the Assistance of People Planning for the Future of People with Impaired Capacity' (2007) 7 *Queensland University of Technology Law and Justice Journal* 255.

that target particular individuals; between planning measures devised by individuals and those achieved only by the actions of external agencies; and, not least, in the degree or kind of support.<sup>22</sup>

### **B The Outer Limits: Autonomous Decision Making and Substitute Decision-Making**

The more linear stairway between the high point of the ideal of untrammelled autonomous authority, and the bottom step of plenary empowerment of a substitute, contains many steps.

At the top of the stairway the options outwardly present as *socially-constructed* confections (some decisions made by individuals unilaterally, some made only after receiving informal advice, or made with social collaboration etc) even though all of these rest on the little seen legal foundation of common law respect for the principle of individual capacity.<sup>23</sup> At the very foot of the stairway, *legally-constructed* adult guardianship laws or previously executed enduring powers of attorney loom large, filling the void of common law incapacity (or partial capacity) by empowering a substitute with plenary or partial powers of legal decision for people who largely present as lacking social functional capacity. Reformed adult guardianship from the 1970s (starting systematically with Alberta's 1976 reform)<sup>24</sup> made the very bottom step of plenary authority a rare one, by strongly preferring partial, time-limited and least-restrictive alternative guardianship.<sup>25</sup> Substituted decision-making pursuant to mental health legislation, involving compulsory treatment in relation to decisions about mental health treatment, is also positioned towards the lower end of this spectrum.

The role of supported decision-making within overall systems for the regulation of decision-making by and for people who may need assistance with their decision-making is contentious. Some commentators and interested bodies see this paradigm as replacing, or inconsistent with, substitute decision-making,<sup>26</sup>

22 For instance in distinguishing between help to *formulate purposes, choose and make a decision, to communicate and agree with others* in making decisions, and to *act on and meet obligations* under decisions: Michael Bach and Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Ontario Law Reform Commission, 2010) <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>>.

23 See Ben White, Lindy Willmott and Shih-Ning Then, 'Adults Who Lack Capacity: Substitute Decision-Making' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thompson Reuters, 2010) 149.

24 *Dependent Adults Act*, SA 1976, c 63.

25 Sarah Burningham, 'Developments in Canadian Adult Guardianship and Co-Decision-Making Law' (2009) 18 *Dalhousie Journal of Legal Studies* 119, 122; for a thorough review of the current international position, see Shih-Ning Then, 'Evolution and Innovation in Guardianship Laws: Assisted decision-making' (2013) forthcoming *Sydney Law Review*. France and Ireland are among countries still retaining more plenary guardianship laws: Power, Lord and deFranco, above n 13, 320–2 (France), 428–9 (Ireland).

26 As Minkowitz writes:



or at least plenary guardianship,<sup>27</sup> whereas the conservative position is that supported decision-making and substitute decision-making should co-exist. According to this latter view, substitute decision-making should not be used where a person can make decisions with less intrusive measures, including supported decision-making, and attempts should be made to provide such support before resort to substitute decision-making.<sup>28</sup> The former ‘replacement theory’ is, however, increasingly being given credence,<sup>29</sup> with the United Nations Committee on the Rights of Persons with Disabilities appearing to promote a wholesale (albeit progressive) shift to supported decision-making.<sup>30</sup>

To ensure the rights of people with disabilities and people who may require assistance to make decisions at different points in their lives are protected to the fullest, research on supported decision-making models should consider the

---

Article 12 means that a person who experiences difficulties with decision-making must be supported to make his or her own decisions, rather than having the right to make decisions taken away and given to another person (substitute decision-maker) to exercise in his or her place. If a person does not want support, he or she has the right to make decisions without using support.

Tina Minkowitz, ‘Abolishing Mental Health Laws to Comply with the Convention on the Rights of Persons with Disabilities’ in Bernadette McSherry and Penelope Weller (eds), *Rethinking Rights-Based Mental Health Laws* (Hart, 2010) 151, 157. See also Amita Dhanda, ‘Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?’ (2007) 34 *Syracuse Journal of International Law and Commerce* 429.

- 27 Council of Europe Commissioner for Human Rights and Anna Nilsson, ‘Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities’ (2012) (Issue Paper, 20 February 2012) <<https://wcd.coe.int/ViewDoc.jsp?id=1908555>>; Mental Disability Advocacy Centre, *Out of Sight: Human Rights in Psychiatric Hospitals and Social Care Institutions in Croatia* (Report, October 2011) 14 <<http://www.mdac.info/en/croatiareport2011>>.
- 28 Victorian Law Reform Commission, *Guardianship*, Final Report 24 (2012) 250–1. The recommendations of the New South Wales Legislative Council Standing Committee on Social Issues in its 2010 Report on provisions for substitute decision-making also envisaged the co-existence of supported and substitute decision-making. The Committee recommended reform of legislation in which the issue of capacity in relation to decision-making is raised (in particular legislation regulating substitute decision-making such as the *Guardianship Act 1987* (NSW) and the *Trustee and Guardianship Act 2009* (NSW)) to: (1) ‘include an explicit statement to the effect that the legislation supports the principle of supported decision making’; and (2) ‘provide for the relevant courts and tribunals to make orders for supported decision-making arrangements’: Legislative Council Standing Committee on Social Issues, Parliament of New South Wales, Legislative Council, *Substitute Decision-Making for People Lacking Capacity* (2010) 63.
- 29 See, eg, Piers Gooding, ‘Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law’ (2012) *Psychiatry, Psychology and Law* 1, 8; Bernadette McSherry, ‘Legal Capacity under the Convention on the Rights of Persons with Disabilities’ (2012) 20 *Journal of Law and Medicine* 22; Fiona Morrissey, ‘The United Nations Convention on the Rights of Persons with Disabilities: A New Approach to Decision-Making in Mental Health Law’ (2012) 19 *European Journal of Health Law* 423, 431–9; Power, Lord and deFranco, above n 13, 37.
- 30 This view was expressed in its 2012 compliance review of Peru: United Nations Committee on the Rights of Persons with Disabilities, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities: Peru*, 7<sup>th</sup> sess, UN Doc CRPD/C/PER/CO/1 (16 May 2012) <<http://www.unhcr.org/refworld/type,CONCOBSERVATIONS,,,5059c96b2,0.html>>.

implications of both reform paths (including the use of a combination approach as a transitional or interim measure prior to replacement).<sup>31</sup>

### C Supported Decision-Making and Other Alternatives to Substitute Decision-Making: Key Distinctions

It is the middle portion of the stairway between autonomous and substitute decision-making that currently attracts the most attention, as policy-makers endeavour to keep individuals on the highest possible step, for the longest possible time, including by mobilising necessary supports. Broadly speaking, a supported decision-making arrangement may be:

informal;

by written agreement between the supported person and their supporter/s or by personal appointment by the supported person (whether statutory or non-statutory); or

by appointment under statute, such as by a tribunal or court.

