

'I lost yesterday': Dementia, Mediation and Decision-making

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Abstract

An estimated one million people in the UK will be living with dementia by 2025. This stark statistic makes it urgent to address our institutional and personal responses and our design of support for decision-making for those living with dementia. We could draw on the social model developed by the disability rights movement, whose slogan is 'Nothing about us without us'. Mediation has a role in this, as a process for collaborative problem-solving and decision-making that puts voice and supported participation at its heart. This article explores how specialist elder mediators can facilitate the involvement of people living with dementia in decision-making that affects their lives. It refers to what people living with dementia say they value and draws on philosophical perspectives on selfhood and on people's decision-making capacity. Using principles drawn from human rights and social work, mediators can help prevent and resolve disagreements about care in a way that prioritises human flourishing and facilitates participation by the person at the centre of the dispute. To do so, mediators must challenge prevalent and paternalistic assumptions about vulnerability and protection.

Key Words: dementia, decision-making, mediation, elder mediation, ageing, rights, human rights, mental capacity

'I lost yesterday. I don't know what happened to it.' Wendy Mitchell, *Somebody I Used to Know*

In her 2018 memoir, *Somebody I Used to Know*, activist Wendy Mitchell writes movingly of the way the present becomes all important to her. She is living with dementia (not 'suffering from it'), and she campaigns to raise awareness of dementia and encourages people to understand that there is life after a dementia diagnosis. But the frustrations she experiences are undeniable, and the temporal reality she inhabits is felt as a loss, especially during times when both the past and the future loom large in our imaginations – holidays, births, new year celebrations. 'For me', she writes, 'the past isn't there, and the future is too scary to contemplate'.¹

¹ Wendy Mitchell (2018), *Somebody I Used to Know*, Bloomsbury, p.229.

How does this present-focus affect decision-making of those living with dementia? It is an issue that requires careful thought about how changes that come with dementia affect one's decision-making abilities and also change one's priorities and values. Does the person living with dementia make decisions, with support, based on previously expressed values or on values expressed now, which might conflict with those earlier ones? And if the person lacks the capacity to make a decision herself, does the person making it on her behalf, in her best interests, base this on what the person before dementia expressed in the past, or what she expresses now?

Mediators working with disputes involving decision-making by, with, or on behalf of older people (an area of practice known as 'elder mediation') are likely to be faced with this dilemma and other challenging ethical issues involving perceptions of vulnerability that are shaped by a paternalistic culture. 'One of the most powerful assumptions' in our ways of thinking about dementia is that cognitive impairment, a loss of reasoning ability, erodes selfhood and precludes involvement in decision-making.² By adopting what are known in social work practice as strengths-based techniques,³ however, elder mediators can facilitate a uniquely collaborative and person-centred approach to supported decision-making.

This paper explores the relationship between dementia and disability rights in the UK, considers debates around issues of autonomy and safety, and discusses how relationships and personal values (even changing values) may take priority over cognitive function in terms of identity and selfhood of a person living with dementia. It proposes that ability to participate in mediation is not dependent on mental capacity, as assessed under the Mental Capacity Act 2005, and suggests that supported decision-making is a potential means of overcoming the limitations of a legalistic view of decision-making capacity. Finally, the paper highlights the value of mediation as a process that is ideally placed to support decision-making for people living with dementia. Bringing in a specialist and independent third party to support participation and shared decision-making can help parties in a dispute to set aside what can be disempowering assumptions about vulnerability and capacity.

About dementia⁴

Dementia is a syndrome – it is not a single condition but a collection of symptoms that arise from a number of conditions (Wicking Dementia Research and Education Centre). Alzheimer's is the most well-known form of dementia, and it is the most common, but other forms also exist, including frontotemporal, Lewy body, and vascular dementia. It is not a 'normal' part of ageing – it does not affect all older people, and it can affect younger

² Bruce Jennings (2009), 'Agency and Moral Relationship in Dementia', *Metaphilosophy*, 40 (3/4), pp.427.

³ Social Care Institute for Excellence, 'Strengths-based approaches (SBA)', available at <https://www.scie.org.uk/strengths-based-approaches/>

⁴ The facts and figures in this section are drawn from the Wicking Dementia Research and Education Centre at the University of Tasmania and its online course 'Understanding Dementia'. This seven-week course is offered free and is available to anyone with an interest in dementia. For more information, see: https://mooc.utas.edu.au/organisation/3/The_Wicking_Dementia_Centre.html

people; Mitchell is an example of someone who has experienced younger onset dementia, which is defined as dementia occurring in people under age 65. The vast majority of dementia cases (90-95%) affect people over age 65, but in this age group, only 10% will have dementia. This increases to 50% for people over age 95.

Dementia's trajectory is both predictable and not; there are stages that feature in most forms of dementia, but not all those living with dementia will experience those in the same way. Early on it can involve cognitive challenges – memory loss, difficulties with planning, changes in mood and behaviour. As it progresses it affects perception, thinking, and reasoning, as well as bringing physical changes in terms of loss of mobility and increased risk of infections. How long someone lives with dementia, and when they experience these changes, is not always predictable. It depends in part on how early they receive a diagnosis, but it may involve other factors as well, including environmental factors and personal circumstances. Currently there is no 'cure' for dementia, and the stark reality is that it is a progressive and terminal condition, but there are treatments that can manage or delay symptoms.

