



## Exploring the potential and the pitfalls of the United Nations Convention on the Rights of Persons with Disabilities and General Comment no. 1 for people with dementia



Laura Pritchard-Jones

School of Law, Keele University, Keele, Staffordshire ST5 5BG, UK

### 1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has widely been heralded as representing a shift in disability politics (Kayess & French, 2008; Quinn, 2010); a 'new way of thinking about disability, centred on citizenship, equality, and inclusion' (Donnelly, 2016, 320; Degener, 2016). This is in part undoubtedly down to the fact that people with disabilities were heavily involved in its drafting and remain involved through their membership on the Committee on the Rights of Persons with Disabilities, and their role in monitoring its implementation under Article 33. Its creation represents a shift in not only *how* we view disability, but also *where* we view disability; it has brought the voices of many persons with disabilities to the forefront of international human rights law-making. These are all features for which the UNCRPD, as a piece of law, has rightly been praised (Jones, 2005; Quinn, 2010).

It is also perhaps trite to say that some aspects of the UNCRPD have generated significant levels of discussion. One of the most prominent of these aspects is Article 12 – the right of persons with disabilities to equal recognition as persons before the law – and its accompanying General Comment 1 (GC1), released in 2014. To date, analysis of Article 12 and GC1 has largely focussed on either conceptual discussions as to what may be required of domestic legal regimes to be UNCRPD compliant and the relative merits and practicalities of these requirements (Dawson, 2015; Donnelly, 2016; Flynn & Arstein-Kerslake, 2014), or the extent to which domestic legal regimes are in fact – or have made progress towards being – UNCRPD compliant (Essex Autonomy Project,

2016; Stavert, 2015). It is only relatively recently, however, that literature – empirical or otherwise – as to the relationship between Article 12 or GC1, and *particular forms* of disabilities or impairments such as intellectual disabilities (Harding & Taşcıoğlu, 2018) or mental health conditions (Szmukler, 2017) has begun to emerge. Such literature is important if legal regimes and legal commentators are to avoid homogenizing the experience of disability.

Given all of the above, it is interesting that notably absent from any discussion of the UNCRPD thus far has been its applicability to people who have dementia, which predominantly – although not exclusively – affects the older population.<sup>1</sup> This is surprising given that people with dementia may in fact represent a large proportion of disabled people worldwide; the World Health Organization estimate that around 50 million people worldwide have dementia, and there are approximately 10 million new diagnoses of dementia each year.<sup>2</sup> Even more surprising, then, is that a consideration of the list of participants in the negotiations leading up to the UNCRPD demonstrates a relative lack of involvement by organisations advocating specifically on behalf of people with dementia in the drafting process.<sup>3</sup> As some commentators have noted, however, '[t]he dementia community has never been part of the disability movement, and did not join forces with the powerful coalition of disabled people's organisations which campaigned for the Convention' (Shakespeare, Zeilig, & Mittler, 2017, 3; Gilliard, Means, Beattie, & Daker-White, 2005).<sup>4</sup> It is perhaps facts such as this that has led some commentators to suggest that the UNCRPD – particularly Article 12 and GC1 – has limited traction in relation to older people with disabilities, and people with dementia. As Denzil Lush, a former

E-mail address: [l.g.pritchard-jones@keele.ac.uk](mailto:l.g.pritchard-jones@keele.ac.uk).

<sup>1</sup> Approximately 800,000 of around 850,000 persons living dementia in England and Wales are over the age of 65 (Alzheimer's Society, 2014, viii-ix). For an early discussion of its potential for older people more generally, see Kanter, 2009).

<sup>2</sup> <http://www.who.int/news-room/fact-sheets/detail/dementia> accessed 2 July 2018. That is not to say that all people with dementia will consider themselves disabled, and as Alzheimer Europe (2017) points out, there is in fact a dearth of literature on the extent to which people with dementia identify with the notion of 'disability' (Alzheimer Europe, 2017, 19). The UK All-Party Parliamentary Group has recently initiated a consultation in to this topic: <https://www.alzheimers.org.uk/about-us/policy-and-influencing/all-party-parliamentary-group-dementia> accessed 2 July 2018.

<sup>3</sup> See <https://www.un.org/development/desa/disabilities/resources/ad-hoc-committee-on-a-comprehensive-and-integral-international-convention-on-the-protection-and-promotion-of-the-rights-and-dignity-of-persons-with-disabilities.html> accessed 10 July 2018.

<sup>4</sup> The definitive reasons for this are complex and unknown in their entirety, however Shakespeare, Zeilig, and Mittler hypothesise that '[t]he point about the social model of disability is that it distinguishes between the health condition, on the one foot, and the social experience of exclusion, on the other. However, dementia still remains trapped within the dominant medical discourse.' (Shakespeare et al., 2017, 4).

England and Wales Court of Protection Judge noted in 2011:

The websites of the Alzheimer's Society or Alzheimer's Disease International contain very few references to the CRPD, and certainly no sense of ownership of it. Similarly, on the websites of organisations representing the broader, older population – organisations such as Age UK (formerly Age Concern and Help the Aged), HelpAge International, Global Action on Aging, and INPEA (International Network for the Prevention of Elder Abuse) – there is no discussion about this Convention, but a call for another convention, on the Rights of Older People, instead. (Lush, 2011, 67)

As a result, Lush suggests that Article 12 and GC1 seem 'to have been driven mainly by the intellectual disability lobby, and whilst their interpretation of the contents of the Convention may appeal to their own constituents, it is not entirely practical, realistic, or even appropriate for the vast number of people who lack capacity for other reasons' (Lush, 2011, 67).

The aim of this paper is not to examine the veracity of Lush's claims in the above quotes,<sup>5</sup> however it does seek to explore a little further one aspect that he touches on; how can Article 12 and GC1 be understood for older people who have dementia? The paper argues that while the focus on 'supported decision-making' is largely to be welcomed, conceptual and empirical literature involving people with dementia<sup>6</sup> can problematize the more hard-line and radical approaches taken by GC1, and some commentators, to two particular issues. The first issue is the role envisaged for 'support' within the concept of 'supported decision-making'. Despite being broadly welcomed as 'relational' in its focus on supported decision-making, an analysis of literature outlining the realities of making decisions with dementia highlights how the role of support envisaged by GC1 and some commentators is, ironically, overly-individualistic, interpreting support simply as a conduit to the enactment of a person's already pre-defined 'will and preferences'. This, it is contended, oversimplifies the reality of what it is like to be an older person with dementia who makes decisions, and, as Skowron (2016) has argued, fails to grapple with the subtler complexities of 'support'.