Towards the top, when social powers are thought to be a little frail unaided (whether due to decline, congenital or fluctuating capacity) the *social* fabric of life may be bolstered by way of extra-legal measures like ‘circles of support’. A circle of support (or a circle of friends) is a group of people, which may include a person’s family, friends and other community members, who meet together on a regular basis to help that person accomplish their life goals.<sup>32</sup> These informal programs essentially boost individual capabilities by *increasing* the social gradient of an individual’s accessible informal social networks, and the programs hardly engage the law at all.

Alternatively, informal measures may acquire more force by virtue of an agreement, signed by both the supported person and their supporter/s and recognised under private law principles, depending upon the terms of the document and how it is executed. An example is the non-statutory model trialed by the Office of the Public Advocate in South Australia. The ‘supported decision making agreements’ used in this trial involve:<sup>33</sup>

31 See Advocacy for Inclusion, *Supported Decision Making, Legal Capacity and Guardianship: Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory* (Report, August 2012) 29.

32 The idea of a circle of friends or a circle of support (or Joshua circle) for people with developmental disabilities first gained currency in North America in the 1980s: Deborah Gold, ‘We Don’t Call it a “Circle”: The Ethos of a Support Group’ (1994) 9 *Disability and Society* 435, 436. A trial funded in Keene, New Hampshire in 1993 (the Monadnock project) was one of the first to test the concept as a basis for a new form of service planning and delivery: Power, Lord and deFranco, above n 13, 102–3.

33 These were agreements which were said to have ‘no specific legal recognition’, signed by a supported person, a supporter and a monitor to keep oversight of the process. Their purpose was to ‘indicate the wish of the supported person to receive support, and the preparedness of the supporter and the monitor to give the support (or monitoring assistance)’: Office of the Public Advocate, South Australia, *South Australian Supported Decision Making Project: Report of Preliminary ‘Phase I’* (2011) 16.

an *appointment* by the supported person of a supporter to assist them to make decisions, specifying the area/s in which decision-making assistance will be provided (such as accommodation, health, work etc) and the ways in which assistance may be provided (provision of information, discussion and assistance to explain the person's wishes to others);

an agreement by the supporter to perform these functions; and

an agreement by an independent party to be a monitor who will keep track of how the arrangement is working.<sup>34</sup>

Further down the stairway are the more ethically slippery and less well lit steps, where it is argued missteps can arise.

Most existing legislative frameworks considered to formalise supported decision-making entail some obligation for the person to accept support, either in relation to specific decisions or decision-making generally. One example is the arrangement termed as 'co-decision-making' as introduced in Saskatchewan in 2000.<sup>35</sup> With co-decision-making, legal decision-making power is held jointly by the person and their supporter such that a legally-binding decision cannot be made by either party alone. Redolent of the fine distinctions between ownership rights under joint tenancies and tenancies in common (whether co-owners do or do not acquire a 'share'), these options are among the most problematic in terms of *public* understanding of their social and legal function: they risk failing to pass the 'corner shopkeeper's understanding' test. First, law cannot constitute the richness and trust of *genuine* social networks; secondly, in practice they may morph into substitute decision-making in the minds of third parties like banks, businesses and others.<sup>36</sup> For their part, the 'representation agreements' used in British Columbia, Canada involve an individual appointing a person to be their supporter, but allow for substitute decision-making on a decision-specific basis,<sup>37</sup> whereas in Yukon, Canada, they involve authorising a representative to make prescribed daily living decisions regarding personal or financial affairs on behalf of an adult who has entered into an agreement.<sup>38</sup>

A supported decision-making agreement or appointment could in theory function in a similar fashion to the South Australian trial discussed above: where the person is not *obliged* to receive assistance in making decisions and the

---

34 In practice these proved difficult to recruit, leaving the role by default to be discharged by the project facilitator in many cases: Margaret Wallace, *Evaluation of the Supported Decision Making Project* (Report, Office of the Public Advocate, South Australia, November 2012) 15-16, 52. Provision of a monitor was seen as necessary protection for 'representation agreements' in British Columbia, Canada, once it was determined not to record them on a public register: Power, Lord and deFranco, above n 13, 174.

35 Burningham, above n 25, 136-8.

36 Ibid 123.

37 See, eg, *Representation Agreement Act*, RSBC 1996, c 405. Under s 16(2), the 'adult representative' when helping the person to make decisions must 'consult, to the extent reasonable, with the adult to determine his or her current wishes' but must only comply with those wishes 'if it is reasonable to do so'.

38 *Decision Making, Support and Protection to Adults Act*, SY 2003, c 21, s 15(2).

contractual agreement can be ended by either party at any time. A statutory model approximating this approach is found in Yukon's *Decision Making, Support and Protection to Adults Act*, under which a person can appoint an associate decision-maker, via a 'supported decision-making agreement', whose role is limited to assisting the person to make and communicate decisions and must not stray into making decisions on the person's behalf. An agreement between the person and a third party can, however, be declared void where the person entered into the agreement without consulting the associate decision-maker.<sup>39</sup>

An important distinction between these lower echelon approaches regards the extent to which the legal decision-making power stays with the supported person. The person may retain sole decision-making authority in all situations. Co-decision-making and representational agreements, however, involve some deviation from this standard, as already shown. Another aspect of the supported decision-making spectrum is what we term 'peripheral law', such as where a supporter is granted dispensations from privacy law barriers in order to facilitate accessing personal information, or supplying material on a person's behalf (as with 'correspondence nominees' in social security<sup>40</sup> and under the soon to be implemented NDIS),<sup>41</sup> a model sometimes distinguished by the term 'assisted' decision-making. Such authorities or powers are peripheral in the sense that they do not legally trench on or derogate from individual autonomy of decision (though the public may or may not grasp this in practice), but of course even these powers carry some risks to individual rights.

Among the many nuances of legislative provisions to encourage forms of supported decision-making approaches, at least three stand out.

### 1 General Recognition

Laws may provide merely that supported decision-making be 'recognised'. Thus section 6(2) of the *Vulnerable Persons Living with a Mental Disability Act* of Manitoba, a statute which mainly regulates substitute decision-making arrangements, states:

Supported decision making by a vulnerable person with members of his or her support network should be respected and recognized as an important means of enhancing the self-determination, independence and dignity of a vulnerable person.<sup>42</sup>

39 *Decision Making, Support and Protection to Adults Act*, SY 2003, c 21, s 12.

40 See *Social Security (Administration) Act 1999* (Cth) ss 44, 123A–123S. For the earlier provisions, which lacked a number of the fiduciary and other protections now legislated, see Robin Creyke, 'Whose Pension Is It? Substitute Payees for Mentally Incompetent Pensioners' (1991) 10 *University of Tasmania Law Review* 102.

41 *National Disability Insurance Scheme Act 2013* (Cth) pt 5 div 1. A correspondence nominee under ss 79–82 has similar rights (to receive information), duties (to consult with the person represented) and responsibilities (to advise the agency of changed circumstances) to those applying to the quite *separate* social security correspondence nominee appointments provided for in relation to Centrelink payments.

42 SM 1993, c V-90, s 6(2).

While the *intent* of these laws is very clear, it does not follow that they will necessarily have any practical effect.