Dementia and disability rights

It is estimated that more than a million people in the UK will be living with dementia by 2025. Yet the rights of people with dementia have not been widely explored. In a Policy Discussion Paper published in 2015, the Mental Health Foundation (MHF) explores the debate on viewing dementia as a disability. 'Dementia, rights, and the social model of disability' explains that this debate is a relatively new one and that '[e]ngaging people with dementia, their families and friends, and those working in the dementia field in a human rights discourse is new for many'.⁵

The social model of disability developed by the disability rights movement, with its focus on social citizenship and its active identification of environments and attitudes as the disabling problem, contrasts with the medical model, which locates the 'problem' in the person with the impairment. The MHF report notes that the 'domains of well-being' outlined in the Care Act 2014⁶ 'are a direct reflection of the social model of disability principles', but it is the medical model that reflects the experiences of most people with dementia: 'the majority of people with dementia frame dementia as an illness or disease', and 'the lived experience of people with dementia is usually articulated as the impairment itself causing a disability'.⁷

Perhaps because of this difference (and arguably also because dementia is usually associated with ageing, which has largely been left out of discussions of disability rights), both the social model of disability and a human rights

⁵ Mental Health Foundation (2015), 'Dementia, rights, and the social model of disability', p.9, available at <https://www.mentalhealth.org.uk/explore-mental-health/publications/dementia-rights-and-social-model-disability>

⁶ Care Act 2014, available at <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>. These domains include personal dignity, protection from abuse, control by the individual over their day-to-day life, physical health, mental health and emotional wellbeing, and the individual's contribution to society.

⁷ Mental Health Foundation (2015), p.15.

lens have 'not been widely applied in relation to the lived experience, the policy response or the services that are provided to people with dementia'.⁸ Instead, those policy responses and services have largely been framed along the medical model. There is a debate about whether a 'wholesale shift' from the medical to the social model is appropriate for how we approach dementia because of the need to recognise the condition's harmful and distressing effects and the desire to continue to seek treatments and cures. This debate may reflect a misunderstanding of the social model; as Crowther notes, 'Contrary to some misconceptions, the social model of disability does not negate the effect of impairments and health conditions or the potential advantages of treatment and therapies.'⁹ There is much in the social model and the disability rights movement that we can draw on as mediators to identify the attitudinal, societal, and political barriers faced by people living with dementia.

Psychologist and academic Tom Kitwood, whose work transformed our understanding of a person-centred culture of care for people living with dementia, wrote that it is 'absurdly reductionist' to suggest that what happens to people with dementia is down to what goes on in their brains. The 'process of dementia is also the story of a tragic inadequacy in our culture, our economy, our traditional views about gender, our medical system and our general way of life'.¹⁰ Dementia's grip on a person, and on selfhood, is therefore not a story only of medicine's ability to respond to changes in the brain, but one of society's ability to respond to disability. As Bruce Jennings asserts, in his essay on agency in dementia care, 'The tragedy of dementia is not so much that it alters brain function and changes what people can think and do; the real tragedy occurs when and if we allow these changes to objectify persons'.¹¹

Noting that 'dementia activism' is being led by younger people living with dementia, who may be more familiar with the disability rights movement, the MHF Policy Discussion Paper suggests that the social model, along with embedding a human rights approach, has the potential to reshape 'how dementia is talked about and, critically, who does the talking'.¹² Despite the rise of dementia rights activism, however, the reality for most older people living with dementia, as Crowther highlights, is that they are 'overwhelmingly presumed or deemed to lack capacity and individual agency. ... Moreover, dominant narratives concerning dementia do emphasise a loss of agency and dependency on others, with few counternarratives'.¹³

The changes that are needed to progress a human rights perspective on dementia are similar to those brought in by the disability rights movement to address stigma and exclusion: implementing dementia-inclusive design in

8 Mental Health Foundation (2015), p.15.

9 Neil Crowther (2022), 'People, Place, Purpose and Power: Promoting the Wellbeing of People Living with Dementia Through Personalised Care and Support', *Dementia Change Action Network*, p.30.

10 Tom Kitwood (1997), *Dementia Reconsidered: The person comes first*, Open University Press, p.41.

11 Jennings (2009), p.427.

12 Mental Health Foundation (2015), p.6

13 Crowther (2022), p.32

the physical environment and the provision of services; educating employers, businesses and other organisations; requiring reasonable adjustments and accommodations to be made so that dementia forms part of everyday, visible life, which increases understanding and knowledge. Mediation played a role early on in advancing these ambitions of promoting inclusion by educating parties in dispute and helping them to identify reasonable adjustments and other solutions. It was one of the mechanisms offered by the Disability Rights Commission (DRC) to address disability discrimination claims under the Disability Discrimination Act 1995, and it was used successfully and much more frequently than the courts.¹⁴ As O'Brien explains, the rights-based model of mediation used by the DRC 'offered the possibility of bringing about "culture change" in public authorities and private organisations in a way that translated abstract rights issues into aspects of everyday life. Just as importantly, it enabled the active engagement of disabled people as citizens in transformative practice'.¹⁵ One of the key contributions it can make is to facilitate supported decision-making so that people living with dementia are part of decision-making processes, both at a strategic level and an individual level.

