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Deciding in Dementia: The Possibilities and Limits of Supported Decision-Making

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Keywords

Dementia; CRPD; Supported decision-making; Representation Agreement Act 2000; Assisted Decision-Making (Capacity) Act 2015

Abstract

Individuals and societies have interacted with people with dementia in different ways for as long as the condition has existed. Sometimes this has involved support; sometimes exploitation; and sometimes something in between. What sets the contemporary context apart is that, since the coming into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008, supported decision-making has assumed a formal legal dimension, one which has been adopted in different ways across different jurisdictions.

This article explores forms of supported decision-making through a dementia-centred lens, looking at the benefits of supported decision-making in dementia but also identifying conceptual and practical challenges. It argues that for people with dementia, the availability of supported decision-making offers a legal choice; a way of maintaining some degree of control for as long as possible. However, the specific challenges need to be appreciated. The article compares two legislative frameworks: the Representation Agreement Act 2000 in British Columbia and the Assisted Decision-Making (Capacity) Act 2015 in Ireland, both of which show the complexities involved in developing legislation in this arena.

1. Introduction

O you kind gods/ Cure this great breach in his abusèd nature/
Th' untuned and jarring senses, O, wind up/ Of this child-changèd father! (Cordelia, *King Lear*, Act IV, Scene VII)

Whether or not, as some have argued, King Lear suffered from Lewy Body Dementia, the play still provides a powerful illustration of both the possibilities and limits of supported decision-making in dementia. Cordelia represents an ideal of how supported decision-making can work; as Lear describes (as he and Cordelia are taken away to prison) 'so we'll live/And pray, and sing, and tell old tales, and laugh/At gilded butterflies' (Act V, Scene III). Goneril and Regan represent the dangers; mendacious and self-serving, they trick their

father into handing over power and then abandon him as his needs grow: 'old fools are babes again' (Goneril, Act I, Scene III).

As *King Lear* reminds us, humans have interacted with their loved ones with dementia in different ways for as long as the condition has existed. Sometimes this has involved support; sometimes exploitation; and sometimes something in between. What sets the contemporary context apart is that, since the coming into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008, supported decision-making has assumed a formal legal dimension. Under the CRPD, ratifying States are required to 'take appropriate measures to provide access by persons with disabilities to the support they require in exercising their legal capacity' (Art. 12(3)). As a direct result of this requirement, several States (including India, Ireland, and several Australian jurisdictions) have reformed their domestic legal frameworks to incorporate elements of supported decision-making.

Although disability NGOs played a central role in the negotiation of the CRPD (Dhanda, 2006-7; Kayess and French, 2012; Arstein-Kerslake, 2017), organisations representing people with dementia were not involved. Thus, the particular context of dementia did not receive attention. Yet, the kind of legal frameworks for supported decision-making which States adopt are of central importance to people with dementia and those who care for them. This article looks at supported decision-making from a dementia-centred perspective. Its core argument is that translating supported decision-making ideals into law is a complex process. Nonetheless, finding ways to maximise supported decision-making should be at the heart of law and policy development for dementia care.

The article begins by exploring the conceptual and human rights underpinnings for legal frameworks for supported decision-making. It then adopts a dementia-centred lens, looking at the benefits of supported decision-making in dementia but also identifying conceptual and practical challenges. The article then compares two legislative frameworks: the Representation Agreement Act 2000 in British Columbia and the Assisted Decision-Making (Capacity) Act 2015 in Ireland, both of which show the complexities involved in attempting to develop legislation in this area.

2. Supported Decision-Making: Conceptual and Human Rights Underpinnings

In evaluating the possibilities and limits of supported decision-making in dementia, it is useful begin by considering how this concept has evolved to a point where it represents a powerful alternative to traditional approaches centred on an 'objective' assessment of the best interests of people with dementia (Donnelly, 2010: 177-181).

2.1 Conceptual Antecedents

The conceptual antecedents for current discourse on supported decision-making derives from several sources. One is the social model of disability, which emerged first in (physical) disability studies in the 1970s. Among other aspects, this approach advances the distinction between impairment (a person's underlying condition) and the person's disability (the way in which the person's impairment has been socially constructed) (Abberley, 1987;

Oliver, 1990, 2009). In this way, this approach draws attention to the ways in which societal actions can reduce or remove the impact of disability.

A second antecedent is the critiques of individualist liberalism which began to emerge, initially from feminist scholarship in the 1980s (Baier, 1985, 1995; Kittay, 1999). Just as individualist autonomy was enjoying its normative heyday (Veatch, 1981; Engelhardt, 1986), feminist scholars began to question its underpinning presumptions. Of particular relevance was the challenge to the 'antecedently individuated' liberal subject (Sandel, 1997: 62). From these critiques, there have emerged constructions of the 'socially embedded' (Mackenzie and Stoljar, 2000: 4) and interdependent, relational subject (Kittay, 1999). This approach offered valuable new ways of thinking about conundrums in respect of female agency. It showed that agency could be enhanced or diminished depending on social context. Individuals are not simply autonomous or not autonomous; rather as Jennifer Nedelsky envisioned, one becomes autonomous or, as she frames it 'able to find and live in accordance with one's own law' (1989: 10). What is key for present purposes is the recognition that the development (or suppression) of autonomy always happens in the context of relationships with others.

