

Mary Donnelly, Rosie Harding and Ezgi Taşcioğlu (Editors) *Supporting Legal Capacity in Socio-Legal Context* (2022) Oñati International Series in Law and Society, Oxford: Hart Publishing

We come to the task of reviewing books from different starting points. As the sister of a man with a learning disability, I often wonder how different our lives would be in different jurisdictions. I write “our lives” because my life, and that of my sisters, is profoundly affected by events in our brother’s life. We have moved into the spaces left by our parents to become his stubborn advocates. I regard this as a handy, shorthand description of so many families whose members have life-long support needs.

The invitation to review this book returned me to an especially bleak time in my family’s life when professionals made decisions about our brother’s accommodation and support without any reference to us. Their decisions led to him being transferred to an unregistered unit and prescribed a course of Lithium due to his protesting behaviour. He changed beyond recognition. It took 12 months for us to spring him from a service staffed by inexperienced, unskilled and unsupervised individuals. The injuries, damage and injustices he suffered were directly caused by a “philanthropic”¹ care system. A complaint determined that this disastrous sequence of events was the result of naïve interpretations of confidentiality and of his “choice.”

Kirsty Keywood, Sarah Fovargue and I put the topic of choice in the spotlight as we considered the healthcare choices of adults with learning disabilities 20 years ago.² It appeared then that “choice” was cherished not wisely but too well. I have since wondered if it has morphed into the status of an “unwise decision” or even “their rights.” That is, a cue for support staff and professionals to abdicate all responsibility for intervening since there are current examples of unwise decisions and “human rights” being perceived irrevocable and decisively beyond challenge.

I contrast my experiential knowledge of how services operate in 2022, with what it was that the Law Commission was grappling with in the 1990s. Then, it was a relief that the Mental Capacity Act 2005 embraced every part of our lives across a huge range of sectors. So now, what does legal capacity look like in England and Wales – and globally?

Mary Donnelly sets the scene by reminding readers of the UN Convention on the Rights of Persons with Disabilities’ (CRPD) conceptualization of support as a legal right, albeit one that coexists with “deeply ingrained paternalistic norms.” In “Support Relationships in Law:

¹ An apt description proposed by Dr Gwyneth Roberts. In Flynn M. (2004) Challenging poor practice, abusive practice and inadequate complaints procedures: a personal narrative. *Journal of Adult Protection* 6, 3, 34-44

² Best Practice? Health care decision-making by, with and for adults with learning disabilities, Manchester: National Development Team; and https://www.researchgate.net/publication/299246175_Health_care_decision-making_by_with_and_for_adults_with_learning_disabilities (accessed 30 November 2022)

Framing, Fictions and the Responsive State,” Mary considers the tensions between support and safeguards when decision-making supporters are appointed, including those that formalize pre-existing relationships and those provided to people who are without access to such informal support. Ireland’s Assisted Decision-Making (Capacity) Act 2015, which allows for the appointment of decision-making assistants and co-decision-makers, is the backdrop to her consideration of Australian and Ontario Law Commission reports. The complexity of relationships and support relationships is acknowledged. The fact that not all relationships are consistently mutual and nurturing and that there may be personal and economic interests in the status quo present occasions for rigorously questioning the power asymmetry. “Joint responsibility for deeply personal decisions raises different issues and presents different challenges” (p28). Mary concludes that support relationships must expand beyond capacity-derived boundaries, that safeguards are necessary, that temporal and structural contexts matter, and “that constructive relationships are not a given but need to be created and nurtured.”

Mary Donnelly and her co-editors, Rosie Harding and Egzi Taşcioğlu bring compelling and fresh perspectives to the challenge of supporting legal capacity. For readers who believe that they have a credible grasp of the Mental Capacity Act (2005) (MCA), check out Rosie Harding’s chapter, “Supporting Everyday Legal Capacity: Navigating the Complexities of Putting Rights into Practice.” This reveals that in England there are 16 informal, quasi-formal and formal support frameworks created by the MCA. For example, there is the Lasting Power of Attorney (Health and welfare, Property and Affairs), a Deputy (Health and welfare, Property and Affairs), an Independent Mental Capacity Advocate, a Relevant Person’s Representative, an Appropriate Person (Care Act 2014 and Liberty Protection Safeguards), an Appointee and best interests decisions. It is unlikely that this proliferation of roles was ever envisaged by the Law Commission. The chapter confirms that life’s more complicated decisions require an informed and consistent approach that is attentive to people’s informal and formal support for decision-making – which may not be available at the relevant time.