The second issue the paper addresses is whether or not there should be any scope at all for acknowledging a person's disability (or impairment) in implementing legal measures to safeguard the rights contained within Article 12. Perhaps somewhat controversially, the paper suggests that in many circumstances for people with dementia it would be unrealistic and improper *not* to take the fact that they have dementia – and the resultant impact on their cognitive functioning – in to consideration.<sup>7</sup> While GC1 and some of the academic debate offers a hard line interpretation of Article 12 against this, such discussions fail to identify a important ethical distinction between identifying impairment on the one hand, and *how* that information is used on the other. As Kitwood (1997) argues, recognizing that a person has dementia means recognizing that they will have declining cognitive functions, which is not problematic or negative discrimination per se. But *how* the information about their impairment is used *sometimes* makes it negative

<sup>5</sup> Although interestingly, Lush may well be correct if participation in the drafting process is representative. Moreover, paragraph 24 of GC1 states that '[o]ne of the aims of support in the exercise of legal capacity is to build the confidence and skills of persons with disabilities so that they can exercise their legal capacity with less support in the future, if they so wish.' While this may well be the case for many people who have either static or improving levels of cognitive ability, dementia almost always entails declining cognitive functioning and therefore increasing levels of support become required (Samsi & Manthorpe, 2013). The wording of this paragraph indicates that this is not something the Committee may have contemplated.

<sup>6</sup> As Shakespeare argues, an analysis of this literature is important in that '[a]cademics who want to make comments about the impact of impairment might do well to base their analysis on empirical evidence about how disabled people feel about their embodiment' (Shakespeare, 2014, 67).

<sup>7</sup> For an analogous argument more generally, see Dawson (2015).

discrimination. In turn, the paper argues that it is these more crucial questions that debate around the UNCRPD should now be confronting.

## 2. Support

In order to be able to analyse the issues outlined in this paper, it is important to try and identify three things: what Article 12 states, what GC1 claims Article 12 requires, and what subsequent debate has claimed that both Article 12 and GC1 demand.<sup>8</sup> First and foremost, Article 12 requires that all persons with disabilities have a right to equal recognition before the law (Art 12(1)), a right to enjoy legal capacity on an equal basis with all others (Art 12(2)), and that state parties must provide the support necessary to exercise that legal capacity (Art 12(3)). Furthermore, Article 12(4) states, *inter alia*, that any measures that relate to the exercise of legal capacity must provide

appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.

On the face of it, then, Article 12 is not necessarily about 'making decisions'; it is about legal capacity and equal recognition before the law.<sup>9</sup> GC1 states that legal capacity

includes the capacity to be both a holder of rights and an actor under the law. Legal capacity to be a holder of rights entitles a person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognizes that person as an agent with the power to engage in transactions and create, modify or end legal relationships (para.12).

For this, it states that 'legal personhood' is a prerequisite (para.11). So neither Article 12 itself, nor the interpretation of legal capacity proffered in GC1, suggests that legal capacity is solely about making decisions. Arstein-Kerslake's interpretation acknowledges this: 'some people, due to impairment, environmental causes or other factors, require support for decision-making in the exercise of legal capacity' (Arstein-Kerslake, 2016, 78, emphasis added). In this analysis, legal capacity is clearly distinct from decision-making, because in order to exercise legal capacity, an individual might require support with making decisions. Making and executing *certain* decisions – such as deciding to marry, deciding to divorce, signing a housing contract, for example – is, of course, one core feature or example of exercising legal capacity. But likewise, some decisions – such as deciding what to wear, what to eat for dinner, or whether to walk the dog – do not, on the face of it, demonstrate any exercise of legal capacity. So Article 12 in itself, is not necessarily about making decisions generally, but it is about making *some* decisions, and ensuring those decisions are legally respected.<sup>10</sup>

<sup>8</sup> Although it is also important to state the obvious point that states who have signed and ratified the Convention are, of course, only *legally* bound by the first of these (Essex Autonomy Project, 2016, 9), although General Comments or decisions by the Committee do usually have persuasive weight.

<sup>9</sup> A full discussion of the precise contours of what these two notions mean is beyond the scope of this paper. For a summary, see Dhanda (2007).

<sup>10</sup> Arstein-Kerslake and Flynn acknowledge this very point: 'Not all decisions involve an exercise of legal capacity. The definition of legal capacity provided in the GC includes issues that involve the exercise of the individual's legal agency (entering, altering or ending legal relationships) and/or the individual's legal personality (the individual as a rights holder)' (Arstein-Kerslake & Flynn, 2016, 480). This then presents the challenge of having to distinguish decisions which result in an exercise of legal capacity and therefore on the face of it fall within the scope of Article 12, from those which do not.

Even less is Article 12 about supported decision-making, which does not appear in the wording of Article 12 at all. All Article 12(3) requires is support to exercise legal capacity, which, if the foregoing argument is correct, does not necessarily equate to support to make decisions, least of all support to make *all* decisions.

Leaving this conceptual problem to one side, in GC1 paragraph 7, however, we see the first conflation between Article 12 and making decisions:

Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner *under substitute decision-making regimes* such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others. (Emphasis added).

Later, in paragraph 50, GC1 states that Article 12 ‘requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities’ (emphasis added). GC1 stipulates that any legal system which purports to take any decision-making power away from disabled people denies their legal capacity, and violates Article 12.<sup>11</sup> States must therefore ‘take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences’ (emphasis added). In summary then, GC1 states that Article 12 requires only supported decision-making regimes – i.e. support to exercise legal capacity – and that all substitute decision-making regimes be dismantled. Moreover, while support ‘is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity’ (para. 16), ‘[s]upport in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities’ (para. 16).<sup>12</sup>

There is considerable debate as to whether or not GC1 is correct in its interpretation of Article 12 (Lush, 2011; Essex Autonomy Project, 2016, 9–14), yet what is clear is that the drafters of the Convention – and GC1 – were motivated by an ethical concern. This concern is that, for many years, people with cognitive or mental disabilities have been denied the right to make many or all decisions about their lives and therefore denied opportunities that are not denied to others in society (Burch, 2017, 390). GC1’s response to this is supported decision-making which respects the rights, will, and preferences of the individual, rather than allowing a legal system to take decision-making power out of those individuals’ hands. This is clearly a welcome focus, particularly for people living with dementia, who may face the ‘double whammy’ of both disability discrimination and ageism. As Carney and Gray argue:

Biological ageing, particularly physical signs of biological ageing, are used to socially impose an inferior status on people as they age. The impact and severity of this inferior status is cumulative; older people with impairments, dementia, disability, or few economic resources are among the lowest status in society. Ageism contributes to the oppression of older people as it is internalised, eventually impacting on the capacity of older people to speak for themselves. (Carney & Gray, 2015, 127).

Historically, such negative discrimination for older people with dementia has been widespread, and taken many different forms.

<sup>11</sup> See also paragraph 27, which states that substituted decision-making regimes is any system in which ‘legal capacity is removed from a person, even if this is in respect of a single decision’.

<sup>12</sup> See also paragraph 28: ‘States parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.’