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These arguments had significant traction, primarily because they are self-evidently in line with experience. It is indisputable that society plays a significant role in constructing impairment as disability and that societal structures can reduce the extent to which people with capacity impairments experience disability. It is also uncontentious that the vast majority of people operate within relational networks and draw on others when making decisions (Gilbar, 2011). No great act of imagination is required to appreciate the role of these networks in enabling people with impaired capacity to develop autonomy skills. Thus, it would seem reasonably safe to say that there is an overlapping consensus that supporting people with impaired capacity to live more autonomous lives is both a good thing and a possibility (Series, 2016). Beyond this, matters become more contentious. The binary opposition between impairment and disability, which the social model posits, is disputed, as is the 'hard' social constructionist model (Shakespeare, 2006, 2013; Terzi, 2004). Thus, as we move more towards the edges eg. situations of profound capacity impairment or situations involving complex relationships, there is much less consensus on the deliverability of supported decision-making (Series, 2016).

2.2 Incorporation into Human Rights Norms

As more developed understandings of supported decision-making were beginning to emerge (and before empirical evaluation of operation in practice had developed), the concept of supported decision-making came to assume centre stage in human rights discourse around impaired capacity. This was because of its inclusion as a key aspect of delivering on the equal right to legal capacity set out in Art. 12(2) of the CRPD. As noted above, Art. 12(3) expressly requires States Parties to provide support to persons with disabilities so that they can exercise their legal capacity. No further direct elucidation regarding what constitutes support is included in Art. 12(3). However, Art. 12(4) requires States Parties to ensure that 'all measures which relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law'. Such safeguards must ensure that 'measures relating to the exercise of legal capacity respect the rights, will and preferences of the person'.

There is an element of deliberate ambiguity regarding the meaning of the equal right to legal capacity in Art. 12 (Dhanda, 2006-7). Although it is clearly stated that decision-making support must be provided, there is no direct indication regarding the status of legal frameworks for substitute decision-making (i.e. legal frameworks which allow (some) decisions to be taken on behalf of a person with impaired capacity). In its first General Comment, the Committee on the Rights of Persons with Disabilities (the body charged with monitoring implementation of the CRPD) rejected all capacity-based distinctions as discriminatory and inconsistent with the equal right to legal capacity (GC No 1, 2014, para 15). It also rejected any basis for decision-making other than the will and preferences of the individual or, where 'after significant efforts have been made, it is not practicable to determine the will and preferences of an individual', the 'best interpretation of will and preferences' (para 21). Of most direct relevance to the discussion here is GC No. 1's interpretation that compliance with Art. 12 requires that all substitute decision-making regimes should be abolished and replaced with supported decision-making frameworks (para 28). In the view of the Committee, this should be immediately realized (i.e put in place without delay) (para 30). GC No. 1, as clarified by a subsequent Corrigendum (2018), provides a description of (prohibited) 'substitute decision-making regimes' (para 27). However, it offers little positive guidance regarding how States should develop their laws to provide for supported decision-making.

GC No. 1 was contentious (Gooding, 2015; Quinn,2016) with critics advancing a variety of normative objections to the down-playing of protective norms (Ward, 2014; Dawson, 2015; Freeman *et al*, 2015; Essex Autonomy Project; Donnelly, 2016). For the discussion in this article, the most significant concern with GC No. 1 is the lack of an evidence base regarding the feasibility of supported decision-making. Ratifying States are advised that compliance requires them to take a step into the unknown, in situations which involve some of the most vulnerable members of their societies. Given this, it is perhaps unsurprising that no ratifying State has, in fact, introduced measures to abolish substitute decision-making and that a significant number of States (Australia; Canada; Egypt; Estonia; Georgia; Ireland; the Netherlands; Norway; Poland; Singapore; Syrian Arab Republic; Venezuela) have ratified the CRPD subject to interpretative declarations/reservations in respect of Art. 12. These generally assert the ratifying State's view that Art. 12 permits substitute decision-making in some cases.

The resistance to the Committee's vision in GC No. 1 does not in any way reduce the normative attractions of supported decision-making as a significant part of any legal framework for impaired capacity. It does however focus attention on the need to develop a convincing evidence base, developed with reference to the different lived realities of people with impaired capacity. It is in this context that the specifics of dementia are now explored.

3. The Dementia Challenge

Every person's experience of dementia is unique. However, there are some common features of life with dementia which have normative significance in developing legal frameworks for supported decision-making.

3.1 Living with Dementia

Dementia is not a single condition but rather a 'clinical state where a decline in cognitive function, such as loss of memory, judgement, language, complex motor skills and other intellectual functions, leads to a decline in independent daily function' (Ash, 2014: 3). This decline may progress rapidly or slowly. In most (though by no means all) cases, the decline will involve a person whose capacity was previously unimpaired. This sets dementia apart from other capacity impairments in that the progressive nature of dementia means that increased impairment is highly likely.

A second relevant feature is that, while dementia is not just a condition of old age, age is the strongest predictor of dementia (Doron, 2014). This has several implications. First, people with dementia may have other health problems and may be moving to the later stages of their lives. Thus, end-of-life issues play an important role in dementia care. Secondly, many people with dementia will have lived full and active lives in which they have developed moral, political, social, religious and other views; built a complex set of relationships; and, acquired financial and other assets.

