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### ***People with Dementia and other Cognitive Disabilities: Relationally vulnerable or a source of agency and care?***

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# PEOPLE WITH DEMENTIA AND OTHER COGNITIVE DISABILITIES: RELATIONALLY VULNERABLE OR A SOURCE OF AGENCY AND CARE?

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## Abstract

This article discusses the role of the law in community and residential care settings for people with dementias. It argues that the richer concept of relational autonomy offers a very useful analytical lens for understanding ethical, social and legal issues in dementia care, while its close companion ‘vulnerability’ also is of some assistance, despite its lack of definitional purchase. It suggests however that their main contribution is grounding discussion more closely in the lived lives of people and the rich ‘harmonies’ sought to be built to better realise the *Convention on the Rights of Persons with Disabilities* ‘will preferences and rights’ of people with dementia, while detecting and correcting for the ‘disharmonies’ in such relationships of care and support.

## I INTRODUCTION

Dementia is a rich site of social policy, legal and ethical questions.<sup>1</sup> Demographic ageing of the population profile has boosted the proportionate share of people in age bands prone to higher incidence of the dementias.<sup>2</sup> At the same time, neoliberal governance reforms to delivery of aged care and disability services have seen community-based or civil society initiatives favoured over a shrinking sector of state-provided or state-funded (and often fairly standardised) services. This is accompanied by preference for delivery of tailor made services under the direct control of recipients (personal budgets). Community care packages in aged care<sup>3</sup> and individualised plans

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<sup>1</sup> See for instance: Charles Foster, Jonathan Herring and Israel Doron (eds), *The Law and Ethics of Dementia* (Oxford, UK: Hart Publishing, 2014).

<sup>2</sup> This has been well known publicly for the last decade and a half: AccessEconomics, ‘The Dementia Epidemic: Economic impact and positive solutions for Australia’ (Canberra: Access Economics Pty Ltd, 2003) <<http://www.accesseconomics.com.au/dementia.htm>>.

<sup>3</sup> Tracee Cash, Wendy Moyle and Siobhan O’Dwyer, ‘Relationships in Consumer-directed Care: An integrative literature review’ (2017) 36(3) *Australasian Journal on Ageing* 193, 202 [special challenges of consumer directed care for people with dementia]; Jenny Day et al, ‘Home Care Packages: Insights into the experiences of older people leading up to the introduction of consumer directed care in Australia’ (2017) 23(2) *Australian Journal of Primary Health* 162. Eligibility for and construction of home care packages is governed by provisions of the *Aged Care Act 1997* (Cth) as amended, see: ss 21.3 (eligibility), 22.4 (assessment), Part 2.3A (prioritisation of home care), Part 3.2 (home care subsidy to providers).

and supports under the National Disability Insurance Scheme (NDIS) for people experiencing serious disability prior to aged pension age,<sup>4</sup> are two examples.

Not only is the social and community picture of the location, expectations and needs of older people with cognitive disabilities changing, there are dramatic changes in how disabilities are conceptualised, with the rise of social construction of disability under the ‘social model’ and the decline if not the death of the ‘medical model’ (of disability inherent in an impairment). This challenges some of the older items in the legal toolkit for advance planning in anticipation of incapacity (the comparatively recent development of the enabling tool of ‘durable powers’) or in managing its consequences (challenging the ancient tool of guardianship, derived from 13<sup>th</sup> century English prerogative powers and even earlier Roman law origins). In place of tools authorising *substitute* decision-making by someone other than the person with the cognitive impairment, the *Convention on the Rights of Persons with Disabilities* (‘CRPD’) calls for a new approach of supporting the person to make their own decision consistent with recognition of their will, preferences and rights. And while the CRPD’s insistence on sending the old tools to the refuse tip has been resisted in practice, supported decision-making philosophy is infusing legal reform proposals and legislative initiatives, with even greater purchase outside the law (in the form of what is better termed ‘decision-making support’<sup>5</sup>).

It is self-evident that the circumstances and life histories of people with a congenital cognitive impairment (intellectual disability ‘ID’) differ from those with acquired brain injury (‘ABI’) or mental illness. People with a dementia, along with those anticipating mental illness, are able to ‘self-plan’ for their future needs should their cognitive capacity decline or be temporarily impaired. They can meaningfully select and appoint someone with authority to act for them (enduring power of attorney, personal care or health care) or in the jurisdictions which

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<sup>4</sup> Christiane Purcal, Karen R Fisher and Carmel Laragy, ‘Analysing Choice in Australian Individual Funding Disability Policies’ (2014) 73(1) *Australian Journal of Public Administration* 88; Gemma Carey et al, ‘The Personalisation Agenda: The case of the Australian National Disability Insurance Scheme’ (2018) 28(1) *International Review of Sociology* 1. Plans are negotiated and funded in accordance with the principles and processes set out in Part 2 of Chapter 3 of the *National Disability Insurance Scheme Act 2013* (Cth). Further, Terry Carney et al, ‘National Disability Insurance Scheme Decision-making: Or when tailor-made caseplanning met Taylorism and the algorithms?’ (2019) 42(3) *Melbourne University Law Review Advance* [available at <https://law.unimelb.edu.au/mlr/issues/forthcoming>].

<sup>5</sup> Chris Bigby and Jacinta Douglas, ‘Support for Decision making - A practice framework’ (Bundoora, Melbourne: La Trobe University Living with Disability Research Centre, La Trobe University, 2016) <<http://hdl.handle.net/1959.9/556875>>.

permit it, appoint a ‘supporter’ to assist in realising future decisions. Neither someone with an ABI nor a person with ID realistically can use such self-planning tools. Instead some other person needs to request or take advantage of some other legal tools. Options include applying for adult guardianship or financial management appointments, taking advantage of any automatic but narrow ‘standing authority’ covering health decisions (provided in some jurisdictions to ‘listed’ persons such as spouses<sup>6</sup>), or turning to very limited tools such as Special Needs Trusts (which allow *others* to lay down viable financial plans for future care and support, free of unnecessary social security traps).<sup>7</sup> Guardianship presently is the most likely of these. This is because, while originally reformed in the 1980s in anticipation of heavy demand from deinstitutionalised ID residents decanted into community living, adult guardianship caters hardly at all to that group, but instead is actually invoked mainly for the aged, especially those in residential care due to dementias.

Because cognitive impairments implicate very different personal circumstances and social contexts, and present such different care and support needs, generalisation across the four main groups is quite perilous. Both in the application of theories (agency, vulnerability, rights perspectives) and in debates around community services and legal options, this article therefore concentrates on the circumstances and context of people with a dementia. So what is special about the case of the dementias, in say the way care and support needs arise? First the condition is of comparatively slow onset and arises after a person has developed relatively settled values, preferences and lifestyle. People with early dementia are also likely to have already formed (if not always maintained) a close interpersonal relationship of choice, though unlike someone with ID they are unlikely to have a living parent, with the closest blood relatives expressing care obligations most likely to be offspring (most commonly daughters) rather than siblings. Community care within the family home from informal carers such as partners or a member of the family living nearby (such as a daughter or son) thus is the setting accounting for the bulk of dementia care and for the majority of the time after diagnosis. This poses issues about how well

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<sup>6</sup> 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 Lawbook Co, 3rd ed, 2018) 207.