Autonomy and safety

Although dementia is not a normal part of ageing, many of society's attitudes towards older people generally are reflected in attitudes towards those with dementia. One prevalent attitude is the paternalism inherent in an emphasis on risk reduction, sometimes referred to in the social work profession as a 'protection imperative'. Safeguarding is often seen as prioritising safety, but for someone who lacks capacity to make decisions for themselves or is unable to carry out activities independently, this can limit their options in a way that would be intolerable to someone who is not reliant on others for these things. Barry argues that in elder mediation, especially in relation to elder abuse, there is a danger that mediators will adopt a paternalistic approach featuring what she calls 'protectionism'. 'To take elder rights seriously', she writes unequivocally, 'will involve putting the genie of protectionism back in the bottle.'¹⁶

This protectionism is evident in the findings of a research project carried out on decision-making by people living with dementia in care settings. The study examined people's desire to participate in a decision on treatment and the factors influencing their participation. It found that 92% of those studied who were living with dementia wanted to participate in the decision, while only 71% of their care partners thought they would want to participate: 'People living with dementia concentrated on involvement in the process, while their care partners focused on their relatives' capacity to participate.' A review of this and other research studies on decision-making by people living with dementia concluded that 'The available evidence suggests that people living

14 See, for example, Margaret Doyle (2007), 'Enforcing Rights Through Mediation', *Legal Bulletin*, 12, Disability Rights Commission.

15 Nick O'Brien (2024), *Politics and Administrative Justice: Postliberalism, Street-Level Bureaucracy and the Reawakening of Democratic Citizenship*, Bristol University Press, p.77.

16 Lise Barry (2015), 'Elder Mediation: What's in a Name?', *Conflict Resolution Quarterly* 32 (4), p.438.

with cognitive impairment want the opportunity to participate in decision-making about their health and care; it can contribute to a sense of worth and has the potential to improve quality of life.¹⁷

This desire to participate in decision-making can be thwarted by a bias toward risk aversion that features particularly in health care practice. In his book *Being Mortal*, surgeon Atul Gawande describes the pernicious effect of the medicalisation of ageing and the way that mortality has been made into a medical experience, a problem to be solved by treatment. He sets out needs on a spectrum, with safety at one end (the need to prevent falls, to provide a balanced diet, to ensure medications are taken) and autonomy at the other (the need to make and act on one's own choices, preferences and decisions). When deciding for ourselves, we will often prioritise autonomy, whereas others deciding for us, or about us, will often prioritise safety. Old age is a relatively recent concept, and generally (particularly in the Global North) we are living far longer than our forebears could imagine. As a result, he writes, '[m]aking lives meaningful in old age is new. It therefore requires more imagination and invention than making them merely safe does.'¹⁸ But we do not yet have that imagination and invention embedded in our institutional response to dementia on issues like providing health care, establishing residential environments, and creating inclusive workplaces and public spaces.

Although, as Gawande describes, risk aversion is prevalent in health care, in social care there has been a notable effort (not always successfully implemented) to embed well-being and take a more nuanced and personalised approach to risk assessment. The Care Act 2014, for example, emphasises well-being and getting the balance right between ensuring safety and respecting the views and wishes of the individual. The strengths-based framework used in social work practice¹⁹ explores in a collaborative way the entire individual's abilities and their circumstances rather than making the deficit the focus of the intervention. It is about gathering a holistic picture of the individual's life, including from their support network and other professionals. Risk is looked at as an enabler, not a barrier, and should be explored with the individual and from their point of view. Martin describes a strengths approach in elder mediation as a focus on the resources, values, and goals of the older person that also takes account of the difficulties and challenges that ageing can bring.²⁰ These challenges include the cognitive impairment experienced by many people living with dementia; a focus on strengths does not require ignoring real challenges in terms of memory, understanding, and decision-making.

17 Rachel Louise Daly, Frances Bunn, Claire Goodman (2018), 'Shared decision-making for people living with dementia in extended care settings: a systematic review', *BMJ Open* 2018;8: e018977. doi:10.1136/bmjopen-2017-018977; p.8.

18 Atul Gawande (2014), *Being Mortal: Illness, Medicine, and What Matters in the End*. Profile Books, p.137.

19 Department for Health and Social Care (2019), 'Strengths-based approach: Practice Framework and Practice Handbook', available at <https://assets.publishing.service.gov.uk/media/5c62ae87ed915d04446a5739/stengths-based-approach-practice-framework-and-handbook.pdf>

20 Jennifer Martin (2015), 'A Strengths Approach to Elder Mediation', *Conflict Resolution Quarterly*, 32 (4), pp.481-98.