3.2 Support in Dementia

In setting out a 'new paradigm' for supported decision-making, Michael Bach and Lana Kerzner identify six different kinds of decision-making supports (2010: 74-82). These are: life planning (choosing priorities in the context of values); independent advocacy (helping the person express his or her will and preferences); communicational and interpretative supports (representing the person's often unique forms of communication); representational supports (representing the person's will and preferences on the basis of long-standing relationships and/or shared life experiences); relationship building supports (assisting the person in building personal support relationships); and, administrative supports (completing formal and procedural requirements). Although Bach and Kerzner were concerned with people with intellectual/developmental disabilities, many of these supports could also operate effectively for people with dementia. Thus, an adaptation of this paradigm could provide part of a framework for supported decision-making in dementia. This approach could enhance the quality of life and maximise the autonomy and dignity of people with dementia; it could help to ensure that, despite dementia, the person remains a player in his or her own life.

However, Bach and Kerzner's paradigm cannot address all the support needs of people with dementia. At least two issues arise. First, as Bach and Kerzner acknowledge, the 'fundamentally different lived experience' of 'older adults' leads to enhanced concerns about abuse and neglect. Therefore, older adults tend to afford greater importance to high levels of review and oversight (2010: 37). It would be dangerously short-sighted to assume that concerns about abuse and neglect are only an issue for older adults. Nonetheless, the range and complexity of life experiences of a person with dementia means that there is a heightened risk of abuse and neglect. These is borne out by the statistics on elder abuse, which indicate that 15.7% of people aged over 60 have experienced abuse of some form (Yon et al, 2017). The challenge for any legal framework is to find a way to balance

empowerment and protective concerns in a way which is maximally appropriate for all the people to whom it applies.

A second issue relates to the norms which underpin the support provided. The fundamental normative question is the relationship between a person's past and present will and preferences. This question first came to attention in the context of advance directives. In a well-known contribution, Ronald Dworkin used the example of Margo, a 54 year-old woman with Alzheimer's Disease to argue that an advance directive made while a person has capacity should take priority over her subsequent wishes and interests if she has lost capacity (1993: 220). In advancing this argument, Dworkin contrasted two kinds of interests which a person might have: critical interests, which concern value judgements and the kind of life a person wants to lead; and, experiential interests, which are concerned with quality of life issues, such as freedom from pain, contentment and pleasure. Dworkin argued that critical interests are protected by the principle of autonomy in a way that experiential interests are not. Accordingly, he advocated that the decisions of a person with capacity regarding her critical interests should be prioritised over her current experiential interests.

Whether or not one agrees with Dworkin in respect of advance directives (and his argument in this context has been criticised on normative grounds (Dresser, 1995)), the case for respecting a person's prior interests is clearly stronger where the person has set these down in a formal instruction, such as an advance healthcare directive. In cases of supported decision-making in dementia, a person's prior underlying values may be far less clear. Nonetheless, Dworkin's argument still resonates in this context. The issue is usefully illustrated by Herring with the following example: Bertha has dementia and has started to visit a mosque, which involves crossing a busy road. Although it is not clear how much she understands, Bertha derives great pleasure from the visits and when stopped she becomes agitated and distressed. Bertha's family are concerned because Bertha had been a vehement atheist all her life and is now putting herself in danger by crossing the road to get to the mosque (2009: 7). For the discussion here, the question which this scenario poses is which norms should underpin Bertha's support: the maintenance of her previous atheism (which in this scenario coincides with greater physical safety) or her current engagement (which coincides with greater physical risk)?

As has been pointed out, a difficulty with Dworkin's approach is that it presumes that 'our critical interests are turned into stone once we lose certain cognitive abilities' (Lindemann Nelson, 2010: 228). However, identifying this weakness does not make the task of selecting the underpinning norms for support frameworks any easier. In fact, the blurring of the neat boundary upon which Dworkin relied raises even more challenges. In attempting to address these challenges, Bruce Jennings rejects both the 'hard' pre-incapacity conception and the simple post-incapacity hedonic conception. He argues instead in favour of an agency model under which dementia care is seen as a 'hermeneutic process, a form of interpretative practice' (2010: 171). Dementia care should be a 'form of reminding' (2010: 172); it should both recall to mind what has been forgotten in the course of the illness and also 're-mind' in the 'more radical sense of reconstructing the subject, the person' (2010: 172). This view seeks to place the 'dynamic, dialogic, or relational aspects of mind and agency' at the heart of dementia care (2010: 172).

Jennings uses the concept of 'memorial personhood' to describe this goal (2010: 176). Memorial personhood 'derives from three components of the individual's ontological situation: need, vulnerability, and the duty called forth by remembered identify' (2010: 176). This approach rejects simple past/present distinctions and seeks new ways to identify underpinning norms. Thus, supported decision-making is not about supporting a person to make the decisions s/he would have made prior to dementia; nor is it about a simple hedonic response post dementia. Somehow, decision-making supports have to combine both the person's past and their present; to recognise the 'moral work done by memory and imagination' (Jennings, 2010: 177) yet simultaneously to respond to the person as a moral subject in his or her current state. While this sounds complex, it probably represents what many supporters of people with dementia actually do in practice; they seek to balance past and present preferences and to help the person they support to reach decisions which best represent both their past and present selves. In this way, they 'hold' the person in their identity, while at the same time adjusting to the changes brought about by dementia (Lindemann, 2010).