<sup>7</sup> Terry Carney, ‘Adult Guardianship and Other Financial Planning Mechanisms for People with Cognitive Impairment in Australia’ in Lusina Ho and Rebecca Lee (eds), *Special Needs Financial Planning: A Comparative Perspective* (Cambridge University Press, 2019) 3.

the will and preferences of the person are respected in such settings, along with the operation of any substitute decision-making (whether informal or formal). Finally, the natural progression of the disease and the ‘rising curve’ incidence rates of dementias with older age, means that higher proportions of people with the most substantial dementia care needs will lie in the ‘old-old’ age brackets. Here the chances of the person living alone (through death/divorce) or with needs that over-tax the capacity of their ‘live in’ carers (due to their own infirmity or relationship strains), raise additional issues. Due to the pressures on family in late stage care, dementia for example accounts for a little over half (52%) of aged care residents.<sup>8</sup>

This article considers how theories of relational autonomy, vulnerability and human rights principles might inform thinking about the role of the law in both community care settings and in residential care, touching lightly on a few of the many questions. Questions such as: how well do family carers perform their informal support and decision-making roles? Are self-planning tools such as enduring powers under- or over-used? Can proxy-decision-making be avoided in late dementia? Is guardianship under- or over-used? Does or could the web of family and close carer relationships truly serve as a ‘natural stabiliser’ against risks of abuse and oppression? Can ‘risk averse’ policies of private sector aged care facilities in insisting on unnecessarily obtaining of substitute decision-making instrument (or guardianship) as a prerequisite of entry be changed through law reform, or is law relatively powerless?

The article argues that the richer concept of relational autonomy is a very useful analytical lens for understanding ethical, social and legal issues in dementia care, while its close companion ‘vulnerability’ also is of some assistance, despite its lack of definitional purchase. However their main contribution is in grounding discussion more closely in the ‘lived lives’ of people and the rich ‘harmonies’ sought to be built to better realise the will preferences and rights of people with dementia, while detecting and correcting for the ‘disharmonies’ in such relationships of care and support.

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<sup>8</sup> NATSEM, ‘Economic Cost of Dementia in Australia 2016-2056’ (Canberra: The National Centre for Social and Economic Modelling, 2017) <<http://www.natsem.canberra.edu.au/publications/?publication=economic-cost-of-dementia-in-australia-2016-2056>> 16.

## II WHERE STANDS LAW AND THEORY?

There are challenging conceptual issues entailed in theorising agency in the context of informal support, formalised supported decision-making or guardianship.<sup>9</sup> The same is true for the concept of vulnerability,<sup>10</sup> drawing as it does on similar ‘networks’ of reciprocal relationships of reliance and support. These can only be sketched here.<sup>11</sup>

### A *Relational autonomy and vulnerability*

Situated in feminist scholarship of writers such as Martha Fineman,<sup>12</sup> relational autonomy – framed not as an atomistic or purist classical liberal conception of human agency but as *socially embedded networks* of human interactions with and reliance on others<sup>13</sup> – has obvious appeal in describing the lived lives of people, whether they be with or without cognitive impairments. Likewise acceptance that everyone is vulnerable in the sense of needing the support of others at various points in their lives, as potential need rises or falls depending on life circumstances – most obviously in early childhood and late in life.

The nub of relational autonomy for people with a cognitive impairment lies in its emphasis on realisation of real world participation in life, and genuine respect for the will and preferences of the person irrespective of their degree of impairment.<sup>14</sup> It seeks to ensure respect for the moral personhood of all, without regard to levels of cognitive impairment or capabilities of the person in engaging their environment. For Eva Feder Kittay, such moral personhood lies

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<sup>9</sup> Terry Carney, ‘Supported Decision-making in Australia: Meeting the challenge of moving from capacity to capacity-building?’ (2017) 35(2) *Law in Context* 44.

<sup>10</sup> Nina A Kohn, ‘Vulnerability Theory and the Role of Government’ (2014) 26(1) *Yale Journal of Law and Feminism* 1.

<sup>11</sup> Further, Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014); Elif Celik, ‘The role of CRPD in Rethinking the Subject of Human Rights’ (2017) 21(7) *International Journal of Human Rights* 933; Yael Braudo-Bahat, ‘Towards a Relational Conceptualization of the Right to Personal Autonomy’ (2017) 25(2) *American University Journal of Gender, Social Policy & the Law* 111; Terry Carney, ‘Vulnerability: False hope for vulnerable social security clients?’ (2018) 41(3) *University of New South Wales Law Journal* 783.

<sup>12</sup> Martha Albertson Fineman, ‘The Vulnerable Subject: Anchoring equality in the human condition’ (2008) 20(1) *Yale Journal of Law and Feminism* 1 1-23; Catriona Mackenzie and Natalie Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press, 2000).

<sup>13</sup> For a recent review of liberal and relational conceptions of autonomy: Braudo-Bahat, ‘Towards a Relational Conceptualization of the Right to Personal Autonomy’, (n 11).

<sup>14</sup> Joanne Watson, ‘Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability’ (2016) 5(1) *Laws* 6 [1 at 5-7].

in the inherent *relationships* between the person with the impairment and others (such as family), irrespective of any (contested) ‘lack of rationality and capacity to determine one’s own good’.<sup>15</sup>

Vulnerability, usually conceived as a universal and fluctuating characteristic of the human condition,<sup>16</sup> has helpfully been said to comprise at least three analytically distinct (but overlapping) types:<sup>17</sup> those which are ‘inherent’ to the person; those which are ‘situational’; and those which are ‘pathogenic’ (exacerbated by, or manufactured by, defective social policies)<sup>18</sup> – of which more below when discussing safeguards and the care dilemma (Part II D). Situational vulnerabilities are ‘context-specific’, and stem from (or are compounded by) ‘the personal, social, political, economic, or environmental situation of a person or social group’ and may be short or long-term.<sup>19</sup> Both inherent and situational vulnerabilities are conceived as either latent or ‘occurent’ (when actualised by external circumstances). The elderly, Henk ten Have observes, are ‘paradigmatic examples’ of a vulnerable category,<sup>20</sup> due to potential intersections of physical and cognitive impairments either in the same individual, or (more commonly in dementia care) between the carer and the person cared for.

So conceived, an impairment of any function or ‘capability’, whether from disability or otherwise, is likely to increase reliance on others, accounting for the salience of relational autonomy and vulnerability paradigms within disability scholarship.<sup>21</sup> Commonly that reliance falls first on natural groupings such as family or friends, followed by any civil society agencies (such as religious or voluntary not-for-profit organisations), with government services, income transfer payments, and other benefits also able to be drawn on, whether in the alternative or by

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<sup>15</sup> Eva Feder Kittay, ‘At the Margins of Moral Personhood’ (2005) 116(1) *Ethics* 100 at 122; re-published as: Eva Feder Kittay, ‘At the Margins of Moral Personhood’ (2008) 5(2-3) *Journal of Bioethical Inquiry* 137; Matti Häyry, ‘Discursive Humanity as a Transcendental Basis for Cognitive (Dis) Ability Ethics and Policies’ (2016) 25(2) *Cambridge Quarterly of Healthcare Ethics* 262.