Despite this welcome emphasis on the views and wishes of the individual older person, individual autonomy in itself is a futile ambition, undesirable and unachievable. Gawande is critical of the notion that autonomy means complete independence or freedom from control or limitation. ‘Our lives’, he writes, ‘are inherently dependent on others’; we are all vulnerable in the sense that we are inter-dependent. ‘The amount of freedom you have in your life is not the measure of the worth of your life. Just as safety is an empty and even self-defeating goal to live for, so ultimately is autonomy’.²¹ Examining the concept of compassion and the literature on an ethic of care, Herring suggests the law prioritises individual autonomy and neglects the importance of our relational selves and our interdependence on others: ‘The muddled give and take of everyday caring life where sacrifices are made and benefits gained, without them being totted up on some giant familial star chart, chimes more with everyday life than the image of independent interests and rights.’²² A relational concept of rights, he argues, would identify someone as both an individual and as a part of ‘a web of relationships of care, attachments and interdependency’.

As Braun explains, feminist legal scholars have ‘reconceptualised autonomy to incorporate these considerations within a “relational” theory of autonomy’ that sets decision-making within a social context and the societal and political structures that support (and also impede) autonomy.²³ She notes that a relational theory of autonomy provides a better foundation for decision-making in elder mediation, which requires taking account of the impact of social environment and of social relationships. For Clough, issues of ‘empowerment, protection, and paternalism’ are not abstract ideals but are embedded within wider ‘configurations’ – including cultural, economic, institutional – in which we are all entangled.²⁴ These entanglements are evident closer to home, too, in our relationships and circles of support. Examining informal care relationships, Clough identifies shortcomings in the individualistic approach of the statutory framework for ‘best interests’ decision-making and argues it is important to recognise ‘that interests within caring relationships are often intertwined and decisions should not be taken without consideration of the impact that this will have upon those within the relationship’.²⁵ Mediation as a collaborative process, operating alongside but not embedded within a legal framework, is designed to accommodate what these writers describe as a web of relationships and intertwining interests. It is essentially about connection, and its ability to accommodate many voices, perspectives and interests gives it a distinct texture, a ‘sensibility’ that takes it beyond a form of one-off dispute resolution.²⁶ Individual legal

21 Gawande (2014), p.140.

22 Jonathan Herring (2017), ‘Compassion, ethics of care and legal rights’, *International Journal of Law in Context*, 13 (2), pp.158–171

23 Joan Braun (2020), ‘Legal Interventions to Protect Vulnerable Adults: Can Relational Autonomy Provide a New Way Forward?’, *Elder Law Review* 2020.

24 Beverley Clough (2022), *The Spaces of Mental Capacity Law: Moving Beyond Binaries*, Routledge, pp.127-128.

25 Beverley Clough (2014), ‘What about us? A case for legal recognition of interdependence in informal care relationships’, *Journal of Social Welfare and Family Law* 36:2, pp.137-38

26 Margaret Doyle and Nick O’Brien (2019), *Reimagining Administrative Justice: Human rights in small places*, Palgrave MacMillan, p.114.

rights and duties are not irrelevant, but mediators must ensure that a focus on individual rights does not compromise the parties' shared interests or the role that relationships play in securing individual well-being.

Identity and values

In social care, terminology changes have helped shift the perspective away from paternalism and towards a more objective use of language.²⁷ 'Vulnerable adults' was replaced with 'adults at risk' and subsequently replaced with 'adults with care and support needs' and 'people who draw on care and support', which includes those living with dementia. The emphasis is on person-centred approaches to providing that care and support – on seeing the person as an individual, with preferences, values and priorities that influence how they want to live. But dementia is different from many other disabilities in that it brings on cognitive changes that mean an individual's preferences, values and priorities expressed at one point might differ from those expressed at another, earlier point. Whose autonomy, whose preferences and values, are to be prioritised – the person before dementia or the person living with dementia? Philosopher Agnieszka Jaworska refers to this as a 'quandary' and asks, 'Should we give priority to the preferences and attitudes this person held before becoming demented [sic], or should we follow the person's present preferences?'²⁸

It is a question that Mitchell asks herself. She writes, '...the now is changing every day. I'm a different me today from the one I was six months ago. A different one then from the one I was a year ago.... Can I rely on this new me, the one with such fuzzy memories of what came before? What about the one who comes six months or a year from now?' Watching a video of a speaking engagement she had in the past, she wonders whether she can rely on her future self to articulate her wishes. She doesn't recognise the woman speaking in this video; 'the me I knew for fifty-eight years has already departed', she writes. 'I keep her alive where I can – in a funny blog post, or a WhatsApp message, an email or a quip written into one of my speeches. Is that the real me trapped inside – or is it the one who speaks on the inside? Is one of them a fraud?'.²⁹

Jaworska discusses how philosophers have taken opposing stances on this 'then and now me', and in particular the contrasting positions of Ronald Dworkin and Rebecca Dresser.³⁰ Jaworska sets out Dworkin's view that one must adhere to the values expressed before dementia, when the person had autonomy and was able to judge for themselves what is needed for their well-being. On the other hand, Dresser, as Jaworska describes, holds that decisions must speak to a person's currently expressed views and values, and

27 For an inspiring discussion of the dangers of the term 'vulnerable', see Bryony Shannon (2021), 'Words that make me go hmmm: Vulnerable', on *Rewriting Social Care* blog, available at <https://rewritingsocialcare.blog/2021/08/20/the-v-word/>

28 Agnieszka Jaworska (1999), 'Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value', *Philosophy & Public Affairs*, 28, 2, Spring, pp.105-138. Note the term 'becoming demented' is no longer widely used.