None of this requires a legal framework in order to happen. Yet, legal frameworks are still important, especially when it comes to interactions with the world outside the relationship. Thus, we turn to two attempts to develop legal frameworks for supported decision-making.

4. Delivering Supported Decision-Making: Legal Frameworks

The translation of the normative complexity identified above into legal frameworks is by no means straightforward. Normative choices always come at a cost. More relaxed legal frameworks make supported decision-making more accessible for people with impaired capacity but they may also leave a potentially vulnerable person at greater risk of abuse. More stringent legal frameworks may reduce the possibility of abuse but they also reduce the accessibility of support and are invasive in the private and family/relational lives of the person and his or her supporters. In this context, it is also worth noting that we lack empirical evidence regarding the link between stringent legal frameworks and reduced instances of abuse. We may have an instinct that stringent legal frameworks reduce abuse but we cannot say definitively that more people are abused when the framework is relaxed and fewer when it is stringent.

4.1 The Representation Agreement Act 2000

The Representation Agreement Act 2000 (RAA) was the first Canadian legislation to establish a comprehensive framework for supported decision-making. The RAA is best understood within the broader Canadian context and so the discussion here begins by placing the RAA in this context.

4.1.1. The Canadian Context

The earliest legislative recognition of supported decision-making in Canada is found in the Quebec Civil Code from 1866 (Gordon, 2000). However, in the early 2000s, a new wave of legislation began to emerge. This was largely in response to the concerns of families and carers of people with intellectual and developmental disabilities and from health and social care professionals working with these people (Nunnelly,2015). From these concerns emerged the community living movement and the family-based advocacy movement, the Canadian Association for Community Living (CACL) (Bach and Kerzner, 2010: 33). This movement, among other initiatives, developed the concept of personal support networks for people with intellectual/developmental disabilities. These encompass a range of options including circles of friends; support circles; Microboards; Arora entities; and self-directed support corporations (Nunnelly, 2015: 16)). These networks endeavour to support a person with intellectual disabilities so as to enable him or her to live independently.

In the 1990s, the CACL launched a task force for legislative reform, including the development of alternatives to guardianship (Bach and Kerzner, 2010: 33). This led to the introduction of legislation in a number of western Canadian states/territories. The RAA in British Columbia was followed by the Adult Guardianship and Co-Decision-Making Act 2001 in Saskatchewan; the Adult Protection and Guardianship Act 2003 in the Yukon and the Adult Guardianship and Trustee Act 2008 in Alberta. With the exception of Alberta, all the initiatives precede the CRPD. In all cases, the legislation falls short of complying with the CRPD (as interpreted in GC No 1) in that supported decision-making frameworks operate alongside, rather than replace, frameworks for substitute decision-making. Beyond this, there are differences in scope and delivery, which in turn reflect different normative approaches. In broad terms, British Columbia and the Yukon adopt a more relaxed legal framework, thus favouring accessibility while the frameworks in Saskatchewan and Alberta tend to be more stringent, thus favouring protection (James and Watts, 2014).

The RAA was 'hailed by the disability community as highly successful legislative recognition of supported decision-making' (Bach and Kerzner, 2010: 53). Because the CACL was a member the International Disability Caucus, which played a crucial negotiating role in the agreement of the CRPD, the RAA model was important in convincing negotiating states of the possibility of legislating for supported decision-making. However, the picture of the RAA is rather more complex than is sometimes presented. The legislation was contentious from the outset (Canadian Centre for Elder Law Studies, 2006). It was criticised by lawyers for its vague drafting (Canadian Centre for Elder Law Studies, 2006: 7; James and Watts, 2014: 17) and also by senior rights advocates for failing to address the needs and concerns of older adults (Bach and Kerzner, 2010: 37). It would seem however that, post CRPD, criticisms have 'quieted down' and that the 'more fluid and modern understandings of capacity and social vulnerability [in the RAA] would raise far fewer eyebrows in 2014 than they did in the early 1990s' (James and Watts,2014: 17). The next section will identify the core elements of the RAA before turning to look at the (limited) empirical data on the operation of the RAA for people with dementia.

4.1.2. The RAA: The Core Provisions

The RAA provides that any adult (there is no link to disability) can make a representation agreement (RA) unless s/he is incapable of doing so (RAA, s. 4). Under the RA, the adult may appoint one or more representatives who may be assigned different areas of authority or may be jointly appointed in the same areas of authority (RAA, s. 5). The powers, scope and method of appointment of a representative depend on the nature of the decisions to which the RA applies. Two different forms of RA are provided for. The first is an RA containing 'standard provisions' (RAA, s. 7). These are decisions about: the adult's personal care; routine management of financial affairs; most healthcare; and obtaining legal services (RAA, s. 7(1)) as well as authority to accept admission to a care facility, provided that the care facility is a family care home; a group home for the mentally handicapped; or, a mental health boarding home (RAA, s. 7(2)). For these decisions, an adult may authorise the representative to help the adult make a decision **or** to make decisions on behalf of the adult (RAA, s. 7(1)). Thus, the RAA permits full substitute decision-making (albeit that the substitute is chosen by the person with impaired capacity).