## 2 *Specific Recognition of a Supported Decision Making Arrangement*

Statutes regulating supported decision-making arrangements may provide that supporters are actively engaged in assisting decision-making (or provide for the appointment of co-decision makers) and set out corresponding powers, such as the *Representation Agreement Act* of British Columbia,<sup>43</sup> or measures under consideration for Victoria. The VLRC proposed reforms are modelled broadly on the Canadian developments, encompassing both personal appointments and appointment by order of the Victorian Civil and Administrative Tribunal ('VCAT') for two types of arrangements: supported decision-making agreements/orders and co-decision-making agreements/orders. Whilst of the view that personal appointments are preferable to VCAT appointments because they involve an exercise of choice by the person affected, the VLRC recommended intervention by VCAT were necessary to protect the rights of the person and to offer an alternative to guardianship and administration appointments. These VCAT orders could not, however, be made without the consent of the person.<sup>44</sup> A role for the Public Advocate in the training and monitoring of support arrangements was also suggested.<sup>45</sup>

## 3 *Associated Duties for Parties Dealing with Supported Decisions*

Laws may additionally provide that third parties have a duty to accept the role of supporters or may refuse to recognise a decision communicated by a supporter if they believe there has been undue influence, fraud or misrepresentation. Such provisions could potentially appear in legislation regulating supported and/or substitute decision-making or legislation relating to services, agencies and institutions dealing with supported decisions (such as legislation governing health services). The VLRC, for example, recommended the following in relation to recognition of decisions made under 'support appointments':

Any decision made with the assistance of a supporter or communicated by or with the assistance of a supporter with the authority of the appointment or order should be recognised as the decision of the supported person for all purposes.<sup>46</sup>

Again, this raises the obvious question of whether the passage of such a provision will alter the practice of external agencies like general government departments, local government authorities, banks, non-government agencies, or shopkeepers in failing to honour such decisions. Indeed, not only may it fail to alter practice or provide reassurance, it may even muddy the waters by creating confusion between the different options.

---

43 *Representation Agreement Act*, BC 1996, c 405.

44 Victorian Law Reform Commission, above n 28, 110–13 [7.85]–[7.106], 115 [7.114].

45 *Ibid* 115 [7.114].

46 *Ibid* 143 [8.111].

The first of these three options could be expressed as a generic *mandate*, ie, an authority which is engaged whenever social arrangements take a supportive form, including informal measures. This has advantages in terms of ease of access (since no prior order or instrument is needed), but may not be widely known by the third parties and institutions whose interactions with the person are intended to be facilitated.<sup>47</sup> By contrast, the second option above can only be triggered by way of a person exercising individual powers to make an agreement in advance, or for a court or tribunal to make a supported decision-making order, making access difficult. Legally and socially then, these are very different animals. Associated duties for parties dealing with supported decisions could of course be incorporated into either or both of the above approaches, however.

*All* (and more) of these different modes and types of ‘supports’ have been suggested as lying within the scope of the encouragement of supported decision-making by article 12(3) of the *CRPD*,<sup>48</sup> although it is arguable that representational agreements and co-decision-making in particular fall foul of this provision by being unduly paternalistic.<sup>49</sup> The VLRC for its part has recommended that laws providing for the appointment of supporters should make it clear that supporters are ‘unable to exercise any kind of substitute decision-making authority on behalf of the person, or use their powers without the knowledge and consent of the supported person’.<sup>50</sup> Tina Minkowitz, who advocates for a wholesale shift to supported decision-making, posits an entirely *voluntary* model, with sole legal decision-making authority residing with the supported person:

Support can only merit the name when it is truly voluntary and when those providing support understand their role as facilitative rather than directive, that is, as an adjunct to the person’s own decision-making process rather than as central participants in that process. While the degree and nature of support must be worked out by the parties to a support relationship, the person receiving support always has the right to a final say in his or her own decisions.<sup>51</sup>

The public/private law boundary line as regards these different supported decision-making arrangements is also not always easy to pin down. Non-statutory written agreements clearly fall within the private law camp, and may

---

47 Not dissimilar issues arise in virtually all Australian jurisdictions that provide a mandate for certain less serious health decisions to be authorised for someone who lacks capacity to do so, by empowering people by way of a hierarchical list of default decision-makers (or ‘responsible persons’): see White, Willmott and Then, above n 23, 199–202.

48 Lana Kerzner, ‘Paving the Way to Full Realization of the CRPD’s Rights to Legal Capacity and Supported Decision-Making: A Canadian Perspective’ (Paper presented at In From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century, Vancouver, 30 April 2011) 16 <[http://www.anth.ubc.ca/fileadmin/user\\_upload/CIC/documents/In\\_From\\_The\\_Margins\\_Paper-Lana\\_Kerzner-FINAL-April\\_22\\_2011\\_2\\_.pdf](http://www.anth.ubc.ca/fileadmin/user_upload/CIC/documents/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011_2_.pdf)>.

49 Advocacy for Inclusion, above n 31, 30–1.

50 Victorian Law Reform Commission, above n 28, 142 [8.107].

51 Minkowitz, above n 26, 158.

give rise to contractual and fiduciary duties.<sup>52</sup> Supported decision-making agreements or appointments provided for by statute, however, could in theory give rise to private law obligations *or* confer statutory public powers on supporters governed by administrative law (or both), depending upon the terms of the statute. Policymakers should therefore consider the practical and philosophical implications of both options. Of course, the state cannot *prevent* people from entering into non-statutory supported decision-making agreements, unless it is thought fit to create new civil wrongs or criminal offences in this regard, so their existence cannot be ignored.

In choosing a combination of policies from within this menu of options in order to advance the goals of the *CRPD* there are therefore a multitude of important questions, including what is a soundly-based choice as distinct from mere 'bricolage' based on picking what is nearest to hand (or most familiar to the law reformer or policymaker). Such bricolage is no mere academic possibility, but a live legal and social policy issue for some of Australia's most vulnerable citizens. This is illustrated by the inclusion in the recently enacted *National Disability Insurance Scheme Act 2013* (Cth) of provisions for appointment not only of the less controversial 'correspondence nominee', but also of a 'plan nominee'<sup>53</sup> who has 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.

Because such appointments are ultimately made by the agency responsible for resourcing the realisation of the plan,<sup>54</sup> a number of submissions to the Senate Committee which considered the Bill expressed two main concerns about these provisions. First, there is a serious conflict of interest (where the responsible agency chooses the person who will act in the discussion of what goals and thus what resources are appropriate to be provided by that agency or others). Secondly, there is a palpable risk of undue paternalism in exercising the power of appointment. This power is fundamentally very different from appointment of social security payment nominees, where the *quantum* of the entitlement is fixed by law, and is neither discretionary in size nor so reliant on drawing out the personal preferences of the person being represented. Allied with this were concerns about undue duplication (the overlap with state and territory guardianship appointments and any future enactment of the *CRPD* required

---

52 Brian Sloan has recently explored the private law doctrines that might be relevant in answering the seemingly simple question of what assistance the law might offer to a person providing 'care' for another individual. As explained in his book, not only are there many different private law categories to consider, but as in the present article, the 'forms' taken by carer relationships are quite varied (ranging from marriage partners to private contractors or charitably minded strangers or not-for-profit agencies): Sloan, above n 6.