<sup>16</sup> Jonathan Herring, *Vulnerable Adults and the Law* (Oxford University Press, 2016).

<sup>17</sup> Wendy Rogers, Catriona Mackenzie and Susan Dodds, ‘Why Bioethics Needs a Concept of Vulnerability’ (2012) 5(2) *The International Journal of Feminist Approaches to Bioethics* 11, 23-25.

<sup>18</sup> Recently Mianna Lotz has explored situations of so-termed ‘discretionary’ (volitional assumption of) vulnerability and conceptualisation of cognate notions of ‘resilience’: Mianna Lotz, ‘Vulnerability and Resilience: A critical nexus’ (2016) 37(1) *Theoretical Medicine and Bioethics* 45.

<sup>19</sup> Rogers, Mackenzie and Dodds, ‘Why Bioethics Needs a Concept of Vulnerability’, (n 17), 24.

<sup>20</sup> Henk Ten Have, *Vulnerability: Challenging bioethics* (Routledge, 2016), 4.

<sup>21</sup> Jonathan Herring, ‘Losing It? Losing What? The Law and Dementia’ (2009) 21(1) *Child and Family Law Quarterly* 3; Kohn, ‘Vulnerability Theory and the Role of Government’ (n 10); Beverley Clough, ‘Disability and Vulnerability: Challenging the Capacity/Incapacity Binary’ (2017) 16(3) *Social Policy and Society* 469.

default. This is often represented as constituting the three ‘pillars’ or sectors of a modern welfare state,<sup>22</sup> though of course the ‘weight’ borne by close interpersonal, civil society and state spheres has varied over the course of history and between countries. All of this is actually very trite.

What is less trite, is how concepts of relational autonomy, vulnerability, or the operation of the pillars of the welfare state might be engaged by someone with a dementia. If that question is posed as one of ‘mapping’ need at a particular point in time it is obvious that there will be quite a large group of people who contemplate the possibility of loss of cognitive capacity and elect (or not) to plan for that future in ways designed to impress their present ‘will and preferences’ onto the management of their future circumstances, as discussed in the next Part.

## B *Legal and Program Issues in Early Stage Dementia Care*

While there is as yet a dearth of legal options for appointing a mere ‘supporter’ (lacking any decision-making powers),<sup>23</sup> there is now no shortage of options for self-planning a future need for proxy decision-makers.<sup>24</sup> However take-up is surprisingly low.

### 1 *Opting out of Self-planning; Why so little Legal Self-planning for the Future?*

Whether because people procrastinate rather than plan, are unaware of or cannot afford advice, or because the legal tools are premised on a somewhat idealised purist liberal conception of individual agency at odds with the preferences of many to ‘trust’ family and friends to sort things

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<sup>22</sup> For an extended historical exposition: Geoffrey Finlayson, *Citizen, State and Social Welfare in Britain, 1830-1990* (Clarendon Press, 1994).

<sup>23</sup> Both of Australia’s two largest jurisdictions may soon rectify this. Victorian legislation already allowed people to appoint a supportive guardian or administrator, but the anticipated 20 March 2020 proclamation of Part IV of its *Guardianship and Administration Act 2019* (Vic) will complete the suite by enabling the relevant Tribunal to do so (while reforming guardianship to privilege ‘will and preferences’ of the person and confine tailored and regularly reviewed substitute decision-making orders to a last resort). The reform package from the NSW Law Reform Commission trumps this in several important ways, including by avoiding the contradictory label of ‘supportive guardian’, dropping disability as a precondition, replacing guardianship and administration with the term ‘representative’, and collapsing guardianship and administration into a single order (or orders if more than one supporter or representative is called for): NSWLRC, ‘Review of the Guardianship Act 1987’ (Sydney: New South Wales Law Reform Commission, New South Wales Law Reform Commission, May 2018) <<http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Report/Report%20145.pdf>>.

<sup>24</sup> Carney, ‘Adult Guardianship and Other Financial Planning Mechanisms for People with Cognitive Impairment in Australia’ (n 7).



out in the future,<sup>25</sup> take-up is low. Only a small minority will it seems ever take advantage of the opportunity to execute enduring powers over say property, personal, or health care matters,<sup>26</sup> or even utilise ‘nominee’ arrangements for pensions (representative payees in the US).<sup>27</sup>

Studies suggest that when used in dementia cases, self-planning often starts rather too late and proves of limited value in shaping care outcomes.<sup>28</sup> And even when timely and implemented as intended, such plans may or may not manage to accurately project how a person would wish to decide as their ‘future self’, instead leaving them bound by values and preferences inaccurately anticipated by their ‘present’ self and personality (a common conundrum with end-of-life decisions about health care).<sup>29</sup> The hard social reality is that most people eschew using such formal substitute planning tools, with all their potential drawbacks from a CRPD standpoint.<sup>30</sup> The point here is that by far the largest proportion of people simply place their trust in the ability of their close circle of acquaintances to ‘muddle through’ on their behalf should cognitive ability be lost. And many continue to opt out and rely on such informal processes even after being diagnosed with a dementia. There are many things in play here, not least deeply held personal values favouring the relational over bare individuality, as well as cultural preferences of some ethnic backgrounds.

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<sup>25</sup> As a recent study details, the autonomy premise of advance planning tools receives serious competition from consensus-driven processes to locate the ‘most agreeable outcome’ in a given situation: Meredith Blake, Olivia Doray and Craig Sinclair, ‘Advance Care Planning for People with Dementia in Western Australia: An Examination of the Fit Between the Law and Practice’ (2018) 25(2) *Psychiatry, Psychology and Law* 197, 209-210, 214.<sup>26</sup> KH Dening, L Jones and EL Sampson, ‘Advance Care Planning for People with Dementia: A Review’ (2011) 23(10) *International Psychogeriatrics* 1535.

<sup>26</sup> KH Dening, L Jones and EL Sampson, ‘Advance Care Planning for People with Dementia: A Review’ (2011) 23(10) *International Psychogeriatrics* 1535.

<sup>27</sup> In the USA, only 9% of those with a severe dementia and 3% of those in early stages opt to appoint a representative: Anek Belbase and Geoffrey Sanzenbacher, ‘Cognitive Impairment and Social Security’s Representative Payee Program’ (Boston College MA Centre for Retirement Research, Centre for Retirement Research, Boston College MA, 2016).

<sup>28</sup> Louise Robinson et al, ‘A Systematic Review of the Effectiveness of Advance Care Planning Interventions for People with Cognitive Impairment and Dementia’ (2012) 41(2) *Age and Ageing* 263, 263-269.

<sup>29</sup> Nina A Kohn and Jeremy A Blumenthal, ‘Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique’ (2008) 42(4) *Georgia Law Review* 979, 1005-1006.

<sup>30</sup> Because these tools provide for ‘substitute’ decision-making, there are thorny issues about the extent to which they are really ‘terminable’ by someone with a dementia as it progresses, or whether it is really any breach of CRPD to ‘delegate’ in this way for the future, given it is not taken to be problematic to do so in the *immediate* present (as any citizen may do under an ordinary power of attorney): further, Terry Carney, ‘Supported Decision-making for People with Cognitive Impairments: An Australian perspective?’ (2015) 4(1) *Laws* 37, 45-46.