It is a heart-sink that the top “poor practice theme” in Safeguarding Adult Reviews in England concerns the MCA. Jaime Lindsey’s contribution suggests why this is so:

“...where an adult subject to a safeguarding enquiry under the Care Act is also believed to lack mental capacity to make a decision for themselves, the MCA can be used to respond to the abusive situation. This might include making a best interests decision that it is not in that person’s best interests to reside or have contact with their abuser. Conversely, where, following a safeguarding enquiry, a person is believed to have the mental capacity to make a particular decision – for example to have contact with their abuser – then the MCA cannot be invoked to protect that person...” (p.256).

Hence the anxieties of safeguarding professionals. However, there is something concertedly upbeat about the incredible efforts of legal scholars to foreground interpretations of a person’s “will and preferences” across the globe. The critical backdrop is the CRPD’s Article 12 which affirms the enjoyment of legal capacity “on an equal basis with others in all aspects of life.” It immerses scholars in understandings concerning autonomy, values,

support and influence, for example, and raises some head-scratchingly complicated matters, to which I add some questions:

- What do individuals (and their families) whose legal capacity is under consideration think about the legal formulations set out? Do they work?
- What account is taken of people's day to day living circumstances? Surely the governance of support services merits attention given what is known about system-justifying tendencies?

Since I am a greedy reader, I wanted to interrogate the authors of each chapter, seek answers to my questions and understand the political backdrop and resource implications required to enact the legislation each describes. Spoiler: the stories of people whose legal capacity is potentially subject to supported decision-making are largely absent. So - I commend *Global Perspectives on Legal Capacity Reform*³ as a valuable companion to this text. For example, the hope-based message of "Getting sucked out of the black hole of India's legal mental capacity machinery" by Lavanya Seshasayee and Maths Jesperson is a powerful preface to Soumitra Pathare and Arjun Kapoor's chapter, "Enabling Supported Decision-Making in India's Mental Healthcare Act 2017: Learnings from a Low-Resource Country Setting."

Two themes are threaded throughout the text: the potential undue influence of relatives and support staff; and to a lesser extent, the disciplinary imperialism of clinicians and legal gatekeepers. In "The Significance of Strong Evaluation and Narrativity," Camillia Kong underlines the importance of attending to the multiple reasons behind motivational genealogy in conceptions of agency. If decision-making authority is lodged with healthcare professionals, then arguably there is agreement concerning their judgements of capacity? In "Functional Capacity Assessments by Healthcare Professionals," Shaun O'Keefe reports research which reveals how little agreement there is among clinicians. He points fingers at the lack of clarity concerning appropriate thresholds; the lack of standardization of assessment and the intrusion of the assessor's personal values. His proposed remedies include giving non-cognitive factors adequate weight in terms of individual and context-specific assessment; challenging such red-flag terms as "executive brain function" and "insight;" caution in using generic, standardised assessment tools; supporting individuals to attain capacity; ensuring procedural safeguards; and having access to advocacy.