53 *National Disability Insurance Scheme Act 2013* (Cth) ss 78, 84.

54 Appointments are made by the delegate of the CEO of the National Disability Insurance Scheme Launch Transition Agency, either at the request of a consumer (called the 'participant') or at the initiative of the delegate of the CEO: ss 86(2), 87(2).

supported decision-making options in those jurisdictions) and with the two parallel nominees for social security matters.<sup>55</sup>

Even though the Committee was sufficiently placated by tighter proposed draft rules providing more reassurance about the principles and criteria to govern appointments, including deference to and consultation with any guardian or other decision-maker under other laws,<sup>56</sup> concerns remain. For example, the rule is by no means as exhaustive as the principles laid down in section 4 (and are not keyed to that section), do not specifically refer to conflict of interest issues, and raise some accountability concerns because review is directly to the less accessible Administrative Appeals Tribunal, with no equivalent of the Social Security Appeals Tribunal lower tier review of equivalent Centrelink appointments.<sup>57</sup> Should a future government proceed with the currently shelved recommendations of the Productivity Commission to also introduce greater

55 Senate Community Affairs Legislation Committee, Parliament of Australia, *National Disability Insurance Scheme Bill 2012 [Provisions]* ('Senate Report') (March 2013) 100–4 [7.8]–[7.27]. Section 80(1) of the *National Disability Insurance Scheme Act 2013* (Cth) provides that it is the 'duty of a nominee of a participant to ascertain the wishes of the participant and to act in a manner that promotes the personal and social wellbeing of the participant'. Subsection (4) authorises promulgation of rules prescribing 'other duties' including a duty 'to support decision-making by the participant personally' or 'to have regard to, and give appropriate weight to, the views of the participant: ss 80(4)(a)–(b). The appointment of a nominee may not be made without the written consent of the participant after taking account of the participant's wishes: ss 88(2)(a)–(b). The appointment must also 'have regard to' the existence of any person already empowered under guardianship order or other appointment conferring power to make decisions for the person: ss 88(4)(a)–(b) (This would include an existing Centrelink nominee). The rules may prescribe persons 'who must not be appointed' and lay down 'criteria to which the CEO is to have regard' in making appointments: ss 88(6)(a)–(b).

56 The draft rules (tabled on 5 March 2013) were much more consistent with the philosophies of supported decision-making, dignity of choice and the least restrictive alternative approach laid down as overarching principles in s 4 of the *National Disability Insurance Scheme Act 2013* (Cth), such as ss 4(1)–(2) (equality of participation); ss 4(4)–(8) (support to exercise choice and control, determine best interests, engage as equal partners in decisions); s 4(9) ('supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs'); s 4(11) (support to realise life goals, independence and participation as citizens); s 4(13) (role of advocacy).

The draft rule requires consideration of:

- (a) whether the participant would be able to participate effectively in the NDIS without having a nominee appointed;
- (b) the principle that a nominee should be appointed only when necessary, as a last resort, and subject to appropriate safeguards;
- (c) any formal guardianship arrangements that might be in place;
- (d) whether the participant has supportive relationships, friendships or connections with others that could be:
  - (i) relied on or strengthened to assist the participant to make their own decisions; or
  - (ii) improved by appointment of an appropriate person as a nominee.

Senate Report, above n 55, 99 [7.3].

57 Appointments of nominees are reviewable decisions: *National Disability Insurance Scheme Act 2013* (Cth) ss 99(l)–(m). However, subject to first obtaining an independent internal review: s 100(6), any external review application is made direct to the Administrative Appeals Tribunal: s 103.



choice and personalisation in aged care<sup>58</sup> as part of the international trend towards reorganising services around personal plans (personal budgets), such ‘plan nominee’ measures risk being duplicated in this or other areas of social policy reform.

Such practical examples give rise to a number of other questions. What supported decision-making option in principle is preferable? What ‘works’ and to what degree does it work? At what social or economic cost? What are the implications for different target groups, and do models need to be tailored to their unique needs? What are the implications for governance and civil society? The next section considers some of these questions.

### III ISSUES IN IMPLEMENTING SUPPORTED DECISION-MAKING

There is now a legion of recent articles on the implications of a transformation towards supported decision-making,<sup>59</sup> together with the impressive report of the VLRC.<sup>60</sup> With few exceptions, these all adopt standard normative, doctrinal or policy analysis methodologies. By contrast, the focus of this section of the article is on more evidence-based or operational issues involved in selecting between public law, private law, hybrid or soft law forms, and leaving the issue to voluntary society arrangements within the domain of civil society.

#### A What Works?

Even though various schemes of supported decision-making were legislated in some Canadian provinces late last century,<sup>61</sup> joining older models from

---

58 These market-based reform recommendations, including the idea of requiring aged care consumers to make a ‘choice’ between competing service packages offered by approved providers, were not adopted by the Gillard Government in the Bills currently before Parliament. For details of the original recommendation see Productivity Commission, *Caring for Older Australians*, Report No 53 (2011) 166–74 <<http://www.pc.gov.au/projects/inquiry/aged-care/report>>. Instead these measures are to be the subject of a trial, see Rebecca de Boer, *Changes to Community Care* (2 May 2012) FlagPost: Information and Research from Australia’s Parliamentary Library (May 2 2012) <<http://parliamentflagpost.blogspot.com.au/2012/05/changes-to-community-care.html/>>.

59 Gooding, above n 29; John Chesterman, ‘The Future of Adult Guardianship in Federal Australia’ (2013) 66 *Australian Social Work* 26; Genevra Richardson, ‘Mental Disabilities and the Law: From Substitute to Supported Decision-Making?’ (2012) 65 *Current Legal Problems* 333.

60 Victorian Law Reform Commission, above n 28. As discussed above, the VLRC proposes two new arrangements, namely supported decision-making and co-decision-making: at 128–30 [8.13]–[8.31]; 137–8 [8.78]–[8.87], to reduce the use of guardianship by offering structured alternatives to it, while offering certainty for third parties and legitimacy for those providing support: at 135–6 [8.64]–[8.67].

61 Burningham, above n 25, 124–5.

continental Europe and other countries,<sup>62</sup> the empirical evidence about outcomes is scant and at best quite equivocal.<sup>63</sup>

In previous contributions to these issues one of us has noted that there are potentially major practical, educative, or ‘cultural’ barriers to devising supported decision-making laws which will *actually* operate differently from reformed (partial, temporary and least restrictive) adult guardianship laws<sup>64</sup> and that legal machinery to realise the ‘service brokerage’ aspect of these laws makes but a slight contribution.<sup>65</sup> This is consistent with the very guarded conclusion about the contribution able to be delivered by formalised supported decision-making as reached by Kohn, Blumenthal and Campbell,<sup>66</sup> raising issues about the most appropriate balance between informal social measures and those implemented through or underpinned by the law.