Marzanski (2000), for example, found that out of 30 participants with dementia, two thirds claimed never to have had the opportunity to discuss their dementia with a medical professional, only 5 had discussed their dementia with their doctor, and only 1 participant had been told of their diagnosis. Moreover, a number of participants reported being given untrue information, or being treated in a disrespectful way by their clinicians (Marzanski, 2000, 109). Research indicates that while not all people with dementia want to know, and telling someone of their diagnosis of dementia may be fraught with its own ethical tensions (Carpenter & Dave, 2004), failing to share the diagnosis of dementia with the person, even in the earlier stages, remains commonplace. This is even where the individual *does* want to know more about their condition or diagnosis (Downs, 1997; Holroyd, Turnbull, & Wolf, 2002). When an individual does have dementia, much research also indicates that even basic decision-making is frequently and routinely denied, regardless of their actual ability to make decisions. Often the very fact that the person has dementia leads to the assumption that they lack decision-making ability in all areas (Gilliard et al., 2005; Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterlé, 2007), and there is frequently a failure to understand their remaining abilities and how they *are* able to assert agency. Even people with an advanced stage of dementia are able to demonstrate some level of agency, often in a creative manner (Boyle, 2014). As Boyle notes, the ‘extant cognitive abilities of people with dementia are under-recognised and their emotions and behaviour are often viewed as symptomatic of the illness’ (Boyle, 2014, 1131). In England and Wales under the Mental Capacity Act 2005,<sup>13</sup> research has also demonstrated that people with dementia are marginalized from decision-making processes. Studies have shown that they are frequently denied decision-making capacity because they appear to have made an unwise decision or disagree with professional opinion,<sup>14</sup> do not have their views listened to during best interests decisions,<sup>15</sup> or even have best interests decisions made for them when the presumption of mental capacity has not been displaced (Emmett, Poole, Bond, & Hughes, 2013; Williams et al., 2012; Williamson et al., 2012).

So in requiring state parties to consider the ways in which legislation can contribute to overcoming such discrimination for people with dementia, Article 12 and GC1 are certainly welcome developments. But aside from this, the notion of ‘support’ within that decision-making that the UNCRPD and GC1 has brought to the fore is also to be welcomed. Much empirical evidence involving people with dementia demonstrates how crucial the notion of support is. Not only is support to make decisions important for people who have dementia precisely because their diagnosis means they will, at various points, experience difficulties making decisions, but support is also crucial for people with dementia in a wider sense. As a number of studies have shown, *good* support interactions with others can enable many people with dementia to retain a sense of their own identity and their own personhood. That is, individuals with dementia are able to retain a sense of identity – even in the face of a declining memory – precisely because of support from and their interactions and engagement with individuals and organisations around them (Pearce, Clare, and Pistrang, 2019; Beard, 2004; Preston, Marshall, & Bucks, 2007; Wolverson, Clarke, & Moniz-Cook, 2016). Likewise, *bad* support or bad interactions can contribute to the destruction of a person’s sense of self (Kitwood & Bredin, 1992). As Sabat and Harré note, this distinction between good and bad support

<sup>13</sup> Whether or not the Mental Capacity Act 2005 is UNCRPD-compliant given that it is a substituted decision-making regime will not be discussed here.

<sup>14</sup> This is notwithstanding section 1(3) of the Act which states that ‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision.’

<sup>15</sup> Notwithstanding the fact that section 4(6) of the Act states that decision makers must take into consideration the person’s past and present wishes, feelings, values, and beliefs.

frequently turns on how the information about an individual's dementia is received by others around them – a point that this paper will return to in section 3. If the person's behaviour 'is founded on story lines that paint the sufferer as inadequate, confused, helpless...then that person will be so positioned and will have his...behaviour interpreted by others in such a way as to confirm the initial storyline' (Sabat & Harré, 1992, 460).

Notwithstanding these points, subsequent interpretations of both GC1 and the Convention ostensibly present a one-dimensional view of supported decision-making. An example of this can be found in the following analysis of the role of support within the UNCRPD and GC1:

Article 12 requires a support model of legal capacity to include a permanent presumption in favour of the will and preferences of the individual...The individual is the decision-maker...and the role of supporters is confined to explaining details of the decision to be made and interpreting the wishes of the individual where necessary...(Flynn & Arstein-Kerslake, 2014, 85, citations omitted).<sup>16</sup>

Similarly, Arstein-Kerslake envisages that 'the goal of the supported decision-maker is to do everything in her power to not impose her own will and preferences on the individual whom she is supporting' (Arstein-Kerslake, 2016, 85). Moreover, while GC1 itself acknowledges that in some circumstances it may not be possible to ascertain an individual's actual will and preferences, in such circumstances it states that action must be taken on the 'best interpretation' of their will and preferences (para. 21). In effect, according to Flynn and Arstein-Kerslake's interpretation, the individual remains solely in charge of the decision to be made, and any support is simply there to enable them to discover their own will and preferences or to execute their decision. Their supporter's will and preferences should never be a factor in the decision to be made.

This interpretation of supported decision-making is problematic on at least two fronts. First, it assumes that a person's will and preferences converge, which, as Szmukler (2017, 93) points out, may not be the case. In situations where the person has dementia this incongruence may be particularly pronounced where current 'will and preferences', which may result from the changes brought about by the dementia, may diverge completely from previous 'will and preferences' from a time before the person had dementia. Consider, for example, someone who was, in their earlier life, a devout vegan. Yet as their dementia advances, they demonstrate a liking for meat and their 'will and preferences' clearly indicate that they would like to eat meat. On the face of it, GC1 offers no guidance as to which 'will and preferences' are to be preferred in cases such as these where a person's will and preferences undergo an apparent U-turn.<sup>17</sup> As such, the UNCRPD, GC1, nor some academic debate on the matter, confront the 'personhood problem' – whether the person with dementia is the same 'person' as they were before they had dementia – and therefore which wishes should prevail (Degrazia, 1999; Dworkin, 1986; Dworkin, 1993). If they are not the same person, as Dresser (1994, 1995) argues, then previously stated wishes should have minimal impact and it is contemporaneous wishes that should carry the greatest weight. Neither does recourse to acting in accordance with the 'best interpretation of will and preferences' as required by paragraph 21 of GC1 help in these situations. According to GC1, this obligation only arises where a person's will and preferences

<sup>16</sup> This quote is also legally inaccurate – Article 12 does not stipulate that there is a presumption in favour of a person's will and preferences. It requires that any 'measures that relate to the exercise of legal capacity must provide appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person' (emphasis added).