So what are the ethical issues here? Is this a kind of ‘de facto’ relational autonomy in action outside the law (in civil society) or a de facto form of paternalism or even abuse and oppression? Are the ‘opt out brigade’ blessed or vulnerable? The answer I suggest is a bit of both.

## 2 *Assessing Informal Management*

People who opt not to engage in formal forward planning are blessed by the opportunities and dignity of continuance (if gradual intensification) of previous life patterns of collaborative discussion, advice, acts of persuasion, and tacit or not so tacit deference to the views of close others. But they are vulnerable to subtle and unintentional, as well as to intentional, forms of abuse or oppression by the very same people.<sup>31</sup>

This duality is encapsulated in the care dilemma of increasing reliance on the boon of unbounded empathetic care by close family and the bane of its associated risks of intended or inadvertent abuse and neglect. A conundrum which exercises service providers and protective agencies alike. As later discussed, the dilemma is one of those ‘wicked’ problems difficult to strike a resolution of, not least due to the very privacy and isolation so valued by members of close family or similar relationships.<sup>32</sup> And it is compounded because it frequently manifests itself in mundane or routine settings like access to bank accounts or pensions, where few or rather cursory (and ineffective) check-and-balance protections are found,<sup>33</sup> and where reforms are not readily devised.<sup>34</sup>

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<sup>31</sup> For recent discussion: Catriona Mackenzie, ‘Moral Responsibility and the Social Dynamics of Power and Oppression’ in Katrina Hutchison, Catriona Mackenzie and Marina Oshana (eds), *Social Dimensions of Moral Responsibility* (OUP, 2018) 59, 62-66.

<sup>32</sup> Further, Carney, ‘Supported Decision-making in Australia: Meeting the challenge of moving from capacity to capacity-building?’ (n 9).

<sup>33</sup> Terry Carney, ‘Searching for Workable Alternatives to Guardianship for Vulnerable Populations?’ (2015) 1(1) *Ethics, Medicine and Public Health* 113, 116; Terry Carney, ‘Australian Guardianship Tribunals: An adequate response to CRPD disability rights recognition and protection of the vulnerable over the lifecourse?’ (2017) 10(Sp) *Journal of Ethics in Mental Health* <http://www.jemh.ca/issues/v9/theme3.html>

<sup>34</sup> But see ALRC, ‘Equality, Capacity and Disability in Commonwealth Laws: Final Report’ (Sydney: Australian Law Reform Commission, 2014), 86-89, 109-111-117, and for a critique: Carney, ‘Australian Guardianship Tribunals: An adequate response to CRPD disability rights recognition and protection of the vulnerable over the lifecourse?’ (n 33); ALRC, ‘Elder Abuse--A National Legal Response’ (Sydney: Australian Law Reform Commission, 2017) <<https://www.alrc.gov.au/publications/elder-abuse-report>> 164-174.

One possible answer to the care dilemma is capacity-building to develop greater insight and ability of carers/supporters to realise the will and preferences of the person being supported, and of their professional care network, to be more alert to and facilitative of such safeguards.<sup>35</sup> This ‘support for the supporter’ appears especially pressing for close relatives supporting someone with dementia. This is because the required care and the associated decline of the person with dementia is so stressful for carers;<sup>36</sup> not least because the decisions they are involved in readily shade into or become heart-renderingly difficult ‘proxy’ decisions such as those about restricting how and where a person lives their life,<sup>37</sup> and because even ensuring participation of the person with dementia in decision-making appears not to readily be realised.<sup>38</sup> Yet, capacity-building of supporters is rendered problematic because, admittedly in common with many programs and laws, we do not have evidence of whether, or for whom, it is effective.<sup>39</sup>

This uncertainty about the efficacy of support in part may account for the glacial international progress in legislating formal supported decision-making,<sup>40</sup> though resourcing and priority-setting considerations may also be in play.<sup>41</sup> Another barrier may be a cultural or

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<sup>35</sup> Christopher Shanley et al, ‘Providing Support to Surrogate Decision-makers for People Living with Dementia: Healthcare professional, organisational and community responsibilities’ (2017) 25(5) *Health & Social Care in the Community* 1563. However, differences between professions are evident: Craig Sinclair et al, ‘Professionals’ views and experiences in supporting decision-making involvement for people living with dementia’ (2019) *Dementia* pre-print DOI 10.1177/1471301219864849

<sup>36</sup> Deirdre Fetherstonhaugh et al, ‘Did I Make the Right Decision?’: The difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia’ (2019) 18(5) *Dementia* 1601.

<sup>37</sup> Kathryn Lord, Gill Livingston and Claudia Cooper, ‘A Systematic Review of Barriers and Facilitators to and Interventions for Proxy Decision-making by Family Carers of People with Dementia’ (2015) 27(8) *International Psychogeriatrics* 1301.

<sup>38</sup> Lyndsey M Miller, Carol J Whitlatch and Karen S Lyons, ‘Shared Decision-making in Dementia: A review of patient and family carer involvement’ (2016) 15(5) *Dementia* 1141.

<sup>39</sup> Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, ‘Supported Decision-Making: A Viable Alternative to Guardianship?’ (2013) 117(4) *Penn State Law Review* 1111; Nina A Kohn and Jeremy A Blumenthal, ‘A Critical Assessment of Supported Decision-making for Persons Aging with Intellectual Disabilities’ (2014) 7(1) *Disability and Health Journal* S40; Terry Carney, ‘Clarifying, Operationalising and Evaluating Supported Decision Making Models’ (2014) 1(1) *Research and Practice in Intellectual and Developmental Disabilities* 46; Chris Bigby et al, ‘Delivering Decision-making Support to People with Cognitive Disability – What has been learned from pilot programs in Australia from 2010-2015’ (2017) 52 *Australian Journal of Social Issues* 222.

<sup>40</sup> For a review of recent progress: Arlene Kanter and Yotam Tolub, ‘The Fight for Personhood, Legal Capacity, and Equal Recognition Under Law for People with Disabilities in Israel and Beyond’ (2017) 39(2) *Cardozo Law Review* 557, 596-607; Shih-Ning Then et al, ‘Supporting Decision-making of Adults with Cognitive Disabilities: The role of law reform agencies – recommendations, rationales and influence’ (2018) 61(Nov/Dec) *International Journal of Law & Psychiatry* 64.

<sup>41</sup> As argued in Terry Carney, ‘Prioritising Supported Decision-making: Running on empty or a basis for glacial-to-steady progress?’ (2017) 6(18) *Laws* 1.

perceptual inability to envision the supported decision-maker within traditional conceptions of citizenship and agency, instead seeing them as ‘cognitive foreigners’.<sup>42</sup> But whether support is formally recognised (bringing greater transparency) or is mainly informal, the care and other dilemmas of balancing autonomy and accountability remain. Relational autonomy and vulnerability clearly make a contribution to understanding the complexity of the issues, but do not in themselves offer solutions.

As shown in the next Part, the same is true at later stages in the lifecourse of the condition.