The most contentious element of the RAA relates to the legal process around the completion of an RA with standard provisions. The RAA provides that an adult may complete this kind of RA even though s/he lacks the capacity to contract; manage his or her healthcare/personal care or legal matters or the routine management of his/her financial affairs (RAA, s. 8(1)). Instead, in determining if a person is incapable of making this kind of RA, all relevant factors must be considered, including whether the person communicates a desire to have the representative help make/ make/stop making decisions; whether the person demonstrates choices and preferences and can express feelings of approval or disapproval; whether the person is aware that making/changing/revoking the agreement will change the authority of the representative; and, whether the person has a relationship with the representative that is characterized by trust (RAA, s. 8(2)).

The standard of capacity is higher for a 'non-standard' RA. This is an RA where the adult authorises his or her representative to do anything the representative considers necessary in relation to the personal care or healthcare of the adult or to make decisions about where the adult is to live and with whom; the adult's participation in employment, educational, social, vocational or other activity; contact and association; application for a licence or permit; day-to-day decisions, including about dress and diet; giving and refusing healthcare; and, physical restraint despite the objections of the adult (RAA, s. 9(1)). For an RA covering these decisions, the test for 'incapability' is that the adult in 'incapable of understanding the nature and consequences of the proposed agreement' (RAA, s. 10).

The other contentious aspect of the RAA is that the contract is private and subject to limited external scrutiny. There are some formal requirements (i.e. the RA must be made in writing and must be witnessed (RAA, s. 13)) but there is no requirement for legal advice. It is possible for a third party to make an objection to the Public Guardian and Trustee in respect of an RA on the basis that the adult was incapable of making the RA or that fraud, undue influence or some other form of abuse or neglect had been used in making, changing or revoking the RA (RAA, s. 30(1)). Beyond this, a degree of protection is provided by the requirement that the adult must include in the RA the name of a person to act as a monitor

(RAA, s. 12(1)). The Monitor must make 'reasonable efforts' to determine if the representative is complying with his or her legislative obligations (RAA, s. 20(1)). In brief, these are to act honestly, in good faith and with care, skill and diligence of a reasonable person; and, within the authority given by the RA (RAA, s.16(1)). In pursuance of his or her obligations, the Monitor may require the representative to produce accounts and records in respect of his or her activities (RAA, s. 16(8)) and may visit and speak with the adult at any reasonable time (RAA, s. 20(2)).

4.1.3 Application in Dementia

From the relatively brief review of the RAA above, it is easy to see why it is celebrated by disability rights activists from a community living perspective. The RAA makes supported decision-making accessible for many people with an intellectual or developmental disability with a minimum of legal formality. Within functional families/relationships (i.e. where the there is no possibility of exploitation and the parties generally have the same goals), this would seem to be an ideal example of a suitable legislative framework. However, it is also easy to see why lawyers have been less than enthusiastic. The drafting is undeniably loose and vague and if one moves beyond the functional family/relationship, it is clear that the legislation could allow for exploitation or imposition of the representative's values and goals. This dissonance emerges from a textual analysis. However, the more interesting question is how the RAA has actually operated in practice. Surprisingly, there has been limited empirical research on this question (James and Watts, 2014) although some work is now emerging.

James and Watts study (2014) of the lived experience of supported decision-making provides important insights into the operations of the RAA in practice. The Study, which was conducted for the Law Commission of Ontario, is relatively small and is described by the authors as 'an initial scoping of the issues' (2014: 4). In brief, the Study found that supported decision-making under the RAA had not been widely adopted and that, insofar as RAs were used, it was primarily by people with intellectual/developmental disabilities and not by older people or people with other kinds of cognitive impairment such as acquired brain-injury (2014: 49-50). There were few concerns about how RAs were working in practice, although examples were given of situations where parties proceeded with an RA notwithstanding that the person being supported had very limited understanding of the RA or the framework (2014: 50). The reasons given by respondents for the lack of concern was that most people using the legal framework were 'members of a small community where representatives were highly engaged in the lives of the people they were supporting' (2014: 50). Thus, the benefits of supported decision-making are not being experienced by older adults notwithstanding the potential of this during the earlier stages of dementia (2014: 52). Instead, there is a 'strong tendency' to move straight to substitute decision-making for this group because this is seen as easier and more convenient (2014: 52).