<sup>17</sup> These sorts of in a person's will and preferences may not be unique to dementia, but they may well also happen in cases of acquired brain injury, or severe mental illness (Szmukler, 2017).

are not ascertainable. It seemingly does not apply where there are two sets of diametrically opposed will and preferences.<sup>18</sup>

More crucially for this paper, these interpretations of GC1 and the UNCRPD indicate that the role of support is simply a conduit for a person's will and preferences. They rest on the assumption that a person already has will and preferences in relation to a particular matter, and the role of the support in decision-making is simply to ensure that these will and preferences are given effect to. They imply that the existence of will and preferences are ontologically prior to the notion of support, and that support merely exists to execute those will and preferences.<sup>19</sup> As Skowron (forthcoming) notes, the concern with this interpretation is that the supporter is seen as simply there to 'discover' the person's will and preferences, and assist in giving effect to them, and as Craigie summarises, "[g]iven the value placed on decision-making liberty in the Convention, 'support' might be interpreted merely as giving the person's expressed wishes effect, however unwise or irrational they may be" (Craigie, 2015, 403).<sup>20</sup> Such an interpretation of support does not envisage that the very act or process of making decisions, or the process of formulating will and preferences on a particular decision, are inherently brought about by interactions with others (Ho, 2008; Verkerk, 1999). It does not leave scope for recognizing that decisions are made and arrived at through a dialogical process with supporters, or that a person may not have a will or a preference as to what decision to make until they have received support, or the input of their supporter, especially where their supporter's interests are inherently woven up with their own. Although the UNCRPD and GC1 have been widely welcomed as being 'relational' (Gooding, 2013; Series, 2015) – and therefore better reflecting the reality of lived experiences for all people, not just people with disabilities – the interpretation of support present in some analyses of the UNCRPD and GC1 is in fact highly individualistic and rely on a superficial characterization of relationships (Kong, 2015). As Burch notes, decision-making is a 'fundamentally collaborative enterprise – we make up our minds with our significant others, and these relationships can enhance (or impair) our decision-making ability' (Burch, 2017, 394).

An exploration of some of the literature detailing the reality of making decisions with dementia – especially those who are married or cared for by close family members – betrays how superficial the conceptualization of support simply as a conduit to enacting a person's will and preferences is. Research by Boyle (2013a) into decision-making by older couples of whom one has dementia, for example, demonstrates that when faced with financial decision-making, 'wills and preferences' are rarely formed in isolation, and nor are such decisions made individually. Such decisions usually rely on a complex array of social factors, including traditional and previous roles within the relationship, and are often made jointly between the person with

<sup>18</sup> In cases such as these it may be that emphasizing recourse to 'respecting their rights, will, and preferences' (para 16, emphasis added) may be of most use in navigating these difficult situations (Gooding, 2013, 55).

<sup>19</sup> Interestingly, in a different article, Arstein-Kerslake suggests that the role of support may well be to assist those with disabilities to reach a decision: 'Article 12...ensures that people with disabilities have their decisions respected by law on an equal basis with others and have access to assistance in arriving at and expressing those decisions.' (Arstein-Kerslake, 2016, 78, emphasis added). Likewise, in an influential report, Bach and Kerzner recognize a role for support in formulating preferences (Bach & Kerzner, 2010, 73), not simply executing them, and Richardson suggests that a 'more relational approach, one that recognizes that we all rely on others for support and assistance in reaching decisions, would more faithfully reflect our common experience' (Richardson, 2012, 342).

<sup>20</sup> Although Craigie does go on to note that "the CRPD literature clearly understands the purpose of support also as facilitating autonomy in the self-expression sense. To this extent it does endorse helping the person make a 'good' decision in a specific sense: part of the aim of support is to help the person make a self-expressive decision" (Craigie, 2015, 403).

dementia and their partner. Sinclair et al. (2018) similarly found that couples employed a range of techniques in making healthcare decisions following a diagnosis of dementia, which were based heavily on 'historical patterns of joint decision-making' (Sinclair et al., 2018, 6). Moreover, Sinclair et al's study also found that many participants with dementia also demonstrated trust in delegating decisions to other people, especially a close family member or partner, and some couples considered 'informal, family-based substitute decision-making by the partner as an ideal scenario' (2018, 6). Likewise, Dening, King, Jones, and Sampson (2016) also found that joint decision-making was common, particularly among older couples where one person had dementia. One participant summarized their approach to joint or shared decision-making:

Well, we discuss it for a start and see what each one would say and then decide to come to a decision ... I would never do anything without asking [name] about it or getting his opinion and he would do the same (Dening et al., 2016, 7).

Such an approach by people with dementia and their carers may be in part down to the fact that decisions are seen as rarely affecting only the person with dementia in isolation. People with dementia often seemed cognizant of the fact that decisions made as a couple affected both people within the spousal or caregiving relationship.<sup>21</sup> As another participant in Sinclair et al's study noted:

While I can talk about [admission to residential care] now, it's not fair if I get really bad and Doug can't manage, that he feels guilty that he has to try to look after me...[aside to Doug] everybody fights about it, but I'm telling you that that's what you've got to do. Is put me in a home whether I tell you I don't want to then or not (Sinclair et al., 2018, 4).

In their analysis of everyday decisions by people with dementia, Samsi & Manthorpe (2013) also found that decision-making techniques were also more complicated than simply supporting the person with dementia to discover and implement their will and preferences. In their longitudinal study involving both people with dementia and their familial caregivers, they found that decision-making in fact occupied something akin to a spectrum from mutual decision-making as the norm at one end, moving towards substituted decisions at the other as the dementia progressed. Interestingly, research participants who had dementia 'seemed particularly surprised at being asked about individual decision-making, indicating they felt that joint decision-making was an inherent part of living with a partner, many had been married over 50 years' (Samsi & Manthorpe, 2013, 955). Moreover, in Samsi and Manthorpe's research there appeared to be a divergence between the views of people with dementia towards decision-making, and their carers. Carers frequently wanted to preserve their relatives' autonomy through varying methods, while the person with dementia often wanted the decisions to be made on their behalf, and trusted their caregivers to make these decisions for them (Samsi & Manthorpe, 2013, 959). This latter finding is not unique, and are represented in studies involving people with dementia, especially in relation to end of life care (Bollig, Gjengdal, & Rosland, 2016). While such findings do not necessarily answer hard questions about what form the law should take, they do serve to illustrate the true complexity of support - and what decision-making means for older people with dementia - a complexity that is perhaps not reflected in some interpretations of the UNCRPD and GC1. The focus on 'supported decision-making' that the UNCRPD and

<sup>21</sup> This is also potentially another criticism of GC1 and certain interpretations of the role of support; they do not pay adequate attention to the interests, will, and preferences of those who care for people with disabilities, or recognize that the 'will and preferences' of the person with disabilities may be inherently bound up with the 'will and preferences' of their supporters or carers. In turn, such an approach arguably continues to marginalise the rights of carers.