### C *Guardianship and Other Challenges of Later Stage Dementia Care*

Differently configured patterns of legal, ethical and service issues present once a dynamic or lifecourse standpoint is adopted. For while pre- or early diagnosis situations allow maximum flourishing of relational autonomy principles, and even avoidance of use of the substitute decision-making seen as incompatible with the CRPD, over time the situation alters in the case of a dementia. Proxy decision-making, whether de facto or formal (such as guardianship), almost inexorably looms.

#### 1 *The drift towards informal but de facto proxy decision-making*

Given the loss trajectory of dementias over time, as the person experiences the inevitable transformation or ‘slow unbecoming’ of the ‘self’, studies suggest that even ideal family or other civil society arrangements that start off honouring principles of supported decision-making, will subsequently transition to de facto substitute decision-making.<sup>43</sup>

Certainly it is true that community living accounts for the bulk of dementia care in Australia, with partners/spouses as the main care-givers.<sup>44</sup> So the generally quite nuanced and values-sensitive decision-making reported in studies of the ongoing legacy of what is termed ‘co-

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<sup>42</sup> Michael Bach, ‘Inclusive Citizenship: Refusing the construction of “cognitive foreigners” in neo-liberal times’ (2017) 4(1) *Research and Practice in Intellectual and Developmental Disabilities* 4.

<sup>43</sup> Kritika Samsi and Jill Manthorpe, ‘Everyday Decision-making in Dementia: Findings from a longitudinal interview study of people with dementia and family carers’ (2013) 25(6) *International Psychogeriatrics/IPA* 949.

<sup>44</sup> Deirdre Fetherstonhaugh, Jo-Anne Rayner and Laura Tarzia, ‘Hanging on to Some Autonomy in Decision-making: How do spouse carers support this?’ (2019) 18(4) *Dementia* 1219.

constructed couple-hood’,<sup>45</sup> can rightly be seen as a form of maximally preserved ‘relational autonomy’. But it is a relational autonomy that *evolves* and *transforms* over time – across a spectrum from facilitation, to the subtle shaping of choices in ‘managed autonomy’, through to more authentic forms of proxy decision-making (if tempered by being maximally informed by the values of the person) – as carers constantly reinterpret the remaining scope of what capability theory would conceive as the ‘functionings’ of the person with dementia.<sup>46</sup> This helps to understand that, in early stages at least, it is the quality of the interactions regarding *retained* functionings that matters more than *loss* of a past functioning (of the ilk that ‘I always wanted to be PM but I’m now happy as a train driver/happy returning to train driving’).

However lack of concern about a shrinking decisional domain does not diminish the safeguards paradoxes of care (care dilemma) when choices are overridden, removed or protested against (Part II D).<sup>47</sup>

## 2 *Pressures for Formalisation of Decisional Powers*

Of course there are many factors that may prompt initiation of advance planning,<sup>48</sup> but as already mentioned, admission to residential care is often powerful here.

The residential care transition is double-edged. For a number it unnecessarily precipitates the making of potential (durable power) or actual (guardianship order) substitute decision-making authority. Others enter care due to other frailties while being cognitively sound, only to develop a cognitive impairment afterwards. Many confront issues of social isolation due to the often quite advanced age of people at entry (and thus diminished community/family networks), coupled with the well documented ‘conformity’ and disempowering effect of living in what Goffman termed a ‘total institution’ where life is lived

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<sup>45</sup> Ibid 12. For an Australian study, see Craig Sinclair et al, ‘How Couples with Dementia Experience Healthcare, Lifestyle, and Everyday Decision-making’ (2018) 30(Sp 11) *International Psychogeriatrics* 1639.

<sup>46</sup> Catherine Le Galès and Martine Bungener, ‘The Family Accompaniment of Persons with Dementia Seen Through the Lens of the Capability Approach’ (2017) 18(1) *Dementia* 55 [the valued things and states that individuals ‘do’ or ‘are’].

<sup>47</sup> Ibid 11ff.

<sup>48</sup> For a review see: JT van der Steen et al, ‘Factors Associated with Initiation of Advance Care Planning in Dementia: A Systematic Review’ (2014) 40(3) *Journal of Alzheimers Disorders* 743; Meredith Blake, Olivia Doray and Craig Sinclair, ‘Advance Care Planning for People with Dementia in Western Australia’ (n 25), 205.

24/7 in the one place, reliant on dealings with a single group of staff carers<sup>49</sup> (giving rise to an unwillingness to protest denials of rights).

Recruitment of potential supporters has proved difficult and costly for the socially isolated,<sup>50</sup> and it is doubly difficult to institute supported decision-making for dementia residents. Not only are formal or family supporters harder to find, they are far removed from the all-important ‘daily lives’ of the people whose significant decisions they seek to support, such as their daily choices of clothing.<sup>51</sup> And of course even a proxy decision-maker such as a guardian or holder of a power of attorney over personal affairs or health may lack adequate knowledge of how to realise a person’s will and preferences, a deficiency a pilot project for legal representatives in Germany sought to tackle.<sup>52</sup> Thought might therefore need to be given to *other* ways in which ‘deliberative assistance’ might be provided to staff to build a residential culture of recognition for active realisation of will and preferences of residents.<sup>53</sup>

While completely at odds with many readings of CRPD obligations contending that no-one ever warrants substitute decision-making,<sup>54</sup> it is nevertheless arguable that formal guardianship at least is preferable to the unconstrained informal *de facto* guardianships found by Samsi and Malthorpe in later stages of community care. This is because the power is official rather than informal (public rather than private), and attracts at least theoretical protections of regular review and potential monitoring. In practice however, the comparatively short durations

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<sup>49</sup> Erving Goffman, *Asylums: Essays on the social situation of mental patients and other inmates* (Doubleday, 1961) 1-124. For an application of this and Goffman’s dramaturgical and frame analysis to infantilisation of residents of nursing homes, see Stephen M Marson and Rasby M Powell, ‘Goffman and the Infantilization of Elderly Persons: A Theory in Development’ (2014) 41(4) *Journal of Sociology & Social Welfare* 143.

<sup>50</sup> Bigby et al, ‘Delivering Decision-making Support to People with Cognitive Disability – What has been learned from pilot programs in Australia from 2010-2015’ (n 39).

<sup>51</sup> Deirdre Fetherstonhaugh et al, “‘The Red Dress or the Blue?’” How Do Staff Perceive That They Support Decision Making for People With Dementia Living in Residential Aged Care Facilities?’ (2016) 35(2) *Journal of Applied Gerontology* 209.

<sup>52</sup> Julia Lühnen, Ingrid Mühlhauser and Tanja Richter, ‘Informed Decision-making with and for People with Dementia: Developing and pilot testing an education program for legal representatives’ (PRODECIDE)’ (2017) *Dementia DOI* 10.1177/1471301217746751.

<sup>53</sup> Braudo-Bahat, ‘Towards a Relational Conceptualization of the Right to Personal Autonomy’(n 11) 143-145 [discussing the idea in the context of hospital care]. For a Finnish ethnographic study of practices that may preserve, or may undermine the continuity of self within a total institution setting such as residential aged care, see: Jari Pirhonen and Ilkka Pietilä, ‘Patient, Resident, or Person: Recognition and the continuity of self in long-term care for older people’ (2015) 35 *Journal of Aging Studies* 95 [the positive factors were ‘privacy, continuing habits, arguing, humor, and active emphasis on residents’ wishes’: *ibid* 99].