For example, the assumption that social networks of support are readily built and sustained in working order has proved fragile. Research on the implementation of the *Vulnerable Persons Living with a Mental Disability Act* of Manitoba in Canada<sup>67</sup> illustrates the complexity of operationalising informal support networks and the difficulties involved in realising the capacity-respecting goals of the Act, without careful attention to the necessary administrative and policy machinery, including how to build networks for the socially-isolated.<sup>68</sup>

The independent evaluation of the small trial of supported decision agreements between the consumer and a supporter, auspiced by the South Australian Office of Public Advocate between November 2010 and 2012, found favourable reactions from consumers, supporters and service providers, but a mixed bag operationally.<sup>69</sup> The trial planned to recruit roughly equal numbers for

62 Morrissey, above n 29, 431–5 (discussing, among others, supported decision-making models in Finland, Norway and Sweden); Kees Blankman, ‘Guardianship Models in the Netherlands and Western Europe’ (1997) 20 *International Journal of Law and Psychiatry* 47; Israel Doron, ‘Elder Guardianship Kaleidoscope: A Comparative Perspective’ (2002) 16 *International Journal of Law, Policy and the Family* 368 (discussing German, Israeli and Japanese options), especially 374–6 (discussing the pre-2000 Japanese ‘curator’ and the post-reform ‘helper’ [hojo seido] option available to the Family Court as an alternative to guardianship).

63 Kohn, Blumenthal and Campbell, above n 10.

64 Terry Carney, ‘Guardianship, Citizenship, & Theorizing Substitute-Decisionmaking Law’ in Israel Doron and Anne Soden (eds), *Beyond Elder Law: New Directions in Law and Ageing* (Springer, 2012) 1.

65 Terry Carney, ‘Participation and Service Access Rights for People with Intellectual Disability: A Role for Law?’ (2013) 38 *Journal of Intellectual & Developmental Disability* 59.

66 Kohn, Blumenthal and Campbell, above n 10.

67 A substitute decision-maker should not be appointed if the person is capable of attending to their personal care or managing their property with the involvement of their support network: *Vulnerable Persons Living with a Mental Disability Act*, SM 2013, c V-90, ss 53(1), 88(1).

68 Hilary Johnson et al, ‘The Pearl in the Middle: A Case Study of Social Interactions in an Individual with a Severe Intellectual Disability’ (2010) 35 *Journal of Intellectual & Developmental Disability* 175; Zana M Lutfiyya et al, Report on the Examination of the Implementation and Impact of the *Vulnerable Persons Living with a Mental Disability Act* (VPA) (Community Living, Manitoba, 2007) 141  
<[http://www.academia.edu/965097/Report\\_on\\_the\\_Examination\\_of\\_the\\_Implementation\\_and\\_Impact\\_of\\_the\\_Vulnerable\\_Persons\\_Living\\_with\\_a\\_Mental\\_Disability\\_Act\\_with\\_a\\_Mental\\_Disability\\_Act\\_VPA](http://www.academia.edu/965097/Report_on_the_Examination_of_the_Implementation_and_Impact_of_the_Vulnerable_Persons_Living_with_a_Mental_Disability_Act_with_a_Mental_Disability_Act_VPA)>.

69 Margaret Wallace, above n 34.

its alternative to guardianship and its early intervention arms, but abandoned the former when guardians failed to refer people on the ground that guardianship already required them to act as supporters, and that those recruited generally lacked capacity to give consent.<sup>70</sup> Just over two dozen (26) participants completed the trial,<sup>71</sup> reporting positively about gains made in advancing defined decision-making and lifestyle objectives (such as accommodation choices). It reported that confidence was built in working with supporters to develop individuals' personal capacity, along with evidence that dignity of risk could be advanced through providing less risk-averse settings for making decisions. However, two supporters fell by the wayside and were unable to be replaced other than by the project coordinator, and no success was experienced in recruiting volunteers for two socially-isolated consumers.<sup>72</sup> The project also excluded potentially more challenging subjects, such as people with mental illness, dementia, or those experiencing abuse, neglect or conflict with family or friends.

Apart from the (not insignificant) transparency provided through the inclusion of a 'monitor' (an intermediary or watchdog role), however, it might be queried what value-adding the non-statutory agreements model offers compared to purely *informal* support networks such as those designed to actively develop the 'good life' for consumers with intellectual disability. For instance, recent research findings regarding some of the subtle rights violations detected when such purely informal networks confront risk-averse policies of service providers,<sup>73</sup> are eerily similar to those touched on in the South Australian evaluation of its supported decision-making scheme. And informal networks appear to confer similar capacity building benefits for consumers.<sup>74</sup> However, non-statutory written agreements, if executed as a formal legal instrument, could potentially provide greater protection in case of abuse or exploitation by the supporter/s, a consideration that may take added significance for, say, the frail aged.

There are also echoes in the South Australian evaluation of the findings reported from the meta-review of international research on utilisation and outcomes of statutory supported decision-making models.<sup>75</sup> Thus Saskatchewan's co-decision-making was favoured over guardianship by just seven per cent of applicants and, while British Columbia doubled this (to 1000 representation agreements over three and a half years), it is difficult to know whether this is an indicator of 'success' given that there is no information on the baseline or

---

70 Ibid 34–46.

71 The majority of the participants had acquired brain injury, intellectual disability or autism spectrum disorder.

72 Margaret Wallace, above n 34, 51.

73 Anne Hillman et al, 'Experiencing Rights within Positive, Person-Centred Support Networks of People with Intellectual Disability in Australia' (2012) 56 *Journal of Intellectual Disability Research* 1065, 1069–70.

74 Ibid 1071.

75 Kohn, Blumenthal and Campbell, above n 9.

regarding which constituencies this taps.<sup>76</sup> Nor is there much information about the gender, age, income and educational profiles of users,<sup>77</sup> though it seems to be more popular among higher income educated people, and 80–90 per cent of choices appear to be family members rather than outsiders.<sup>78</sup> Results suggestive of reluctance by low income and ethnic minorities to use advance directives (favoured by more affluent, non-ethnic constituencies)<sup>79</sup> indicate another needed line of research on supported decision-making. While differential take-up of legal options (or social programs) is common, any very low usage of options or pattern of significant distributional inequity would be an added reason for caution in their introduction.

Actual outcomes achieved under these arrangements proved to be even less explored, as found in the review by Kohn, Blumenthal and Campbell of existing empirical studies, and then not in much depth. Thus, although there was evidence of reasonable frequency of discussion between supporters and those who undertook representation agreements in British Columbia, including canvassing issues of values and preferences, the possibility that the values of supporters prevail due to subtle or deliberate paternalism or coercion was found to remain an open question.<sup>80</sup> Likewise the claim that frequent contact should yield the therapeutic self-enhancing cognitive involvement in life decisions that the qualitative data from the South Australian evaluation hints at, since the substance may yet prove to be a form of paternalism writ large.<sup>81</sup> The vexed issues of whether consumers have a sufficiently settled pattern of values and preferences, and if so how well they are translated into the action of supporters, or the real *quality* of decisions, were found to be quite bereft of research.<sup>82</sup>

## B What are the Potential Slippage Risks?

Divergence between the aspirations of policymakers keen to expand personal autonomy of action and personalised decision-making, and the harsh realities of actual experience, are neither new nor confined to experiences of a few countries.<sup>83</sup> Such unintended consequences of laws and programs, or of diminution and distortion of normative or other objectives, is a well-documented

---

76 Ibid 17.

77 Ibid 19.

78 Ibid 19–20.

79 Rebecca S Allen and John L Shuster Jr, 'The Role of Proxies in Treatment Decisions: Evaluating Functional Capacity to Consent to End-of-Life Treatments within a Family Context' (2002) 20 *Behavioral Sciences & the Law* 235.