29 Mitchell (2018), pp.284-85.

30 Jaworska (1999), pp.108-110.

that the person with dementia is not the same person as before dementia.³¹ Jaworska suggests an alternative approach is possible, one that does not assume that autonomy relies on decision-making capacity and the ability to perceive one's life as a whole. The changes that dementia brings can make it impossible to turn current experiences into longer term memories; this is what Dworkin refers to 'a past joined to a future'. Instead, Jaworska argues, autonomy should be associated with the capacity to value and to promote one's own well-being by living in accordance with one's current values.

Dementia affects the part of the brain that maintains the ability to see and plan one's life as a whole (past, present, future), but that ability is not crucial to valuing. To express a value, Jaworska proposes, does not require the ability to see one's life as a whole; it is instead something you would regret not having. Essential to valuing, in her alternative approach, are that the person believes they are correct in valuing what they value and that achieving it contributes to their sense of self-worth. We can, she suggests, value experiences and pleasure; and we can be supported to act on values that we cannot act on independently. Values are expressed in both big, life-changing decisions and in what Series calls the 'micro-choices' of everyday life – 'how one arranges one's furniture, which night you watch a movie, whether to water a houseplant or let it die ...opportunities for the expression and flourishing of self do not wait for the 'big' decisions, but are tightly woven into our everyday lives and surroundings'.³²

Furthermore, how one is treated – having a sense of being valued as a human being – is not reliant on the ability to grasp one's life as a whole or indeed even to connect one experience to another through memory. Writing about his father's experience with dementia, and his own in learning to care for him, Sandeep Jauhar draws on this perspective of valuing that Jaworska describes. What is argued for, by Dworkin and others, is a psychological continuity based on sound memory; but Jauhar notes that such continuity is a myth, even for people without dementia. As adults we are not the same person we were as a child. In any case, memory is not necessarily the basis for continuity, which is 'also served by intentions, beliefs, values, habits, and other unconscious behaviours that are often preserved in patients with dementia'.³³ Jauhar's father might not remember that they went to House of Dosa for lunch each Sunday, but he knew that this person took him there, and he knew how it made him feel; whether or not he remembered him as his son is less important than the shared experience in the moment and his father's valuing of it. Our relationships and connections contribute to our personhood as much as our intellect does. As Jauhar writes, citing Kitwood, the conventional paradigm of personhood, so often located in autonomy, reason and intellect, neglects the social: 'Human beings exist not only in an

31 Another discussion of the Dworkin/Dresser debate on psychological continuity is in Mary Donnelly (2009), 'Best Interests, patient participation and the Mental Capacity Act 2005', *Medical Law Review* 17, pp.1-29

32 Lucy Series (2022), *Deprivation of Liberty in the Shadows of the Institution*, Bristol University Press, p.108.

33 Sandeep Jauhar (2023), *My Father's Brain: Understanding life in the shadow of Alzheimer's*, Oneworld Publications, p.164.

inner world but also in a public space. It is that space that continues to give meaning to the lives of people living with severe dementia'.³⁴

This process of 'giving meaning to' is a key component of mediation as practised by elder mediators. What is meaningful for someone living with dementia might be grounded in the moment, in the sense of being connected to others, in feeling valued and heard. Crowther explores the dimensions of personhood and the meanings attached to each: places and things, people and relationships, power and agency, and purpose and routines.³⁵ The flexibility of mediation allows for space in which to explore these dimensions and their meanings for the individual older person. In fostering collaboration between parties in disagreement, mediation highlights how connections and relationships are a resource, even when the nature of that relationship is unclear to the individual or when interests appear to be at odds. It also provides support to parties in the mediation process to jettison assumptions about identity that suggest cognitive impairment 'must of necessity erase the ability to make meaning and erode one's membership in the human moral community'.³⁶

Capacity and participation

When considering decision-making, that social and relational aspect of identity is crucial. Decision-making in mediation is a collaborative endeavour, not a solo pursuit. Clearly there can be a tension between the need to recognise shared and competing interests in a collaborative process and at the same time to ensure the voice of the person at the centre of decisions is heard and their involvement is facilitated.³⁷ That tension is exacerbated when the person is deemed to lack capacity. It is also important to distinguish between 'capacity' and 'ability to participate' – someone might be deemed to lack *capacity* for a particular decision (because of cognitive impairment, for example), as determined under the Mental Capacity Act 2005, but be *able to participate* in mediation and even to contribute to decision-making. This also is in keeping with the UN Convention on the Rights of Persons with Disabilities (CRPD), which requires supported rather than substituted decision-making.³⁸ The MCA sets out five principles that apply to decisions and actions taken under the Act; in addition to presuming that a person has capacity unless it is established otherwise, the principles make clear that someone should not be treated as lacking capacity for decision-making 'merely because he or she makes an unwise decision' and 'unless all practicable steps to help him or her to do so have been taken without success'.³⁹

34 Jauhar (2023), p.165

35 Crowther (2022), p.10.

36 Jennings (2009), p.427.

37 See Clough (2014), p.14.

38 See Article 12 of the CRPD, https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

39 The MCA's five principles are set out in the legislation here: <https://www.legislation.gov.uk/ukpga/2005/9/section/1> For a discussion of the development of the MCA 2005, see Clough (2022), Chapter 2, 'Spatial dynamics and disability: Interrogating the terrain of the Mental Capacity Act 2005', pp.29-51.