<sup>54</sup> For discussion, Carney, ‘Supported Decision-making for People with Cognitive Impairments: An Australian perspective?’ (n 30) 38-44.

of residential dementia care and resource constraints on the work of guardianship tribunals or watchdogs such as offices of the public guardian, may largely empty these protections of meaningful value.

### 3 *The adult guardianship order challenge*

Certainly the equality principle of Article 12 of the CRPD poses major challenges internationally in dementia management,<sup>55</sup> not least in Australia.<sup>56</sup> This is because the overwhelming bulk of rising demand for CRPD problematic guardianship orders, are made on the basis of such diagnoses.<sup>57</sup>

Ultimate reliance on guardianship orders in late stage dementia care, especially in residential settings, is no surprise given the evidence about progression by informal carers from genuinely facilitative support to full de facto proxy decision-making. This starts with taking over the ‘bigger’ or more complex decisions while often leaving room to respect the autonomy of the person with a dementia over less complicated (and less risky) decisions. In a sense, then, guardianship is a formal *continuation* of a previously de facto status. However, despite principles of the least restrictive alternative, best interests, and partial rather than plenary authorities, guardianship at heart *removes* the person’s decisional powers. This breach of the equality principle of Art 12 of the CRPD, and retention of some form of (in)capacity test for making an order – even if that is now more a functional than cognitive test in Australia<sup>58</sup> – is what makes guardianship so problematic here.

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<sup>55</sup> Thomas Klie and Jörg Leuchtner, ‘Mental Capacity: The meaning of the convention on the rights of persons with disabilities for people with dementia in Germany’ (2015) 28(1) *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry* 7.

<sup>56</sup> Anita Smith and Danny Sullivan, ‘A New Ball Game: The United Nations Convention on the Rights of Persons with Disabilities and assumptions in care for people with dementia’ (2012) 20(1) *Journal of Law and Medicine* 28.

<sup>57</sup> For modelling of demographic and other changes and implications for guardianship see VLRC, ‘Guardianship: Final Report’ (Melbourne: Victorian Law Reform Commission, Victorian Law Reform Commission, 2012), paras [4.16]-[4.37]; also NSWLRC, ‘Review of the Guardianship Act 1987’ (n 23) 15-16 paras [3.2]-[3.4] (significant shifts in composition and complexity of caseload).

<sup>58</sup> The critique of the disembodied abstraction involved in the search for the so-called ‘perfect capacimeter’ test of a person’s capacity to reason is well rehearsed (see Terry Carney, ‘Judging the Competence of Older People: An alternative?’ (1995) 15 *Ageing and Society* 515). More recent research also shows that most life decisions are made ‘quickly’ (intuitively) rather than through careful logical reasoning (‘slow thinking’): Daniel Kahneman, *Thinking Fast and Slow* (Penguin Random House UK, 2012).

Vulnerability theory has been suggested as a replacement test for when to make a guardianship order,<sup>59</sup> but as a *criterion* vulnerability to date has proved too fluid and ill-defined to trump the (admittedly itself problematic) current Australian test of last resort ‘functional need’.<sup>60</sup> Indeed Margaret Hall’s recent elaboration of vulnerability as a four-step process for appointing a guardians after discarding all other alternatives,<sup>61</sup> still cleaves quite closely to the foundational principles of Australia’s 1982 Cocks’ report.<sup>62</sup> Notions now nicely captured and blended with CRPD principles in the NSW Law Reform Commission proposals for assessing decision-making ability.<sup>63</sup> A vulnerability test also risks more rather than less paternalism. More promising for development of vulnerability thinking perhaps is the ‘narrative congruence’ perspective brought to bear on capacity by Gibson, in endeavouring to better accommodate the diachronic (life-course ‘video’) history of individuals in place of single-point-in-time pictures often obtained under medico-legal assessments of capacity.<sup>64</sup> But it is one thing to devise a new test or process of decisional ability, and quite another to find the resources of time (and money) for its operationalisation. The average Australian investment of around \$550 a guardianship hearing in current values,<sup>65</sup> buys very little ‘space’ for such assessments of whether the existing social context already ‘absorbs’ (negates) vulnerability, or could do so with capability building support for those people around the person needing assistance.

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<sup>59</sup> Margaret Hall, ‘Mental Capacity in the (Civil) Law: Capacity, autonomy and vulnerability’ (2012) 58(1) *McGill Law Journal* 61.

<sup>60</sup> Carney, ‘Australian Guardianship Tribunals: An adequate response to CRPD disability rights recognition and protection of the vulnerable over the lifecourse?’ (n 33); Carney, ‘Prioritising Supported Decision-making: Running on empty or a basis for glacial-to-steady progress?’ (n 41).

<sup>61</sup> Margaret Hall, ‘Situating Dementia in the Experience of Old Age: Reconstructing legal response’ (2019) 66(Sept/Oct) *International Journal of Law and Psychiatry* in press doi.org/10.1016/j.ijlp.2019.101468, pre-print p 5 [Part 4.3].

<sup>62</sup> Victoria, ‘Report of the Minister’s Committee on Rights and Protective Legislation for Intellectually Handicapped Persons’ (Melbourne: Victorian Government Printer, 1982) <[http://u.b5z.net/i/u/10196230/f/LISA\\_Cocks\\_Report\\_on\\_Guardianship\\_1982.pdf](http://u.b5z.net/i/u/10196230/f/LISA_Cocks_Report_on_Guardianship_1982.pdf)>.

<sup>63</sup> NSWLRC, ‘Review of the Guardianship Act 1987’ (n 23) 58-59 (‘assessing decision-making ability’). The Commission proposes an all-embracing *Assisted Decision-making Act* covering both supported and substitute decision-making (supporters and representatives respectively) made by way of advance agreements by the person or as orders of the tribunal: *ibid*, especially at xxii-xxxi, 1-2, 25-34, 41-46, 48-49, 56-59, 71-91, 93-97, 105-107, 121-152.

<sup>64</sup> David Gibson, ‘Negotiating Relationality: Mental capacity as narrative congruence’ [2017](23) *International Journal of Mental Health and Capacity Law* 49.

<sup>65</sup> Carney, ‘Australian Guardianship Tribunals: An adequate response to CRPD disability rights recognition and protection of the vulnerable over the lifecourse?’ (n 33) 5-6.