80 Kohn, Blumenthal and Campbell, above n 10, 1138–9.

81 Ibid 1139–40.

82 Ibid 1140–1.

83 Jan Šiška and Julie Beadle-Brown, 'Developments on Deinstitutionalization and Community Living in the Czech Republic' (2011) 8 *Journal of Policy and Practice in Intellectual Disabilities* 125.

phenomenon in other areas,<sup>84</sup> so it would be surprising if supported decision-making proved to be exempt.

This has already been shown with cognate reforms. Thus a British study found that ‘best interests’ policy required to be pursued in respect of intellectually-disadvantaged residents was translated not in terms of the actual values and preferences of residents, but those *projected* on the basis of the values of their close carers.<sup>85</sup> Another study of a decade-old British policy of identifying and respecting even quite uncontentious life choices found that they are often confined to a rather paternalistic ‘menu’ of choices, which emptied the exercise of much of its substance.<sup>86</sup>

Likewise an Australian study of financial decision-making in aged care residential settings found patchy understanding of the law about enduring powers of attorney or respect for the presumption of legal capacity.<sup>87</sup> This study of care facility staff and policies in four institutions made two consistent findings:

Firstly, that constraints were placed upon their ability to be involved in decision making, both at the level of managing assets and in the day-to-day handling of money and valuables. Secondly, that only limited support was provided for the residents who were capable and wanted to be involved. The frequent outcome was the use of substitute decision makers as the easier option. These findings indicated the impediments to implementing a task-specific approach to the assessment of the capacity to make financial decisions.<sup>88</sup>

This failure was attributed to risk minimisation policies, resource constraints and an attitude that the issue of individual decision-making lay in the province of the family rather than the facility. Enduring powers of attorney were frequently misunderstood by staff as a global empowering of family as substitute decision-makers, even when the person had capacity to make, and wished to make, a particular decision.<sup>89</sup> Law reform on its own, however well-grounded in principles of presumed capacity or respect for the dignity of choice, may do little to alter entrenched cultures of paternalism.

---

84 This phenomenon has been demonstrated in hundreds of studies of the law in action: see generally, Peter Cane and Herbert Kritzer (eds), *The Oxford Handbook of Empirical Legal Research* (Oxford University Press, 2010); see especially Julia Black, ‘Financial Markets’ in Peter Cane and Herbert Kritzer (eds), *The Oxford Handbook of Empirical Legal Research* (Oxford University Press, 2010) 151, 164–5. For more accessible discursive interview transcripts of conversations with the leaders of iconic studies, see Simon Halliday and Patrick Schmidt, *Conducting Law and Society Research: Reflections on Methods and Practices* (Cambridge University Press, 2009), such as ch 2 where Stewart Macaulay talks about the path-breaking study showing the gap between formal rules of contract and the way business is actually conducted.

85 Michael C Dunn, Isabel C H Clare and Anthony J Holland, ‘Living “A Life Like Ours”: Support Workers’ Accounts of Substitute Decision-Making in Residential Care Homes for Adults with Intellectual Disabilities’ (2010) 54 *Journal of Intellectual Disability Research* 144.

86 Andrea Hollomotz, ‘Are We Valuing People’s Choices Now? Restrictions to Mundane Choices Made by Adults with Learning Difficulties’ (2013) forthcoming *British Journal of Social Work*.

87 Cheryl Tilse et al, ‘Managing Older People’s Money: Assisted and Substitute Decision Making in Residential Aged-Care’ (2011) 31 *Ageing & Society* 93.

88 Ibid 103.

89 Ibid 100, 104.

One possible unintended consequence of any additional legal avenue is that of ‘net widening’ – where supported decision-making orders extend to an additional population rather than apply to those otherwise liable to a guardianship order;<sup>90</sup> a phenomenon that may variously be both a risk (via unnecessary incursions on autonomy and privacy) or a benefit (in facilitating the provision of necessary support and the recognition of such support by third parties). An allied worry is that people dealing with such orders will mistakenly attribute decisional powers and responsibilities to people appointed as supporters, meaning that they operate as de facto guardianship orders without some of the checks and balances of true guardianship.<sup>91</sup> On the other hand, there are unintended consequences associated with informal arrangements as well. While informality advances autonomy through compliance with statutory least restrictive alternative principles<sup>92</sup> (or the common law<sup>93</sup>) it comes at the cost of enhanced opportunities for abuse and/or misreading of wishes.<sup>94</sup> Such risks can of course be mitigated through active outreach work of bodies such as Offices of the Public Advocate or other educative rights-oriented programs (modelled on consumer protection programs), but these adverse consequences are magnified by the fact of being more distant from the oversight or purview of public sector bodies and agencies.

Paradoxically, because supported decision-making as an alternative to guardianship is predicated on the adequacy of informal networks, isolated individuals risk discriminatory resort to guardianship, unless steps are taken by the state to constitute a viable network or find a supporter.<sup>95</sup> While there are precedents for this (such as the Victorian Office of the Public Advocate ‘community guardian’ program to avoid impersonal guardianship in such cases),<sup>96</sup> one difference is that guardianship is *under* state agency purview, while informal guardianship by definition is not, so the most opportune moment to build the relationships may be lost. Older members of the frail aged population who lose previous networks through aging, and younger male schizophrenia

90 Lutfiyya et al, Report on the Examination of the Implementation and Impact of the *Vulnerable Persons Living with a Mental Disability Act* (VPA), above n 68, 50.

91 Carney, above n 64, 10–11. The VLRC has suggested that if supported decision-making applies to financial matters, close consideration should be given to the potential legal liability of supporters and the person receiving assistance, noting concerns raised by the Australian Bankers Association and the State Trustees: Victorian Law Reform Commission, above n 28, 114 [7.110]–[7.112].

92 *Stuart v Kirkland-Veenstra* (2009) 237 CLR 215, 250 [98] (Gummow, Hayne and Heydon JJ); *McDonald v Guardianship & Administration Board* [1993] 1 VR 521, 531–2 (Fullagar, Tadjell and Phillips JJ); *Public Trustee v Blackwood* (1998) 8 Tas R 256, 264–7 (Underwood J); *Edwards v Edwards* (2009) 25 VR 40, 47 [26] (Forrest J); *S v South Eastern Sydney & Illawarra Area Health Service* [2010] NSWSC 178 (Brereton J); *SU (Review Guardianship and Medical Consent)* [2012] TASGAB 23 (31 August 2012).

93 *Moore v Guardianship and Administration Board* [1990] VR 902.