GC1 has engendered is undoubtedly to be welcomed, especially in light of the long history of silencing the voice of many people with disabilities, including dementia. On the other hand, the focus is equally important given that support is clearly important in a plethora of ways for people with dementia. However, this section has sought to explore a number of the critical limitations of the focus on support offered by GC1 and some academic commentary. In doing so it is argued that the role envisaged for support by such commentators is both internally and externally inconsistent. It is internally inconsistent because even *within* some academic literature on GC1 itself, it is unclear as to whether the role of support should be to help a person decide, or whether the role should just be to assist in enacting a person's decisions and giving effect to their preferences. But those that interpret support according to this latter conceptualization are also inconsistent with external literature detailing the realities of making decisions, especially with dementia. As this section has demonstrated, such an interpretation of support is one dimensional, overly individualistic, risks marginalizing the interests of carers, and does not always fully grapple with the complexities of support for people with dementia.

### 3. Disability (or impairment?)

The second issue this paper seeks to address is the role that disability (or impairment)<sup>22</sup> plays in the exercise of legal capacity and supported decision-making as envisaged by the Convention itself, GC1, and academic debate. In order to do this, it is important to note briefly the difference between disability and impairment. Paragraph 5 of the preamble to the Convention establishes this distinction: 'disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.' So there are two elements to disability: an impairment, and social barriers. Interaction between the two leads to disability. Oliver summarises this interaction thus:

...impairment is defined as 'lacking all or part of a limb, or having a defective limb, organism or mechanism of the body...disability is defined as the 'disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.' (Oliver, 1996, 22).<sup>23</sup>

In light of the above, disability is not a status, but a negative process of interaction between impairment and society. In many respects, the Convention itself is clear on the role of disability in relation to legal systems which purport to regulate decision-making: Article 12(3) requires that state parties recognize 'that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.' Moreover, Article 12(4) states that 'States Parties shall ensure that all measures that 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 shall ensure that

<sup>22</sup> In this section the terms 'disability' and 'impairment' are used interchangeably. This is not to signal a return to the 'medical' model of disability. It is done so as to reflect the fact that in much literature there seems to be a conceptual confusion between the two terms. If disability results from a process of engagement between impairment and social environment, as suggested in this paper and through the social model literature, then in reality those who disallow interventions based on *disability* arguably mean to disallow interventions based on *impairment*, i.e. the underlying impairment that leads to the disabling process.

<sup>23</sup> As can be seen from Oliver's quote, the origins of the social model are grounded in physical impairments, and as such there has been criticism of the social model for neglecting discussion of mental impairments (Mulvaney, 2000, 584).

measures relating to the exercise of legal capacity...are proportional and *tailored to the person's circumstances...*' (emphasis added). In effect, persons with disabilities must never be denied legal capacity in a situation where someone without a disability would not be denied it – such as where they purport to marry or sign a contract – and any safeguards that relate to exercising this legal capacity must be tailored to the person's circumstances.

This is expanded upon in GC1 paragraph 9, which states that 'a person's status as a person with a disability or the existence of an impairment (including a physical or sensory impairment) must never be grounds for denying legal capacity or any of the rights provided for in Article 12.'<sup>24</sup> Later, in paragraph 15, it is contended that any decision-making regime that provides for substitute decision-making is in contravention to Article 12 because in such regimes,

a person's disability and/or decision making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity.

GC1 goes on to suggest, in paragraph 29, that '[t]he provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.' So while GC1 requires supported decision-making regimes to replace substituted decision-making regimes, it goes even further than this and states that any assessment of precisely *what* supports are required to make the decision cannot be decided on the basis of a person's mental capacity – such as their ability to understand information, retain information or use and weigh it, or communicate their decision.<sup>25</sup>

Again, the precise implications of these provisions have been the subject of much debate. Arstein-Kerslake and Flynn, for example, state that 'if a state would not restrict the legal capacity of a woman without disabilities who chooses to stay in an abusive domestic relationship, it should also not restrict the legal capacity of a woman with disabilities in those circumstances.' (Arstein-Kerslake & Flynn, 2016, 479). Moreover, they go on to argue in a later article that 'it is important to search for universal criteria for state intervention and describe how these might apply to all adults, rather than developing separate and more intrusive criteria for intervention that only apply to people with disabilities' (Flynn & Arstein-Kerslake, 2017, 40). Furthermore, because mental capacity assessments are seen to be inherently discriminatory towards people with cognitive and mental disabilities, some have argued there should be no room for any functional assessments of decision-making ability within the provision of support for decision-making, or support to exercise legal capacity, because there is a danger of "such 'functional' assessments becoming status contingent" (Flynn & Arstein-Kerslake, 2014, 89). As Dawson surmises, the view of the Committee on the Rights of Persons with Disabilities – as well as some authors – is that.

the concept of mental impairment should be removed completely from legal standards, even when used in combination with other standards, such as those based on risk of harm to self or others. In sum, functional capacity tests should be expunged from legal reasoning — regardless, it seems, of the consequences. (Dawson, 2015, 73).

<sup>24</sup> It is also arguable that GC1's interpretation of disability as a *status* is incorrect. As I have indicated earlier, if disability is an interaction of impairment with social context – as the Convention itself says it is in the preamble – then disability is a process rather than a status.

<sup>25</sup> These elements form part of the current test for mental incapacity found in the Mental Capacity Act 2005 in England and Wales: Mental Capacity Act, s.3(1).

Yet such an approach is not universally accepted or welcomed. As Dawson continues, the evidence of impairments in mental functioning may well be relevant to deciding what supports to provide (Dawson, 2015, 74). Likewise, Bartlett argues that 'it does seem that the mental condition of the individual may in some circumstances be relevant to the appropriate social response to that individual's care' (Bartlett, 2012, 764). Moreover, it is not just an assessment of an individual's functional decision-making ability that might be useful in providing appropriate supports (Gooding, 2013, 438; Dawson, 2015, 74), but knowledge of their precise mental impairment may also be beneficial in order to provide *appropriate* support. It is one thing to say that capacity or incapacity should be divorced from disability or impairment, but it is entirely different to argue that *support* should be divorced from disability or impairment. The crucial point here, which GC1 overlooks, is that of itself, recognizing that a person has different decision-making abilities is not inherently negative discrimination (Gooding, 2013, 58–59); neither is simply recognizing that a person has a medical condition or impairment that leads to those differences in decision-making abilities. As the moral philosopher, Mary Midgley, argues:

Neither can a belief in equality possibly be a belief that we are all identical, standard pieces of white paper, equally capable by nature of passing some test or other. Equality is a moral principle, not a factual one, and it means that we all have the same basic right to fair treatment, whatever our capacities. (Midgley, 1983, 35).<sup>26</sup>

It is *how* information about our differences is used that sometimes makes interventions discriminatory, or, to use Flynn and Arstein-Kerslake's term, 'intrusive' (Flynn & Arstein-Kerslake, 2017, 40). In UNCRPD terms, it is how the information about a person's decision-making ability or their impairment is used that is important in identifying whether something is discriminatory or fails to comply with Article 12. If the information is used to – in the UNCRPD's terms – deny legal capacity, then this may well be discriminatory in a negative way under Article 12. But if that information is used to put appropriate supports in place, then is this not a positive use of such information, and one that is UNCRPD compliant given that Article 12(4) requires safeguards that are tailored to the person's circumstances – of which the fact that they have dementia or a disability is precisely one of those relevant circumstances?