From the standpoint of the more promising lens of relational autonomy, it is well understood that the relationships in which personhood is embedded can either foster or undermine agency. This is true of the current toolbox of legal options. For its part, guardianship as currently constructed largely elides the relational; at best the relational network is relegated to its members being *consulted* in making an order, in constituting the favoured *group* when picking a guardian, and in serving as the social backcloth informing the *exercise* of proxy powers. Formally legislated or recognised supported decision-making leaves the workings of that relational network intact but elevates by their appointment, one or more network members to the facilitative role of helping to realise will and preferences. Informal decision-making, for its part, simply leaves everything in its natural state. Michael Bach contends that the reluctance to replace guardianship with a *right* to supported decision-making, effectively constitutes framing people with cognitive disabilities as ‘cognitive foreigners’ (whose political claims are foreign to traditional conceptions of citizenship and agency).<sup>66</sup> For the time being he therefore reluctantly advocates directing the political claim for enhanced rights into the rather utopian goal of ‘building communities where all belong. ... strengthen[ing] the foundations for legal recognition at some point in the future.’<sup>67</sup>

But whether located in the purely informal sphere, or accorded legal recognition under supported decision-making provisions, the relationships themselves retain their character of being boon or bane. For as Yael Braudo-Bahat observes

Paternalism, oppression and exploitation might characterize the relationships provided by the state, even when it makes an effort to formulate them as autonomy-enhancing relationships. Moreover, *the dynamic nature of relationships makes it rather difficult to regulate them, supervise them, or ensure that they are indeed constructive.*<sup>68</sup>

This very human, but dynamic interactive fluidity poses considerable problems in ensuring adequate safeguards and accountability in any and all settings. As next discussed, vulnerability

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<sup>66</sup> Bach, ‘Inclusive Citizenship: Refusing the construction of “cognitive foreigners” in neo-liberal times’ (n 42).

<sup>67</sup> Ibid 20.

<sup>68</sup> Braudo-Bahat, ‘Towards a Relational Conceptualization of the Right to Personal Autonomy’ (n 11) 142 [emphasis added].

and relational autonomy may shed light on why so little progress has been made on safeguards so far.

#### D *The Safeguards Care Dilemma Challenge Across the Dementia Lifecourse*

The safeguards challenge in community living settings is a product of the vulnerabilities associated with the previously mentioned ‘care dilemma’ implicit in *all* care relationships, where support for relational autonomy may degrade into unhealthy dependence, oppression or overt or covert abuse. In residential care settings it is the vulnerability associated with living in a closed environment, reliant on the quality of staff and administrative systems to guard against mistreatment. These are emblematic examples of the previously mentioned ‘situational’ vulnerability (context specific products of the ‘the personal, social, political, economic, or environmental situation of a person or social group’), while any avoidable failure to implement otherwise feasible safeguards against that risk constituting a pathogenic vulnerability.<sup>69</sup>

Provision of adequate safeguards and accountability in these settings is hard to realise because relationships of care and dependence arguably are one of those ‘wicked’ problems characterised by a multiplicity of interconnected issues and dilemmas, sometimes spoken of as ‘polycentric’ matters.<sup>70</sup> It is difficult to distinguish between genuinely assistive and facilitative support or care, and forms of ‘abuse’ or oppression of individuality.<sup>71</sup> One way to ameliorate this in Herring’s view is never to assess the needs or rights of a person in isolation, but always in a ‘situational context... in the context of their relationships’.<sup>72</sup> And to consider starting not with the interests of an autonomous individual, but the ‘norm of vulnerable, interdependent, caring people’, elevating among other things ‘upholding and preserving’ those relationships, including by ‘re-examining the distribution of support’.<sup>73</sup> Such a paradigm shift certainly resonates with

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<sup>69</sup> Respectively nn 19 and 18 and accompanying text above.

<sup>70</sup> Carney, ‘Supported Decision-making in Australia: Meeting the challenge of moving from capacity to capacity-building?’ (n 9).

<sup>71</sup> Anna Arstein-Kerslake, ‘An Empowering Dependency: Exploring support for the exercise of legal capacity’ (2016) 18(1) *Scandinavian Journal of Disability Research* 77; Carney, ‘Supported Decision-making in Australia: Meeting the challenge of moving from capacity to capacity-building?’ (n 9).

<sup>72</sup> Herring, ‘Vulnerable Adults and the Law’ (n 16) 16.

<sup>73</sup> *Ibid* 18-19.

Kelly Johnson's critique of the CRPD as unduly favouring *individual* civil rights, such as agency, over communal values of care and supportive relationships.<sup>74</sup>

However a process protection involving mere *consideration* of the social context of any networks of relationships of the person arguably is no panacea. Most of the wicked dilemmas remain; for example the subtle (and not necessarily conscious) shift from 'caring support' to exploitive or repressive paternalism,<sup>75</sup> or the messy mixture of realisation of will/preferences and paternalism found in Canadian fieldwork on informal support networks.<sup>76</sup> While particularly acute for people with ID<sup>77</sup> or others with a history of being raised within a family ethos of paternalism (sometimes quite subtle and sometimes very explicit),<sup>78</sup> the risk arises in dementia care as well, and irrespective of the residential setting.<sup>79</sup>

Recognising the realistic prospect that vulnerability risks undue paternalism, and finding ways of overcoming that risk, is taken seriously by Herring,<sup>80</sup> not least within the relationships of dependence considered here.<sup>81</sup> Of course everyone is influenced by family, friends or society at large,<sup>82</sup> but care/support relationships pose heightened risks 'because of the special

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<sup>74</sup> Kelley Johnson, 'The UN Convention on the Rights of Persons with Disabilities: A Framework for Ethical and Inclusive Practice?' (2013) 7(3) *Ethics and Social Welfare* 218, 227.

<sup>75</sup> Law Commission of Ontario, *Legal Capacity, Decision-Making and Guardianship* Interim Report (Toronto: Ontario Law Commission, Law Commission of Ontario, [released 11 Jan 2016] October 2015), 146.

<sup>76</sup> Sophie Nunnolley, 'Personal Support Networks in Practice and Theory: Assessing the implications for supported decision-making law' (Toronto: Law Commission of Ontario, 2015), 67, 75.

<sup>77</sup> Bernadette Curryer, Roger J Stancliffe and Angela Dew, 'Self-determination: Adults with intellectual disability and their family' (2015) 40(4) *Journal of Intellectual and Developmental Disability* 394 ('[d]espite the aspiration for choice and control espoused within the UNCRPD and Australian disability policies, the reality for many adults with intellectual disability is different.': 395.

<sup>78</sup> *Ibid* 396.

<sup>79</sup> See for example: ALRC, 'Elder Abuse--A National Legal Response' (n 34); Senate Community Affairs References Committee, 'Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability' (Canberra: Senate Community Affairs References Committee, 2015) <[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Violence\\_abuse\\_neglect/Report](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report)> Rae Kaspiew, Rachel Carson and Helen Rhoades, 'Elder Abuse' (Research Report Number 35, Australian Institute of Family Studies, 2016) <<https://aifs.gov.au/sites/default/files/rr35-elder-abuse.pdf>>.

<sup>80</sup> Herring (n 16) 24-25, 35.

<sup>81</sup> *Ibid* 36-37.