94 Kohn, Blumenthal & Campbell, above n 10, 1136–7.

95 As was tried without success for ‘Alex’ in the SA project: Margaret Wallace, above n 34, 26.

96 Mark Feigan, *The Victorian Office of the Public Advocate: A First History 1986–2007* (PhD Thesis, La Trobe University, 2011) 17 <[http://www.publicadvocate.vic.gov.au/file/file/Research/Reports/Feigan\\_OPA\\_history\\_thesis\\_final.pdf](http://www.publicadvocate.vic.gov.au/file/file/Research/Reports/Feigan_OPA_history_thesis_final.pdf)>.

sufferers whose behaviour alienates family and friends, are likely to be at particular risk.

More broadly, there is the risk that supported decision-making, in particular when operating in tandem with substitute decision-making, may lead to substantial informal coercion being brought to bear upon people with cognitive and psychosocial disabilities in relation to how they make personal and health decisions. If supported decision-making becomes a widely accepted paradigm, it is conceivable that individuals who do not have 'support' to make decisions, or who do not make decisions in line with supporters' notions of what is best for them, will be more likely to be made subject to a substitute decision-making order. It would be contrary to the spirit of article 12 of the *CRPD* if supported decision-making and substitute decision-making came to form something akin to a binary opposition that limits the opportunity for independent autonomous decision-making – or if people felt coerced into accepting 'support', such as in order to access services.

Any assessment of supported decision-making options needs to secure empirical evidence on the frequency and magnitude of such effects.

### C Where Do Community Services Fit In?

The objectives of the *CRPD* are agnostic as to the need for law to achieve their implementation, and are equally directed at the way community services are delivered, or the way civil society operates. This means that arrangements in these sectors which may interact with supported decision-making must also be critically examined.

Personalised budgets in place of direct in kind delivery of services and supports are designed to respect choice rights of recipients, but these too take many forms and raise a multitude of different mixes of the underlying value preferences.<sup>97</sup> However, three potentially divergent constituencies remain in play under such reforms – the interests of consumers, carers and also service providers.<sup>98</sup> The design priorities differ from country to country (with some European models concentrating on the interests of service providers rather than consumers) and at program level,<sup>99</sup> though evaluations of British reforms have generally found favour with consumers and carers.

While personalised budget reforms can be grounded by legislation, they are often achieved solely by policy and program changes, as in Britain. As with other withdrawals from the purist Weberian form of government-funded and

---

97 Michele Foster et al, 'The Politics of Entitlement and Personalisation: Perspectives on a Proposed National Disability Long-Term Care and Support Scheme in Australia' (2012) 11 *Social Policy and Society* 331.

98 Kate Baxter, Mark Wilberforce and Caroline Glendinning, 'Personal Budgets and the Workforce Implications for Social Care Providers: Expectations and Early Experiences' (2011) 10 *Social Policy and Society* 55. For the most thorough recent review of international experience, see Power, Lord and deFranco, above n 13, especially ch 3.

99 Nicola Moran et al, 'Personalisation and Carers: Whose Rights? Whose Benefits?' (2012) 42 *British Journal of Social Work* 461.

government-delivered services, the shift necessarily transforms not only the relationship between citizens and state (such as altering the respective burdens of risk and administrative responsibility) but also the *type* of law backing the new configuration, or the means for resolving any disputes about its operation. Public law is increasingly substituted by private law. Administrative law as the auspice or source of remedies is replaced by the law of contract, equity and the private law of torts. And, once the state is no longer ‘rowing’ (delivering services) but only ‘steering’ (through dispensing funding), the locus of responsibility for policy objectives and accountability moves to civil society organisations (corporations, voluntary associations) or citizens (consumers/carers as recipients of funds). Government and other funders can then only rely on good faith or contractual agreements as a governance form (hence the labels ‘contracting out’, and neoliberal governance for this transformation).

As with vulnerable groups more generally, any purist neoliberal assumption of equality and freedom of contract, or of capacity to exercise choice in meaningful and responsible ways, becomes highly questionable;<sup>100</sup> indeed special support is often required to actualise the theoretical values of market choice factors.<sup>101</sup> Personalised budgets *necessarily* risk exposing the most isolated and marginalised.<sup>102</sup> Certainly there are private law doctrines that can potentially be invoked to mitigate such risks or remedy problems which arise. To take informal money management as an example, equitable principles of undue influence may enable defective transactions to be set aside, while fiduciary obligations can constrain malfeasance by informal supporters who act contrary to the disabled consumer they are assisting.<sup>103</sup> However, these remedies are ill-suited in practice to the needs of ordinary people lacking the financial and other resources to successfully correct financial abuse or mismanagement.

Isolated from the wider community and reliant on the informal assistance of family or friends responsible for the problem, concerns are less likely to come to public attention, and much less be remedied. Empirical evidence about these issues is scant.

#### **D How Uniform Are the Needs and Required Responses?**

So what is the likely contribution of supported decision-making and personal budgets, and what alternative approaches should be considered? Is it likely that the answer will be the same for the aged, those with psychosocial disability and those with a cognitive disability? Or can a one-size-fits-all program even be

---

100 Rachel Fyson and John Cromby, ‘Human Rights and Intellectual Disabilities in an Era of “Choice”’ (2013) forthcoming *Journal of Intellectual Disability Research*.

101 Carmel Laragy and Goetz Ottmann, ‘Towards a Framework for Implementing Individual Funding Based on an Australian Case Study’ (2011) 8 *Journal of Policy and Practice in Intellectual Disabilities* 18.

102 Carmel Laragy, ‘Snapshot of Flexible Funding Outcomes in Four Countries’ (2010) 18 *Health & Social Care in the Community* 129, 131.

103 Fiona R Burns, ‘The Elderly and Undue Influence Inter Vivos’ (2003) 23 *Legal Studies* 251; Fiona R Burns, ‘Undue Influence Inter Vivos and the Elderly’ (2002) 26 *Melbourne University Law Review* 499.



delivered across any one of these groups? The evidence does not yet exist to assay a definitive answer, but human variability and differences in the social gradient of human capability and social capital (access to close networks and levels of local resources) – as well as inequalities of income, community tolerance and geographic difference – suggest that the answer is a resounding ‘no’.

For example, if the lodestone for supported decision-making includes authentic reading of the values and wishes of the person being assisted, then there is arguably a greater difficulty in doing so for a person with a profound intellectual disability than for someone who suffers an acquired brain injury as an adult, or an aged person with dementia, where there is a greater stock of prior autonomous life experience on which to draw. There are greater operational challenges for intellectual disability because of the absence (or limited stock) of prior knowledge about the values and wishes of the person.<sup>104</sup> Turning to people with psychosocial disability, the fact that the capacity of people in this group is more likely to fluctuate may call for unique supported decision-making arrangements.

Recent Australian research on three types of informal support networks for people with an intellectual disability, ranging from tightly organised ‘circles of support’ to more informal operations, for instance, found many examples of ‘incidental and subtle’ rights violations across all of the nine networks studied.<sup>105</sup> Likewise, in the cautionary words of the review by Kohn, Blumenthal and Campbell, while supported decision-making has the potential to greatly expand human agency and choice for consumers, there is also ‘reason to be concerned that supported decision making may facilitate largely unaccountable third parties improperly influencing the decisions of persons with disabilities, thereby disempowering persons with disabilities and undermining their rights.’<sup>106</sup>

It is imperative that research on different supported decision-making models explores the views of people with disabilities about both the theory and reality of supported decision-making. Some consumers for example may be flatly opposed to the notion that they require a supporter to assist them to make decisions, let alone a substitute decision-maker.