The MCA explains that an assessment of mental capacity applies to individual, specific decisions and may vary according to the nature of the decision; someone might be deemed to have capacity to make a decision about one issue (e.g. what to eat for breakfast) and not another (e.g. where to live and with whom). A key underlying principle in the Act is the presumption of capacity; an individual is presumed to have capacity unless otherwise determined by an assessment. Unless deemed to lack capacity under the Act, a disabled person is as entitled as any non-disabled person to make unwise decisions for themselves, even if others consider those decisions are not in the person's best interests. This can be difficult for family members and carers to accept, however. As in the specialist field of mediation in special educational needs and disabilities (SEND), involving educational support for disabled pupils, where the MCA applies to pupils over age 16, there is a tendency to leapfrog straight to the concept of 'best interests decisions' made on the person's behalf before capacity for a specific decision has been determined.⁴⁰ Often this is intended as a way to protect the disabled person from harm and distress. In my own experience as an elder mediator, I have often heard family members explain their concern that involving the older person with dementia in a mediation might cause distress to that person. Mediators must resist getting drawn into that protectionism and help parties to understand that distress and other emotions may be an inherent part of conflict, for all those involved. As Barry writes, 'There is no getting away from the fact that conflict can upset people; however, older people have a right to experience life's full range of emotions, including those that are traditionally regarded as negative or harmful.'⁴¹

In the context of the Court of Protection, where mediation is sometimes used in decisions about health, care and welfare of people deemed to lack capacity, Lindsey has explored participation of the central subject ('P' or the Person). This is a context in which, as in elder mediation, protectionism is evident.⁴² Lindsey sees that mediation offers clear opportunities for participation, something that is essential for securing procedural justice, but her empirical work has identified that 'mediation has not yet facilitated the Person's participation in practice'.⁴³ Participation in this context can be direct or indirect and can mean attending the mediation (with or without support), being legally represented at the mediation, and conveying wishes and feelings to those attending. Lindsey gives examples of good practice and reasonable adjustments drawn from her interviews with mediators. She cites Barry's call for mediation standards to be explicit about the ways mediators should facilitate participation: 'In this regard, it is important to remember that a Person "may have capacity to attend, observe, and have input into a mediation process, even if there are questions about his or her capacity to enter into a mediation agreement."⁴⁴

40 Margaret Doyle (2019), 'A Place at the Table: A report on young people's participation in resolving disputes about special educational needs and disabilities', *UK Administrative Justice Institute*, University of Essex, p.38.

41 Barry (2015), p.440.

42 Jaime Lindsey (2022), *Reimagining the Court of Protection: Accessing Justice in Mental Capacity Law*, Cambridge University Press, pp.135-136.

43 Lindsey (2022), p.130.

44 Lindsey (2022), p.136, citing Barry (2015), p.439.

Elder mediation literature emphasises the complexity of the issue of capacity, but there is no clear directive to mediators as to their role in assessing capacity. The Code of Ethics published by the Elder Mediation International Network (EMIN), the accrediting body for elder mediators, requires mediators to ‘explore whether the participants are cognitively capable of engaging in the mediation process’ and if not, to explore whether a family member, adviser, or advocate is able to represent the person’s wishes.⁴⁵ The Code also requires elder mediators to ensure, as far as possible, that all parties’ voices are represented in the mediation process. Because the Code is an international one and covers different legal jurisdictions, it does not refer explicitly to capacity assessment under the MCA, but it suggests that mediators should rely on expert assessments of ‘diminished capacity’. The elder mediation literature reveals a lack of consensus on what responsibility elder mediators have for assessing capacity, however, and the line is sometimes blurred between capacity assessment and assessment of ability to participate (directly or indirectly) in mediation. While Barry is clear that elder mediators must distinguish between capacity to participate in mediation and capacity to make decisions and enter into an agreement, she is also clear that mediators should not be involved in assessing the capacity of older people to mediate.⁴⁶ Doing so, she suggests, would risk limiting the person’s access to the process and compromising the mediator’s impartiality. In contrast, in her overview of the potential pitfalls faced by elder mediators, Braun notes that mediators are not in a position to assess participants’ decision-making capacity but must determine capacity to participate in the mediation.⁴⁷ Martin, however, suggests that it is the mediator’s role to ensure that the older person’s ‘decision-making capacity’ is not impaired and to arrange for an assessment if capacity is in doubt, citing assessment criteria set out by the Law Society of New South Wales.⁴⁸

Distinguishing between these two aspects of capacity is an important safeguard for the older person at the centre of the mediation. As Wood has highlighted, ‘The question is not so much “does the party have capacity to mediate” as “can the party mediate with support?” and “what can the mediator do to facilitate the understanding of the party?”’.⁴⁹ This suggests a need to articulate more clearly the elder mediator’s role in facilitating participation rather than assessing capacity.