Neither does such an argument necessarily sit in discord with the social model of disability, upon which the UNCRPD is predicated.<sup>27</sup> In fact, the UNCRPD itself highlights that disability arises through impairments and their interaction with 'attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.'<sup>28</sup> As Davis argues, 'disability is not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference' (Davis, 2002, 50). To this extent, proponents of the social model of disability do not deny the existence of impairments or suggest that impairments are not relevant to understanding disability and disabled peoples' experiences. To adopt such an approach would be 'Pollyanna-ish' (Shakespeare et al., 2017, 9).<sup>29</sup> The core concern for most disability theorists who advocate the social model is the construction and reception within society of that impairment; in effect, how impairments or differences are received and interpreted by others in society. Consider examples from other domains. In law, for example, in England and Wales under the Equality

<sup>26</sup> I would like to thank Paul Skowron for this point.

<sup>27</sup> Although Degener (2016) argues that the UNCRPD in fact represents a shift beyond the social model, towards a human rights model of disability.

<sup>28</sup> Preamble, paragraph 5.

<sup>29</sup> Beyond this, failing to recognize or take in to consideration specific impairments also risks homogenizing or presenting the experience of disabilities as 'monolithic' (Mulvany, 2000, 586), rather than recognizing that people with disabilities experience their impairments in different, unique ways; 'your experience is not my experience' (Devlioger & Albrecht, 2000).

Act 2010, there are certain protected characteristics such as gender, race, or disability. But in order for the legislation to operate effectively, and in order to 'protect' such characteristics – that is, remove unfair negative discrimination or disabling barriers – it is necessary to first recognize that an individual possesses that characteristic, and – in the case of disabilities – for reasonable adjustments to be put into place in light of that. The same argument can be made in relation to mental illness or cognitive impairment in the context of the UNCRPD and GC1. For example, the knowledge that a person has a type of frontotemporal dementia, which predominantly affects their behaviour and language, may well indicate that the individual requires – among other things – linguistic supports such as speech and language therapy to make and communicate their decisions. But in order to recognize this need for speech and language therapy, we must recognize that the individual has this particular mental impairment, and the nature of the effect it has on their ability to make decisions.

That *how* we understand and respond to impairment is the more crucial question also comes forward from older people with dementia themselves. The following quote from a person with dementia exemplifies this nuanced distinction well:

...more distressing was the realisation I was viewed as a lesser person. It was obvious that institutions such as banks, employers, statutory bodies favour a complete cognition as opposed to my now altered one. And I was slowly being denied the rights and responsibilities of being a fully recognised member of civil society and being denied self determination (Dementia Policy Think Tank, DEEP, and Innovations in Dementia, 2017, 33).

The person with dementia in this quote does not deny their altered cognition due to their dementia. The crucial problem for this person would seem to be how that altered cognition is treated and received by the people they engage with; preferring, instead, 'complete' cognition. It is this preference for complete cognition that the person feels leads to the denial of rights. Yet at no point does the person deny their altered cognition, and in fact indicates that organisations *should* understand this altered cognition in order to be better able to uphold their rights. Such an approach has been behind many positive developments in the field of dementia-care in recent years such as Memory Cafés, Dementia Friendly Communities,<sup>30</sup> and Sensory Gardens. As the Alzheimer's Society note, "society often tries to fit the symptoms of dementia into 'normal' life. It takes flexibility and empathy to recognise that supporting someone with the condition may need a different and personalised approach" (Alzheimer's Society, 2017, 12). Likewise, evidence also suggests that some people with dementia do find importance in receiving a diagnosis, in order to facilitate appropriate support mechanisms. As one person with dementia commented:

It is important to get the correct diagnosis. "Dementia" is not enough, there are many kinds of dementia, which can benefit from different medications. They wouldn't just say "You have cancer" and send you away. We have the right to more specific information (Dementia Policy Think Tank, DEEP, and Innovations in Dementia, 2017, 35).

This mirrors empirical evidence, which suggests that while an individual's relationship to their dementia is complicated, in many circumstances the fact that they have dementia is a relevant consideration in different ways. Wolverston, Clarke, and Moniz-Cook, for example, undertook a systematic review of literature detailing mechanisms by which people with dementia continued to find positivity, and found

<sup>30</sup> Interestingly, some commentators have argued that such language perpetuates exclusion, and focus should be on 'universal design in society more generally: 'Even a phrase like 'dementia friendly', while apparently positive, could be considered patronizing and inappropriate... we might ask instead for 'Dementia Enabling Communities' (Shakespeare et al., 2017, 7).

evidence that "[e]ngaging with dementia actively and positively seems to be underpinned by a process of 'facing' and accepting the condition" (Wolverston et al., 2016, 693). Moreover, in a study of 114 people with dementia, Powers, Dawson, Krestar, Yarry, and Judge (2016), found that a number of participants (28.1%) wished that other people – particularly in caregiving relationships – understood the impact of the memory loss from their perspective. Moreover, many participants (20.2%) also indicated they wished others understood the etiology, symptoms, and progression associated with dementia, and the impact that this has on their cognition and functioning (Powers et al., 2016, 1061). As one participant notes, 'I wish they would remember that I forget.'

Finally, recognizing that a person has dementia and the specific changes it may bring about is also important in more practical ways on a day to day level for those working with and caring for people with dementia in order to ensure they are provided with *proper* support and care. As noted above, recognizing and understanding that someone has frontotemporal dementia may enable appropriate supports such as speech and language therapy to be put in place. But in addition to this, certain forms of dementia, such as Alzheimer's, for example, can bring fluctuations in cognitions even on a daily basis. As a result of the physiological changes to the brain, cognitive abilities may present as worse in late afternoon or early evening. This is referred to as 'sundowning'. If Article 12 and GC1 do require supported decision-making, then recognizing sundowning, and the reasons as to why a person's cognition may be worse at those times of day, may enable practitioners to appropriately plan support for decision-making. For example, planning decision-making and providing support earlier in the day in order to maximize the person's decision-making ability (Boyle, 2013b, 232). Again, far from being discriminatory in a negative sense, recognizing such fluctuations and changes arising from dementia enables practitioners and carers to plan appropriate support. In these cases, recognition of the impairment and its impact on a person's mental functioning of itself is not problematic. Indeed, if we are to uphold the rights of people with dementia – not least because Article 12 requires supports that are tailored to a person's circumstances – recognizing their dementia and the effects this has on their cognition *is required*. It is what society – of which the law is a feature – has sometimes chosen to do with that information that creates a problematic process of disablism.