#### IV CONCLUSION

Both Australia’s disability reforms scheme<sup>107</sup> and proposals for aged care<sup>108</sup> involve expanding the space for personal choice (and the range and complexity

---

104 Carney, above n 64, 61.

105 Hillman et al, above n 73, 1068.

106 Kohn, Blumenthal and Campbell, above n 10, 1157.

107 Maree Dyson and Sally Canobi, ‘A Long Term Disability Care and Support Scheme for Australia: Opportunities for Disability Sector Reform’ (2011) 5 *Asian Social Work and Policy Review* 138; Productivity Commission, *Disability Care and Support* (Inquiry Report, 10 August 2011) <<http://www.pc.gov.au/projects/inquiry/>

of choices) for groups whose decision-making may require assistance. Around the world a wide variety of forms of law, hybrids of different forms of law and social processes (such as legal ‘recognition’ of informal arrangements) and civil society or family processes (such as ‘circles of support’) have been deployed to advance the rights of people with disabilities to participate in society as active citizens, with choice and control over the resources that they need to maximise their participation in all aspects of social life, in accordance with the ‘equality’ principle of the *CRPD*.

Power, Lord and deFranco sum up the ‘key building blocks of personalisation’ as revealed by their international comparison as follows:

[T]he study has identified a number of demand-side reforms centred on restoring power ... [including] independent planning/brokerage, individualised funding allied with fiscal facilitation, and access to a support coordinator/direct support worker. Alongside these mechanisms, the [law] needs to enable supported decision making.<sup>109</sup>

In other words, supported decision-making forms one of a suite of mainly social or community services and civil society measures. While some of the legal encapsulations of such supported decision-making measures have been informed by public enquires such as the work of law reform commissions, there is a distinct lack of evidence-based evaluations. The measures devised so far often appear to have been created from whatever ideas were to hand. Just as Australian bush pioneers were famed for ‘repairing’ complex machinery with bits of fencing wire, this sometimes works out well, and sometimes not.

Supported decision-making has been promoted as a primary means of respecting the right to legal capacity without discrimination on the basis of disability recognised in article 12 of the *CRPD* and more broadly facilitating the participation of people with disabilities in society on an equal basis with others. Legislative models have been implemented in some countries, most prominently in Canada, and informal approaches are on the increase around the world. However, there has been only minimal research to date on the practical implementation of supported decision-making in its different guises. Might Kohn, Blumenthal and Campbell be correct in cautioning policymakers to hasten slowly,<sup>110</sup> just as Brayley<sup>111</sup> is right to remind of the importance of evaluating supported decision-making from the perspective of a system or the whole of society? This article argues that this is indeed wise advice. The issues at stake for people with cognitive and psychosocial disabilities and the public interest are too significant and potentially grave to be decided on the basis of the ‘muddling

---

disability-support/report>.

108 See above n 57 and accompanying text. The issues were most fully canvassed in the draft report: Productivity Commission, *Caring For Older Australians* (Draft Report, 21 January 2011) <<http://www.pc.gov.au/projects/inquiry/aged-care/draft>>.

109 Power, Lord and deFranco, above n 12, 493–4. For a short synopsis of what is entailed by each of the items on this list, see Power, Lord and deFranco, above n 12, 442–4.

110 See Kohn, Blumenthal and Campbell, above n 9.

111 Brayley, above n 10.

through' of bricolage, or on the basis of normative arguments alone. Supported decision-making, in its various social, quasi-legal and legal forms, warrants careful empirical research and pilot programs to guide legislative and social policy reform.

A preliminary question that may be enlivened by empirical research is: what exactly is, or should be, meant by the term 'supported decision making'? Although a number of informal and legal arrangements are considered to fall within this middle portion of the stairway between autonomous and substitute decision-making, our understanding of this concept requires refinement as the implications of different arrangements are teased out. The extent to which legal decision-making power resides with the supported person is another critical issue; how it is resolved will fundamentally alter the practical operation of supported decision-making and whether it is genuinely distinct from substitute decision-making. That is not to say that supported decision-making cannot exist as one step along the stairway from autonomous to substitute decision-making, alongside other new models in the neglected long middle portion, but its form needs to be informed by evidence.

Public appointments, subject to oversight and approval by agencies like courts and tribunals, are likely to work very differently to informal approaches, such as 'circles of support', and non-statutory agreements. On the one hand private-arranging is the most empowering measure and the one arguably most consistent with the *CRPD*'s equality principle. But if the arrangement remains entirely shielded from outside gaze (in not being notified to say a body like an Office of Public Advocate on its creation) or if it is not required to incorporate some protective mechanism (such as the South Australian trial study use of a third party 'monitor', or the inclusion of reporting obligations for supporters), some hesitation must surround the potential for its misuse and even abuse. Of course even the most altruistic and progressive of the purely informal support arrangements have already been found to come with the baggage of 'incidental and subtle' rights violations,<sup>112</sup> and even personal budget reforms to community service provision arrangements carry similar risks.

Empirical evidence is needed to assess the frequency and magnitude of a number of possible unintended consequences of supported decision-making. For example, will supported decision-making lead to net widening, such that even greater numbers of people with disabilities become subject to measures diminishing rather than expanding the exercise of their legal capacity? Will supported decision-making operate in practice as *de facto* guardianship? Or will any overspill actually unintentionally benefit certain groups, such as say the frail aged, by protecting against neglect and exploitation and boosting their capacity to make decisions they would otherwise struggle with? To what extent do the different models give rise to rights violations, and how can such violations best be guarded against? Do isolated individuals risk discriminatory resort to guardianship? Existing research on supported decision-making and cognate

---

112 Hillman et al, above n 73, 1068.

reforms already highlights the need for educative measures to ensure respect for the capacity respecting goals of the *CRPD* in implementation of supported decision-making (and more broadly in furthering the participation of people with disabilities in society as well as decisions about their lives) and for administrative and policy machinery to ensure that support networks are actually available for the isolated, but much more is needed.

What are the wider implications of this preliminary sketch of issues arising in one illustrative area where public law, private law, educative soft law, hybrid forms of law and social arrangements, and pure civil society voluntary arranging are combining in a 'bricolage'? We remain at best agnostic to normative answers to this question on the basis of this review. The evidence to date, scant as it is, raises too many doubts about the risks and unintended outcomes for even tentative answers to be advanced in favour of say private-arranging at one extreme, or strong public law accountability machinery at the other. Realisation of the right to equality of participation on the part of people with cognitive and psychosocial disabilities is too fragile to be entrusted to experimental lawmaking or well-intentioned but ultimately mistaken application of normative principles. When it comes to drawing lines between traditional forms of private or public law in this regard, evidence-based law and policymaking is surely required at these new sites of 'bricolage'. When solid research is to hand for this and other examples, only then may it be possible to begin to devise some more general principles to guide medium term development in similar hybrid situations.