4.2 The Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision-Making (Capacity) Act 2015 (ADMCA) was signed into law by the President of Ireland on 30th December 2015. However, the substantive elements of the ADMCA will not come into effect until at least 2019. Ireland has come late to the process of capacity law reform and, until the ADMCA commences, the applicable legal framework remains the Lunacy Regulation (Ireland) Act 1871. Although the ADMCA is part of a series of law reforms introduced in order to enable Ireland to ratify the CRPD, it does not comply entirely with the interpretation of Art. 12 in GC. No 1 (2014). Thus, the ADMCA operates on the basis of a functional test for capacity (ADMCA, s. 3) and permits substitute decision-making. Nonetheless, it advances the CRPD agenda in important respects (Donnelly, 2016; Kelly, 2017). First, the test for capacity includes various requirements to provide assistance and support to the 'relevant person' (RP) before a determination of incapacity may be made (ADMCA, s.3). Secondly, substitute decision-making (through the appointment of a Decision-making Representative (DHR)) may only be used as a last resort where the Court has found that the decision-making support frameworks cannot be utilised (ADMCA, s. 37-38). Thirdly, the ADMCA makes provision for the person to appoint his or her own substitute decision-makers through an Enduring Powers of Attorney (EPA) and, (for healthcare decisions), a Designated Healthcare Representative (DHRs) appointed under an Advance Healthcare Directive (AHD). Fourthly, decisions are not made on the basis of 'best interests' but instead all decision-makers and supporters must act in accordance with a set of principles. These include encouraging participation by the RP; giving effect in so far as is practicable, to the past and present will and preferences of the RP relevant person; taking into account the beliefs and values of the RP, and any other factors which the RP would be likely to consider if s/he were able to do so (s. 8). Fifthly, and most significantly for the current discussion, the ADMCA establishes two forms of decision-making supports which may be utilised where an RP believes that his/her capacity is in question or may shortly be in question.

4.2.1 Support Frameworks under the ADMCA

The first support framework in the ADMCA involves the appointment of a decision-making assistant/s (DMA) who may be appointed in respect of decision/s relating to personal welfare (including healthcare) and/or property and affairs (ADMCA, s. 10). The RP can appoint as many DMAs as s/he chooses and/or appoint different DMAs for different decisions (ADMCA, s. 10). The DMA's role is to assist the RP in obtaining and explaining information relevant to the decision; to ascertain the RP's will and preferences and assist the RP in communicating them; to assist the RP in making and expressing a decision; and to endeavor to ensure that the RP's relevant decisions are implemented (ADMCA, s. 14(1)). However, the DMA may not make a decision on behalf of the RP (ADMCA, s. 14(2)) and any decision made is deemed to be the decision of the RP (ADMCA, s. 14(3)).

The second, and more extensive, form of support involves a co-decision maker/s (CDM) who jointly makes the decisions which are specified in the CDM Agreement with the RP (ADMCA, s. 17).The CDM must explain relevant information and considerations to the RP; ascertain the RP's will and preferences and assist the RP with communicating these; assist the RP in obtaining relevant information; discuss with the RP the known alternatives and likely outcomes of a decision; make a decision jointly with the RP; and, make reasonable efforts to ensure that the decision is implemented as far as practicable (ADMCA, s. 19(1)).

Although decisions are jointly made by the RP and the CDM, the CDM must acquiesce with the wishes of the RP and, where the decision requires a document to be signed, the CDM may not refuse to sign the document unless it is reasonably foreseeable that the acquiescence in the RP's wishes or signing the document would result in serious harm to the RP or another person (ADMCA, s. 19(5)).

Unlike the RAA, the same standard for capacity applies to all appointments and decisions under the ADMCA. Thus, in order to appoint a DMA or a CDM, a person must be able to understand the nature and consequences of this decision in the context of the available choices at the time the appointment is made (ADMCA, s. 3(1)). A person lacks the capacity to do this if s/he is unable to understand the relevant information; to retain that information long enough to make a voluntary choice; to use or weigh that information as part of the process of making the decision; or to communicate the decision (ADMCA, s. 3(2)).

There are limited formalities for the appointment of a DMA. There is no statutory requirement for registration or for a formal assessment of capacity. However, provision is made to set out formalities in secondary legislation (ADMCA, s. 10(4)) which presumably is intended to allow some flexibility in adjusting the applicable standards as the area develops. The relevant regulations have not been published at the time of writing. In contrast, the process for the appointment of a CDM is very tightly circumscribed. There must be a formal assessment of capacity by both a registered medical practitioner and another healthcare professional. These must certify that the RP has capacity to make the decision to enter the CDM Agreement; that s/he requires assistance in decision-making in respect of decisions covered by the CDM Agreement; and, that s/he has the capacity to make these decisions with the assistance of a CDM (ADMCA, s. 21(4)(f)). As Brendan Kelly points out, this requires 'a very subtle assessment of differential mental capacities' (2017: 355). There are also requirements for statements by the RP that s/he understands the nature of the CDM Agreement and wishes to enter it (ADMCA, s. 21(4)(b)). The CDM Agreement must be registered with the Director of Decision Support Services (DDSS) (the body charged with oversight of the ADMCA (ADMCA, s. 21(1)) and the DDSS must make several substantive evaluations before registering the Agreement (ADMCA, s. 22(1)). There will also be obligations to provide notice of the application for registration to various parties (these will be set out in secondary legislation (ADMCA, s. 31(c)) and provision is made for objections to be made to registration (ADMCA, s. 24). CDMs must also make annual reports to the DDSS (ADMCA, s. 27(1).

4.2.2 **ADMCA in Dementia**

Given that the ADMCA has not yet commenced, there is a degree of speculation in considering how it will operate in a progressive illness such as dementia. However, some points may be made based on the available evidence. In the first instance, it is difficult to predict how many people preparing for dementia will avail themselves of the option to put in place supported decision-making arrangements. The Canadian example (not just in British Columbia but also in the other relevant jurisdictions) suggests that uptake will be limited at least initially (James and Watts, 2014). It is likely to require substantial efforts in terms of public education and awareness, not to mind the development of public trust in the new processes, for the Irish experience to be different.