#### 4. Conclusion

The UNCRPD – and, to some extent, GC1 – are laudable; they represent the culmination of many years of work attempting to dismantle the countless inequalities faced by disabled people around the world. Within this framework, support for people with disabilities to make decisions is undoubtedly a good thing. Numerous studies and reports – some of which have been cited above – demonstrate the perpetual and systemic silencing of the voice of people with dementia from decisions that affect them. Yet as Jones (2005, 185) argues, bad law can have the effect of legitimizing exclusion. While the paper has not suggested the UNCRPD is an example of bad law – indeed, it has suggested the very opposite – what the paper has sought to do is show how interpretations of this law through certain aspects of GC1, and academic debate, may exacerbate and legitimize the exclusion of people with dementia. Alzheimer Europe rightly note that in order to avoid such exclusion, 'it is important to consider the lived experiences of people with dementia and the complexity of human relationships and not to rely solely on abstract principles' (Alzheimer Europe, 2017, 5). In many ways, neither the UNCRPD, nor GC1, go any way to actually addressing any difficulties faced by practitioners or carers working with people with disabilities on the ground (Bartlett & Schulze, 2017, 12). Nor do they really grapple with any of the fundamentally ethical questions that they throw up: what is meant by 'support'? What is good support and what is bad support? Should we acknowledge a person's impairment and if so, *how* should we use the information about that person's impairment?

How we use the evidence of a person's impairment, and what counts as 'appropriate' support, are fundamentally ethical questions, which, in simply reciting the 'mantra' of supported decision-making (39 *Essex Street*, 2017, 31), GC1 and some of its commentators, fail to explore. This paper has suggested that less needs to be done promoting this mantra of 'supported decision-making' and 'will and preferences', and more work now needs to be done in translating 'good' support from rhetoric to reality on the ground. In order to do so we must not ignore the fact that a person has dementia. By drawing such a hard line on these issues, GC1 - if not the UNCRPD itself - may well, as Appelbaum suggests, represent 'extreme agendas, failing to pay close attention to the implications of the resulting documents' (Appelbaum, 2016, 368), not least where people with dementia are concerned.

## Acknowledgements

I would like to thank Felicity Adams, who provided research assistance for an early version of this paper. I would also like to thank Paul Skowron for his comments on the paper.

## References

- Alzheimer Europe (2017). *Dementia as a disability? Implications for ethics, policy and practice*. Luxembourg: Alzheimer Europe.
- Alzheimer's Society (2014). *Dementia UK: Update*. London: Alzheimer's Society. [https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2759](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2759) Accessed 2 July 2018.
- Alzheimer's Society (2017). *Turning up the volume: Unheard voices of people with dementia*. London: Alzheimer's Society.
- Appelbaum, P. (2016). Protecting the rights of persons with disabilities: An international Convention and its problems. *Psychiatric Services*, 64, 366–368.
- Arstein-Kerslake, A. (2016). An empowering dependency: Exploring support for the exercise of legal capacity. *Scandinavian Journal of Disability Research*, 18, 77–92.
- Arstein-Kerslake, A., & Flynn, E. (2016). The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law. *The International Journal of Human Rights*, 20, 471–490.
- Bach, M., & Kerzner, L. (2010). A new paradigm for protecting autonomy and the right to legal capacity. *Toronto: Law commission of ontario* [www.lco-cdo.org/disabilities/bach-kerzner.pdf](http://www.lco-cdo.org/disabilities/bach-kerzner.pdf) Accessed 25 July 2018.
- Bartlett, P. (2012). The United Nations Convention on the Rights of Persons with Disabilities and mental health law. *Modern Law Review*, 75, 752–779.
- Bartlett, P., & Schulze, M. (2017). Urgently awaiting implementation: The right to be free from exploitation, violence and abuse in Article 16 of the Convention on the Rights of Persons with Disabilities (CRPD). *International Journal of Law and Psychiatry*, 53, 2–14.
- Beard, R. (2004). In their voices: Identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies*, 18, 415–428.
- Bollig, G., Gjengedal, E., & Rosland, J. (2016). They know!—do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. *Palliative Medicine*, 30, 456–470.
- Boyle, G. (2013a). 'She's usually quicker than the calculator': Financial management and decision-making in couples living with dementia. *Health & Social Care in the Community*, 21, 554–562.
- Boyle, G. (2013b). Facilitating decision-making by people with dementia: Is spousal support gendered? *Journal of Social Welfare and Family Law*, 35, 227–243.
- Boyle, G. (2014). Recognising the agency of people with dementia. *Disability & Society*, 29, 1130–1144.
- Burch, M. (2017). Autonomy, respect, and the rights of persons with disabilities in crisis. *Journal of Applied Philosophy*, 34, 389–402.
- Carney, G., & Gray, M. (2015). Unmasking the 'elderly mystique': Why it is time to make the personal political in ageing research. *Journal of Aging Studies*, 35, 123–134.
- Carpenter, B., & Dave, J. (2004). Disclosing a dementia diagnosis: A review of opinion and practice, and a proposed research agenda. *The Gerontologist*, 44, 149–158.
- Craigie, J. (2015). A fine balance: Reconsidering patient autonomy in light of the UN Convention on the Rights of Persons with Disabilities. *Bioethics*, 29, 398–405.
- Davis, L. (2002). *Bending over backwards: Disability, dismodernity and other difficult positions*. New York: New York University Press.
- Dawson, J. (2015). A realistic approach to assessing mental health Laws' compliance with the UNCRPD. *International Journal of Law and Psychiatry*, 40, 70–79.
- Degener, T. (2016). A human rights model of disability. In P. Blanck, & E. Flynn (Eds.). *Routledge handbook of disability law and human rights* (pp. 31–49). Abingdon: Routledge.
- Degrazia, D. (1999). Advance directives, dementia, and 'the someone else problem'. *Bioethics*, 13, 373–391.
- Dementia Policy Think Tank, DEEP, & Innovations in Dementia (2017). Our lived experience: Current evidence on dementia rights in the UK. An alternative report to the UNCRPD committee. Available at [http://dementiavoices.org.uk/wp-content/uploads/2017/07/Our-Lived-Experience-270717\\_1.pdf](http://dementiavoices.org.uk/wp-content/uploads/2017/07/Our-Lived-Experience-270717_1.pdf) Accessed 29 July 2018.
- Dening, K., King, M., Jones, L., & Sampson, E. (2016). Healthcare decision-making: Past, present and future in light of a diagnosis of dementia. *International Journal of Palliative Nursing*, 23, 4–11.
- Devlieger, P., & Albrecht, G. (2000). Your experience is not my experience: The concept and experience of disability on Chicago's near west side. *Journal of Disability Policy Studies*, 11, 51–60.
- Dhanda, A. (2007). Legal capacity in the disability rights Convention: Stranglehold of the past or lodestar for the future? *Syracuse Journal of International Law and Commerce*, 34, 429–462.
- Donnelly, M. (2016). Best interests in the Mental Capacity Act: Time to say goodbye? *Medical Law Review*, 24, 318–332.
- Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society*, 17, 597–607.
- Dresser, R. (1994). Missing persons: Legal perceptions of incompetent patients. *Rutgers Law Review*, 46, 609–719.
- Dresser, R. (1995). Dworkin on dementia: Elegant theory, questionable policy. *Hastings Center Report*, 25, 32–38.
- Dworkin, R. (1986). Autonomy and the demented self. *The Millbank Quarterly*, 64, 4–16.
- Dworkin, R. (1993). *Life's dominion*. London: HarperCollins.
- Emmett, C., Poole, M., Bond, J., & Hughes, J. (2013). Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards. *International Journal of Law and Psychiatry*, 36, 73–82.
- Essex Autonomy Project (2016). *Three jurisdictions report: towards compliance with CRPD Art. 12 in capacity/incapacity legislation across the UK*. Essex: University of Essex.
- Essex Street (2017). *Mental Capacity report – September 2017*. Available at <https://www.39essex.com/mental-capacity-report-september-2017/> Accessed 25 July 2018.
- Flynn, E., & Arstein-Kerslake, A. (2014). Legislating personhood: Realising the right to support in exercising legal capacity. *International Journal of Law in Context*, 10, 81–104.
- Flynn, E., & Arstein-Kerslake, A. (2017). State intervention in the lives of people with disabilities: The case for a disability-neutral framework. *International Journal of Law in Context*, 13, 39–57.
- Gilliard, J., Means, R., Beattie, A., & Daker-White, G. (2005). Dementia care in England and the social model of disability. *Dementia*, 4, 571–586.
- Gooding, P. (2013). Supported decision-making: A rights-based disability concept and its implications for mental health law. *Psychiatry, Psychology and Law*, 20, 431–451.
- Harding, R., & Taşcıoğlu, E. (2018). Supported decision-making from theory to practice: Implementing the right to enjoy legal capacity. *Societies*, 8, 1–17.
- Ho, A. (2008). Relational autonomy or undue pressure? Family's role in medical decision-making. *Scandinavian Journal of Caring Sciences*, 22, 128–135.
- Holroyd, S., Turnbull, Q., & Wolf, A. (2002). What are patients and their families told about the diagnosis of dementia? Results of a family survey. *International Journal of Geriatric Psychiatry*, 17, 218–221.
- Jones, M. (2005). Can international law improve mental health? Some thoughts on the proposed Convention on the Rights of People with Disabilities. *International Journal of Law and Psychiatry*, 28, 183–205.
- Kanter, A. (2009). The United Nations Convention on the Rights of Persons with Disabilities and its implications for the rights of elderly people under international law. *Georgia State University Law Review*, 25, 527–573.
- Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review*, 8, 1–34.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and wellbeing. *Ageing and Society*, 12, 269–287.
- Kong, C. (2015). The Convention for the Rights of Persons with Disabilities and Article 12: Prospective feminist lessons against the "will and preferences" paradigm. *Laws*, 4, 709–728.
- Lush, D. (2011). Article 12 of the United Nations Convention on the Rights of Persons with Disabilities. *Elder Law Journal*, 1, 61–68.
- Marzanski, M. (2000). Would you like to know what is wrong with you? On telling the truth to patients with dementia. *Journal of Medical Ethics*, 26, 108–113.
- Midgley, M. (1983). *Heart and mind: The varieties of moral experience*. (London: Methuen).
- Mulvany, J. (2000). Disability, impairment, or illness? The relevance of the social model of disability to the study of mental disorder. *Sociology of Health & Illness*, 22, 582–602.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. Basingstoke: Macmillan.
- Pearce, A., Clare, L., & Pistrang, N. (2019). Managing sense of self: Coping in the early stages of Alzheimer's Disease. *Dementia*, 1, 173–192.
- Powers, S., Dawson, N., Krestar, M., Yarry, S., & Judge, K. (2016). 'I wish they would remember that I forget': The effects of memory loss on the lives of individuals with mild-to-moderate dementia. *Dementia*, 15, 1053–1067.
- Preston, L., Marshall, A., & Bucks, R. (2007). Investigating the ways that older people cope with dementia: A qualitative study. *Ageing & Mental Health*, 11, 131–143.
- Quinn, G. (2010). The United Nations Convention on the Rights of Persons with Disabilities: Toward a new international politics of disability. *Texas Journal on Civil Liberties and Civil Rights*, 15, 33–52.
- Richardson, G. (2012). Mental disabilities and the law: From substitute to supported decision-making? *Current Legal Problems*, 65, 333–354.
- Sabat, S., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12, 443–461.
- Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: Findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics*, 25, 949–961.
- Series, L. (2015). Relationships, autonomy and legal capacity: Mental capacity and support paradigms. *International Journal of Law and Psychiatry*, 40, 80–91.