Mediation and supported decision-making

The dilemma, or ‘quandary’, as Jaworska describes it, about the basis of personhood permeates disputes that arise when people living with dementia face fundamental decisions about where they live, with whom, and what care and support to access or treatment to have. Those around the person – carers, friends, family members, health professionals – often make assumptions about capacity for decision-making. It is not uncommon in such disputes for

45 ‘Code of Ethics for Elder Mediators’ (2021), Elder Mediation International Network, s. 6.4.4; available at <https://elder-mediation-international.net/code-professional-conduct/>

46 Barry (2015), p.439.

47 Joan Braun (2012), ‘Elder Mediation: Promising Approaches and Potential Pitfalls’, *Elder Law Review* (7), p.10.

48 Martin (2015), p.490.

49 Erica Wood (2003), ‘Addressing Capacity: What Is the Role of the Mediator?’, <https://mediate.com/addressing-capacity-what-is-the-role-of-the-mediator/>

carers and family members to step in and take over decision-making. Usually this is with good intentions, to protect the person at the centre of the dispute from stress or distress, but it is often disempowering. As the authors of the systematic review of research on decision-making concluded, 'People living with cognitive impairment value opportunities to be involved in everyday decision-making about their care and involvement in the decision-making process appears to be as important as the decision itself.' Yet '[t]his desire to share in decision-making is consistently underestimated by care partners and workers'.⁵⁰ Bringing in a specialist and independent third party to support participation and shared decision-making can help parties in a dispute to set aside those assumptions.

How would approaching this through a strength-based and human rights lens change a mediator's practice when working with an older person with dementia? Practitioners specialising in elder mediation are required to have an expert understanding of ageing and issues of capacity and autonomy. They must be familiar with signs of elder abuse, which can be physical, financial, and emotional and which can be disguised as protectionism. Elder mediators also require the skills to facilitate participation and supported decision-making by the older person who is at the centre of the dispute. Elder mediators use critical reflection to take account of power imbalances and the potential for exclusion and paternalism. They also prioritise the views and wishes of the older person; in this sense they are not neutral actors and should be explicit about this, a point made powerfully by Barry.⁵¹ They have a responsibility to ensure that the older person is supported to be involved in decision-making on issues that affect them while maintaining the person's sense of dignity, value, and identity.

In a recent guide to supported decision-making, Series writes of the way that supported and facilitated decision-making maximises a person's agency. She also warns of the risk that 'mental capacity law can also be used to dismiss a person's wishes and feelings and rights to decide.'⁵² The guide explains that when someone is unable to express a clear preference (which can include where to live and whether to have or to reject a proposed medical treatment), 'facilitated decision making' offers a process that fits with international human rights approaches by identifying a 'best interpretation' of the person's preferences. 'In other words, we try and work out what the person would be likely to say or what they'd want, if they were able to tell us. Under the Mental Capacity Act 2005, we could call this trying to ascertain their 'wishes, feelings, values and beliefs, and thinking about factors' the person would be likely to think about if they were making the decision themselves.'⁵³

Some of the barriers to supported or facilitated decision-making identified in the guide include presumptions about what people want, being risk averse, not feeling competent to provide support, and inheriting a culture of 'this is how it's done'. The assumptions and behaviours underlying

50 Daly, Bunn, Goodman (2018), p.9.

51 Barry (2015), pp.436-37.

52 Paradigm (2023), 'A Practical Guide to Supported Decision-Making', Paradigm and partners; available at: <https://paradigm-uk.org/2023/06/13/the-practical-to-supported-decision-making-is-now-here/>

53 Paradigm (2023), p.10.

these obstacles can be challenged in mediation, with a mediator taking on responsibility for supporting those involved to be more confident to move away from established practices. Facilitating effective communication (which might require reasonable adjustments such as adaptive technology) and ensuring the older person is at the centre of decision-making are key roles for the mediator.⁵⁴ In practice, however, we should recognise that supporting decision-making is a complex issue that requires particular skills. Harding describes the findings from her Everyday Decisions research project that show that the approach under the MCA works well in supporting straightforward, ‘everyday’ decision-making (e.g. what to wear, what to eat), but for more complex decisions, ongoing and nuanced support was necessary, and not always available. Indeed, it is not only how the support is provided, but who provides it, that matters. Professional independent advocates and informal carers have different, but both valuable, knowledge and skills. Harding argues that combining ‘formal and informal support is likely to give...the best chance to make decisions that are well-informed and in line with’ the individual’s preferences, wishes and values.⁵⁵