Based solely on the text of the ADMCA, several difficulties may be identified. First, the ADMCA is highly complex and at times impenetrable, even for experienced lawyers. Secondly, there are is uncertainty as regards the boundary between appointing a DMA or CDM. Although the ADMCA seems to presume that a CDM will be more involved in the decision-making process, there is no clear legislative statement in this regard and the differences between a DMA and a CDM appear 'chiefly quantitative rather than qualitative' (Kelly, 2017: 355). In both cases, the decision-making process itself must be centred on the applicable principles, which apply identically to DMAs and CDMs, and therefore, in theory it should make no difference to the decision made whether the support of a DMA or a CDM is utilised. Yet, the procedural requirements for the two processes are strikingly different.

Thirdly, there is also uncertainty regarding the boundary when the authority of a CDM expires (because the person no longer has capacity to make decisions jointly with the CDM) and the authority of a substitute decision-maker (DMR; Attorney; or DHR) is required. Again, the applicable decision-making principles are identical and so the practical difference in terms of the decision made should, in theory, be minimal. It is, of course, possible for a person to avoid uncertainty by appointing someone to be their CDM and then, when they no longer have capacity for this to operate, to be their Attorney under an EPA. However, this requires that two separate and relatively complex processes be employed. Given that the administrative burdens for the creation of a CDM are almost as onerous than those for an EPA, a person who is putting a framework in place to deal with impending (or possible) dementia and his or her advisors might prefer to use the more long-established EPA option instead of the newer CDM option (or a combination of the two). Having said that, the sheer depth and scale of procedural requirements for a CDM may mean that there is greater trust in this option in the context of dementia than has been the case with the more relaxed framework in British Columbia. Time will tell; however, it is by no means unimaginable that the supported decision-making options under the ADMCA will be no more popular for people with dementia than those in the RAA.

Conclusion

Supported decision-making has a valuable role to play in dementia care; it keeps the person with dementia at the centre of decision-making and offers the possibility of preserving past identity while recognising current circumstances. However, as seen here, the task of establishing legal frameworks for the delivery of supported decision-making in dementia is far from straightforward. After almost two decades in operation, it would appear that, in spite of its success for adults with intellectual/development disabilities, the RAA has not delivered a workable framework for people with dementia in British Columbia. This seems to be primarily because it fails to provide the degree of protection and oversight which people preparing for dementia and their advisors regard as important. The textual evaluation of the ADMCA suggests that protection and oversight is likely to be less of a problem, at least with CDM Agreements. However, the sheer complexity of the legislation and the novelty of the idea of co-decision-making may mean that CDM Agreements will be overlooked in favour of the more established Enduring Power of Attorney in situations of advance planning for dementia in Ireland.

It may take several iterations to establish appropriate legal frameworks for supported decision-making in dementia. After all, it is only relatively recently that

normative conversations about impaired capacity have begun to emerge from the 'shadow of the Enlightenment-derived fixation on (capacity-based) autonomy' (Donnelly, 2017: 305). The law will take time to catch up. Yet, this remains an important endeavour in law and policy making for dementia care. For people with dementia, the availability of supported decision-making offers a legal choice; a way of maintaining some degree of control for as long as possible. The value of this in the face of a progressive illness like dementia should not be underestimated. More generally, the concept plays an important educative role, serving as a reminder that cognitive decline in dementia does not mean an end to moral personhood.

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References

Abberley, P. (1987). The Concept of Oppression and the Development of a Social Model of Disability. *Disability, Handicap and Society*. 2(1), 5-19.

Arstein-Kerslake, A. (2017). *Restoring Voice to People with Cognitive Disabilities: Realising the Right to Equal Recognition Before the Law.* Cambridge: Cambridge University Press.

Ash, E. (2014). What is Dementia?. In C. Foster, J. Herring and I. Doron (eds). *The Law and Ethics of Dementia*. Oxford: Hart Publishing.

Bach, M. and Kerzner, L. (2010). *A New Paradigm for Protecting Legal Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice.* Toronto: Law Reform Commission of Ontario. Available at https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf.

Baier, A. (1985). *Postures of the Mind: Essays on Mind and Morals.* Minneapolis: University of Minnesota Press.

Baier, A. (1995). *Moral Postures: Essays on Ethics.* Cambridge, MA: Harvard University Press.

Canadian Centre for Elder Law Studies and British Columbia Law Institute. (2006). A Comparative Analysis of Adult Guardianship Laws in BC, New Zealand and Ontario. CCELS Report No. 4/BCLI Report No. 46. Vancouver: CCELS/BCLI.

Committee on the Rights of Persons with Disabilities (2014). *General Comment No. 1 on Equal Recognition before the Law*. CRPD/C/GC/1.

Committee on the Rights of Persons with Disabilities (2018). *General Comment No. 1 on Equal Recognition before the Law: Corrigendum*. CRPD/C/GC/1/Corr.1.

Dhanda, A. (2006-7). Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future? *Syracuse Journal of International Law & Commerce.* 34, 429-462.

Donnelly, M. (2010). *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism*. Cambridge: Cambridge University Press, 2010.

Donnelly, M. (2016). The Assisted Decision-Making (Capacity) Act 2015: Implications for Healthcare Decision-Making. *Medico-Legal Journal of Ireland.* 22(2), 65-77.