- Shakespeare, T. (2014). *Disability rights and wrongs revisited* (2<sup>nd</sup> ed.). Abingdon: Routledge.
- Shakespeare, T., Zeilig, H., & Mittler, P. (2017). Rights in mind: Thinking differently about dementia and disability. *Dementia*. <https://doi.org/10.1177/1471301217701506> Online First.
- Sinclair, C., Gersbach, K., Hogan, M., Bucks, R., Auret, K., Clayton, J., ... Kurrle, S. (2018). How couples with dementia experience healthcare, lifestyle, and everyday decision-making. *International Psychogeriatrics*, 30, 1639–1647.
- Skowron, P. (2016). The implications of Meno's Paradox for the Mental capacity Act 2005. *Medical Law Review*, 24, 379–395.
- Skowron, P. (2019). *Giving substance to "the best interpretation of will and preference"* (forthcoming).
- Stavert, J. (2015). The exercise of legal capacity, supported decision-making and Scotland's mental health and incapacity legislation: Working with CRPD challenges. *Laws*, 8, 296–313.
- Steeman, E., Godderis, J., Grypdonck, M., De Bal, N., & Dierckx de Casterlé, B. (2007). Living with dementia from the perspective of older people: Is it a positive story? *Aging & Mental Health*, 11, 119–130.
- Szmukler, G. (2017). The UN Convention on the Rights of Persons with Disabilities: 'Rights, will and preferences' in relation to mental health disabilities. *International Journal of Law and Psychiatry*, 54, 90–97.
- Verkerk, M. (1999). A care perspective on coercion and autonomy. *Bioethics*, 13, 358–368.
- Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T., & Heslop, P. (2012). *Making best interests decisions: People and processes*. London: Mental Health Foundation.
- Williamson, T., Boyle, G., Heslop, P., Jepson, M., Swift, P., & Williams, V. (2012). Listening to the lady in the bed: The Mental capacity Act 2005 in practice for older people. *Elder Law Journal*, 2, 185–192.
- Wolverson, E., Clarke, C., & Moniz-Cook, E. (2016). Living positively with dementia: A systematic review and synthesis of the qualitative literature. *Aging & Mental Health*, 20, 676–699.