<sup>82</sup> Jonathan Herring and Jesse Wall, 'Autonomy, Capacity and Vulnerable Adults: Filling the gaps in the Mental Capacity Act' (2015) 35(4) *Legal Studies* 698, 709. See also Piers Gooding, 'Navigating the "Flashing Amber Lights" of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns' (2015) 15(1) *Human Rights Law Review* 45, 57 [while the problem calls for

accommodations required to assist the individual in the decision-making process and also because of the increased risk of domination and control'.<sup>83</sup> So safeguards are vital. Camillia Kong has criticised the CRPD for failing to adequately address issues of accountability and fidelity of purpose of its supported decision-making model,<sup>84</sup> but law in general struggles to accommodate the *mutuality* involved in 'care' and the 'support' aspects of interdependent social relationships.<sup>85</sup> This is especially problematic for severely disempowered groups such as those with advanced dementia. This is because transactions of ordinary social discourse or care which *actually* negate the will and preference of the individual can so easily go undetected and thus uncorrected for,<sup>86</sup> unless accountability safeguards operate on a very high state of alertness to such risk.<sup>87</sup> Understandable tendencies for families to withdraw into themselves,<sup>88</sup> isolating the person being supported from community interactions which might bring problematic situations to notice, adds a further layer of difficulty in constructing adequate safeguards in community settings. And as already discussed, residential care entails its own isolation and disempowerment.<sup>89</sup>

This is why construction of adequate safeguards against vulnerabilities is such a 'wicked' problem for supported decision-making;<sup>90</sup> and it is why the Rogers et al taxonomy of pathogenic vulnerabilities stemming from subtle shades of 'dysfunctionality' within social relationships, or any concerning features of 'oppression, domination...[etc.]', offers such a potentially fruitful new lens for their resolution. For, however difficult the challenge of resolving the 'care/support/paternalism' conundrum, it is argued that this is surely where academic analysis

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'concerted efforts to encourage maximal autonomy' it is an issue 'that all adult people must grapple with at an interpersonal level'].

<sup>83</sup> Arstein-Kerslake, 'An Empowering Dependency: Exploring support for the exercise of legal capacity' (n 71) 77.

<sup>84</sup> Camillia Kong, 'The Convention for the Rights of Persons with Disabilities and Article 12: Prospective Feminist Lessons against the "Will and Preferences" Paradigm' (2015) 4(4) *Laws* 709.

<sup>85</sup> Herring, 'Vulnerable Adults and the Law' (n 16) 15.

<sup>86</sup> Jillian Craigie, 'A Fine Balance: Reconsidering Patient Autonomy in Light of the UN Convention on the Rights of Persons with Disabilities' (2015) 29(6) *Bioethics* 398, 404.

<sup>87</sup> Herring and Wall, 'Autonomy, Capacity and Vulnerable Adults: Filling the gaps in the Mental Capacity Act' (n 82) 700.

<sup>88</sup> Kong, 'The Convention for the Rights of Persons with Disabilities and Article 12: Prospective Feminist Lessons against the "Will and Preferences" Paradigm' (n 84) 714.

<sup>89</sup> See (n 49) and accompanying text above.

<sup>90</sup> Carney, 'Supported Decision-making in Australia: Meeting the challenge of moving from capacity to capacity-building?' (n 9).

and empirical enquiry should now concentrate energies, so that the aspirations of supported decision-making can be realised to the maximum feasible degree.<sup>91</sup>

### III CONCLUSION

Social policy constructs of dementia have been shown to be fluid and responsive to a variety of different pressures.<sup>92</sup> Critics of the traditionally dominant ‘deficit’ model of dementia have rightly argued for new paradigms of active citizenship,<sup>93</sup> an approach with stronger resonance with relational autonomy or social citizenship scholarship. In similar vein the capability approach has been applied as a lens for understanding the way close family members act as supporters/proxy decision-makers for someone with dementia, mostly finding that they strive to provide what translates as ‘accompaniment’ (much as an orchestra accompanies a soloist).<sup>94</sup> As Le Gales and Bungener write,

Adopting the capability approach directs attention not to who gives care and why or for what result, in the sense of what final result, but on how one gives care, according to what ways things are done, what specific modes of accompaniment are used and for what reasons or motivations.<sup>95</sup>

Many of the issues canvassed in this article have been shown to be deeply implicated and embedded in the lived lives and relationships of the person with dementia. It is here that the richer concepts of relational autonomy and vulnerability prove their worth in helping to understand the ethical, social and legal issues in dementia care – searching out and promoting relational harmonies while remaining vigilant to correct disharmonies such as abuse and neglect, or even the ‘pathogenic’ vulnerability manufactured by poor legal processes. These concepts may also enrich understandings of the CRPD itself, as Camillia Kong suggests in arguing for a more ‘relational’ approach to strengthening required safeguards and protections when

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<sup>91</sup> Carney, ‘Prioritising Supported Decision-making: Running on empty or a basis for glacial-to-steady progress?’ (n 41).

<sup>92</sup> Ann-Charlotte Nedlund and Jonas Nordh, ‘Crafting Citizen(ship) for People with Dementia: How policy narratives at national level in Sweden informed politics of time from 1975 to 2013’ (2015) 34 *Journal of Aging Studies* 123.

<sup>93</sup> Linda Birt et al, ‘Shifting Dementia Discourses from Deficit to Active Citizenship’ (2017) 39(2) *Sociology of Health & Illness* 199.

<sup>94</sup> Le Galès and Bungener, ‘The Family Accompaniment of Persons with Dementia Seen Through the Lens of the Capability Approach’ (n 46).

<sup>95</sup> *Ibid* 20.

implementing the Convention. This is advanced as an antidote to application of unduly narrow classical liberal notions of autonomy and human agency,<sup>96</sup> a relational autonomy and vulnerability perspective recently also brought to bear by Kirsty Keywood in her critique of British arrangements for protection of vulnerable adults.<sup>97</sup>

However it would be a mistake to think that such conceptual insights are a *substantive policy* panacea, or that programs and laws are easily instituted to secure quality care outcomes. They are not. Isolation compounds risk, whether within the community or in residential care settings. And attitudes of carers, whether unpaid family or paid carers in residential aged care, are shaped by many forces beyond easy influence by others, much less by the law. Undue paternalism of a family member, or paternalistic policies like ‘requiring’ substitute decision-making instruments as a condition of admission to residential care, cannot be eliminated at the stroke of a law or social policy reformer’s pen. Nor are the concepts themselves rolled gold. Vulnerability proves rubbery.<sup>98</sup> And, for all its resonance with lived lives, relational autonomy predicates a synergistic partnership between the individuality of personhood and a (constructive) contribution from a personal network.<sup>99</sup> The shrinkage and diminution of individuality under the thrall of a dementia ultimately leaves will and preference increasingly to be read by the ‘other’. And if individuals are unable to envision the values, emotions, preferences (and will) of their future self in advance planning, surely so much more so for even a ‘close’ other?

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<sup>96</sup> Kong, ‘The Convention for the Rights of Persons with Disabilities and Article 12: Prospective Feminist Lessons against the “Will and Preferences” Paradigm’ (n 88).

<sup>97</sup> Kirsty Keywood, ‘The Vulnerable Adult Experiment: Situating vulnerability in adult safeguarding law and policy’ (2017) 53 *International Journal of Law and Psychiatry* 88.

<sup>98</sup> Further, Carney, ‘vulnerability: False hope for vulnerable social security clients?’ (n 11).

<sup>99</sup> Braudo-Bahat, ‘Towards a Relational Conceptualization of the Right to Personal Autonomy’ (n 13) 135ff.