Donnelly, M. (2016). Best Interests: Time to Say Goodbye?. *Medical Law Review.* 24(3) 318-332.

Donnelly, M. (2017). Changing Values and Growing Expectations: The Evolution of Capacity Law. *Current Legal Problems.* 70, 305-336.

Doron, I. (2014). The Demographics of Dementia. In C. Foster, J. Herring and I. Doron (eds). *The Law and Ethics of Dementia*. Oxford: Hart Publishing.

Dresser, R. (1995). Dworkin on Dementia: Elegant Theory, Questionable Policy. *Hastings Center Report*. 25(6), 32-38.

Dworkin, R. (1993). *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*. New York: Alfred A. Knopf.

Engelhardt, T. (1986). *The Foundations of Bioethics.* New York: Oxford University Press.

Freeman, M.C. *et al*. (2015). Reversing Hard Won Victories in the Name of Human Rights: A Critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities. *The Lancet Psychiatry.* 2(9), 844-850.

Gilbar, R. (2011). Family Involvement, Independence and Patient Autonomy in Practice. *Medical Law Review.* 19(2) 192- 234.

Gordon, R. (2000). The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making. *International Journal of Law and Psychiatry.* 23(1), 61-77.

Gooding, P. (2015). Negotiating 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. *Human Rights Law Review.* 15(1), 45-71.

Herring, J. (2009). Losing it? Losing What? The Law and Dementia. *Child and Family Law Quarterly.* 21(1), 3-29.

James, K. and Watts, L. (2014). *Understanding the Lived Experiences of Supported Decision-Making in Canada*. Ontario: Law Commission of Ontario.

Jennings, B. (2010). Agency and Moral Relationships in Dementia. In E. Feder Kittay and L. Carlson (eds). *Cognitive Disability and its Challenge to Moral Philosophy.* Chicester: Wiley-Blackwell.

Kayess, R. and French, P. (2008). Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review.* 8(1), 1-34.

Kelly, B. (2017). The Assisted Decision-Making (Capacity) Act 2015: What it is and why it matters. *Irish Journal of Medical Science.* 186(2), 351-356.

Kittay, E. (1999). *Love's Labour: Essays on Women, Equality, and Dependency.* Abingdon: Routledge.

Lindemann, H. (2010). Holding One Another (Well, Wrongly, Clumsily) in a Time of Dementia. In E. Feder Kittay and L. Carlson (eds). *Cognitive Disability and its Challenge to Moral Philosophy.* Chicester: Wiley-Blackwell.

Lindemann Nelson, J. (2010). Alzheimer's Disease and Socially Extended Mentation. In E. Feder Kittay and L. Carlson (eds). *Cognitive Disability and its Challenge to Moral Philosophy.* Chicester: Wiley-Blackwell.

MacKenzie, C and Stoljar, N. (2000). *Relational Autonomy: Relational Perspectives on Autonomy, Agency and the Social Self.* New York: Oxford University Press.

Martin. W. *et al.* (2014). *Achieving CRPD Compliance.* Essex Autonomy Project. Available at https://autonomy.essex.ac.uk/wp-content/uploads/2017/01/EAP-Position-Paper-FINAL.pdf

Nedelsky, J. (1989). Reconceiving Autonomy: Sources, Thoughts and Possibilities. *Yale Journal of Law and Feminism.* 1(1), 7-36.

Nedelsky, J. (2011). *Law's Relations: A Relational Theory of Self, Autonomy and Law.* New York: Oxford University Press.

Nunnelly, S. (2015). *Personal Support Networks in Practice and Theory: Assessing the Implications for Supported Decision-Making Law.* Ontario: Law Commission of Ontario.

Oliver, M. (1990). *The Politics of Disablement.* Basingstoke: Macmillan

Oliver, M. (2009). *Understanding Disability: From Theory to Practice*. 2nd Ed. Basingstoke: Palgrave Macmillan.

Quinn, G. with Rekas-Rosalbo, A. (2016) Civil Death: Rethinking the Foundations of Legal Personhood for Persons with a Disability. *Irish Jurist.* 56, 286-325.

Sandel, M. (1997). *Liberalism and the Limits of Justice*. 2nd Ed. Cambridge: Cambridge University Press.

Series, L. (2016). Relationship, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms. *International Journal of Law and Psychiatry.* 40, 80-91.

Shakespeare, T. (2006). *Disability Rights and Wrongs.* Abingdon: Routledge.

Shakespeare, T. (2013). *Disability Rights and Wrongs* Revisited. Abingdon: Routledge.

Terzi, L. (2004). The Social Model of Disability: A Philosophical Critique. *Journal of Applied Philosophy.* 21(2), 141-157.

United Nations. (2006). Convention on the Rights of Persons with Disabilities. A/RES/61/106 Annex 1.

Veatch, R. (1981). *A Theory of Medical Ethics.* New York: Basic Books.

Ward, A. (2014). Abolition of all Guardianship and Mental Health Laws. *Elder Law Journal*. 4(1), 71-75.

Yon, Y., Mikton, C.R., Gassoumis, Z.D., Wilber, K.H. (2017). Elder Abuse Prevalence in Community Settings: A Systematic Review and Meta Analysis. *Lancet Global Health*. 2017 Feb;5(2):e147-e156