Mediators specialising in disputes involving older people and decisions made by and for them, including people with dementia, could adopt tools such as the guide on supported decision-making and the strengths-based framework used in social work and focus on capabilities instead of perceiving ageing as primarily about loss. As elder mediators (or indeed mediators working in any field related to disabilities), we should also take account of the MHF’s principles for a human rights-based approach. Described with the acronym PANEL, these principles are Participation, Accountability, Non-discrimination and equality, Empowerment, and Legality of rights. We should free ourselves and the parties we work with from the legal definitions of capacity for decision-making and instead focus on how to facilitate supported decision-making, participation, and the expression of views, priorities, and values – to accept, as Small suggests in *The Long Life*, Jaworska’s ‘argument that the threshold level necessary to lend prudential authority to a person’s current wishes should be set at the ability to espouse coherent and consistent values, and not at the ability to grasp one’s life as a whole’.⁵⁶

Conclusion

Small writes that ‘our sense of the depletions of old age is sometimes so preemptively strong that it overrules a just recognition of how much remains’.⁵⁷ When dementia is present, this sense of depletion can be exacerbated and result in a form of dehumanising. As Kitwood and Bredin write, ‘Dementia

54 Chapter 3 of the Mental Capacity Act Code of Practice, which provides practical guidance on supporting people to make decisions for themselves or be involved in decision-making, is a useful resource for elder mediators working with parties with dementia. Department for Constitutional Affairs (2005), *Mental Capacity Act 2005 code of Practice*, available at: <https://assets.publishing.service.gov.uk/media/5f6cc6138fa8f541f6763295/Mental-capacity-act-code-of-practice.pdf>

55 Rosie Harding (2022), ‘Supporting Everyday Legal Capacity: Navigating the Complexities of Putting rights into Practice’, in *Supporting Legal Capacity in Socio-Legal Context*, Mary Donnelly, Rosie Harding, and Ezgi Tascioglu, eds, Hart Publishing, p.307.

56 Helen Small (2010), *The Long Life*, Oxford University Press, p.269.

57 Small (2010), p.269.

is often presented as a dire condition, a terrible and progressive loss. It is easy to characterise it as a state of continuing and ever-deepening ill-being. This can hardly be disputed if attention is focused on highly developed cognitive powers to the exclusion of other human faculties.⁵⁸ On a very personal level, writing of his father's experience living with Alzheimer's, Jauhar describes how this bias of the 'hypercognitive world' excludes people: 'In this world swirling with information, we prioritise intellect and reason as the dominant virtues. If you do not possess these virtues, you are marginalised. If you cannot follow or add to the endless conversation, you are rendered invisible.'⁵⁹

Mediators have an important role in combatting this narrative. As mediators, we focus on the abilities people have and not on their weaknesses, identifying sources of resilience. This does not only mean strengths that people have within themselves, and it does not mean ignoring capacity challenges. It is a fact that dementia is associated with losses that can require support – losses in cognition, memory, reasoning, mobility, physical strength. Those losses can also justify restrictions in choice and autonomy, such as prohibitions on activities such as driving that put others at risk. But strength can also be in the resources and support that people can draw on, in the 'relational welfare approach' set out by Braun, Clough, Herring and others. Autonomy is something we often need help to attain, and it is not a worthwhile ambition if it can only be achieved alone.

Strength and resilience are also found in the ways that people living with dementia find to manage and cope with changes in their cognitive abilities, including memory prompts, planning aids, and new perspectives. Although Mitchell is frustrated with the limitations of the present-focus that dementia has put on her life and her sense of self, she also recognises it as a gift. She has spoken of dementia giving her the gift of time in the sense that she has a new-found appreciation for the here and now, for seeing tiny details. She writes in her memoir of the pleasure of re-experiencing activities (reading a good book again or watching a much-loved film over and over). She describes the peace she finds in a busy cityscape when she sits and observes the rushing of people, seagulls, tugboats: 'How strange', she writes, 'that Alzheimer's has reminded me of the calmness to be found in a little time out when, simultaneously, I feel in a rush to make the most of every moment before it deserts me.'⁶⁰ To perceive dementia as relentlessly grim is to ignore the experiences of those living with it, and, to adapt an observation made by Small about ageing, to perceive dementia as only a loss 'is already to have decided in favour of one set of options [about what life is and what we want from it] rather than another.'⁶¹

This reframing is essential if older people living with dementia are to be supported to participate in mediation. Reframing is needed of the commonly held view of dementia as all about loss and deficit, as is reframing of our own perspectives on ageing that are too often shaped by paternalism. If elder mediation is to be widely recognised as a specialist area of practice, it will

58 Tom Kitwood and Kathleen Bredin (1992), 'Towards a Theory of Dementia Care', *Ageing and Society* 12, p.278.

59 Jauhar (2023), p.109.

60 Mitchell (2018), p.105.

61 Small (2010), p.265.

require mediators to jettison assumptions about vulnerability and capacity, to engage with disability rights, and to draw on resources and techniques, such as those used in social care and human rights work, that enable them to facilitate meaningful participation of the person living with dementia. We also need to continue to debate the larger issue about identifying the role of the elder mediator in assessing capacity to mediate and the skills and knowledge required to provide an effective forum for supported decision-making.

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