I am undecided about whether my family would be better served by:

- 1) Ireland's yet to be enacted Assisted Decision Making (Capacity) Act (2015). Eilionóir Flynn's chapter "The (Contested) Role of the Academy in Activist Movements for Legal Capacity Reform: A Personal Reflection" is remarkable since it describes the zig-zag trajectory and heart-ache of her activist-academic role in collaborating with people with lived experience, negotiating principles, engaging with civil servants and parliamentarians, and providing solutions to the problems identified in the draft Bill, only some of which were included in the Act; or by

³ E. Flynn, A. Arstein-Kerslake, C. de Bhailís and M.L. Serra (Editors) *Global Perspectives on Legal Capacity Reform: Our voices. Our stories* Abingdon: Routledge, 2019

- 2) Scotland's support for the exercise of legal capacity. In "Adapting or Discarding the Status Quo? Supporting the Exercise of Legal Capacity in Scottish Law and Practice," Jill Stavert reflects on the Adults with Incapacity (Scotland) Act (2000), the Mental Health (Care and Treatment) (Scotland) Act (2007) and the Adult Support and Protection (Scotland) Act (2007). Investment in the Capabilities Approach of Martha Nussbaum and Amartya Sen aligns with autonomy in physical and mental health and the necessity of considering non-consensual interventions which impact on a person's autonomy.

My indecision does not result from disappointment with jurisdictions beyond the UK and Ireland. Every society teaches a collage of norms and there are differences in determining limits on individual agency and what is desirable for individuals with support needs, their worlds and journeys. Greater familiarity with the impact of these worlds on people's lives may render some jurisdictions more attractive.

Patricia Cuenca Gómez considers the reform of Spanish legislation. Formerly, the status approach prevailed which was determined by a diagnosed impairment. The practice of distinguishing "full incapacitation," requiring the services of plenary guardian, from that of "partial incapacitation," requiring a guardian was overused. Its legal reforms prioritise "voluntary" support measures entitling people of legal age to arrange personal or financial support matters before a notary. There is a "permanent judicially established" curatorship to advance an individual's will, wishes and preferences; and self-curatorship allows the designation of a curator before a notary. The fact that the reforms retain traditional institutions, albeit with adaptations, and that the best interests model persists, is not suggestive of a break with previous legislation, not least because in certain extreme cases, individuals may be appointed against a person's will.

In "Performing Disability Rights: State Reporting and Turkey's (Non) Engagement with the CRPD," Ezgi Taşcıoğlu confirms that Turkey was one of the first signatories of the CRPD. Although the Turkish Disability Act (2004) was amended in 2014, its implementation has been limited in terms of accessibility in public spaces and transport and the "language of deficiency" withholds the rights of intellectually disabled people. This renders little protection under Turkish laws. The result is "a rigid substituted decision-making regime" which is disconnected from the day to day lives of all citizens with disabilities.

In the "Autonomy of a Person under Guardianship: Self-Determination in the Theory and Practice of Guardianship Law in Finland," Anna Mäki-Petäjä-Leinonen considers the right of a legally competent person to make decisions; the right to be heard as part of self-determination; and respect for the previously expressed or presumed wishes of an incapacitated person. The Finnish Guardianship Act (1999) provides that a court may appoint a guardian for an adult who is incapable of looking after their own interests, personal or financial affairs. Although this does not impact on lesser decisions, if significant interests are endangered, then a court may order that a guardian must be involved in specific transactions. Guardians have considerable discretion and their views concerning clients' financial interests, for example, may be assigned greater priority than those of their clients. It follows that the guardians' unquestioned wishes and preferences may be

disproportionately influential. Clients have a right to be consulted and heard and assistance is available to allow them to consider options and make decisions accordingly. Clients with memory problems are advantaged if they have undertaken advance care planning, however, such planning tends to be rare. Guardians have a duty to respect their clients' "relational autonomy," that is, the clients' relationships in decision-making may be tempered with discretion in establishing whose interests are in the foreground, most particularly if these individuals are to benefit from the transfer of assets. Of post-capacity decisions, Anna notes, "The way we approach changes in capacity thus reveals our understanding of personhood, as it forces us to question whether a person remains the same or becomes different" (p229).

The trend towards the provision of home-based care for older people is pronounced in Sweden. It is in the support of people with dementia that particular challenges arise. In "Autonomy, Capacity and Vulnerability: Making Decisions on Social Services for People with Dementia," Titti Mattson describes attempts to steer a course between expecting a family member to assume a limited guardian role and providing the person with dementia with decision-making assistance which will require adjusting as their decision-making skills diminish. The refusal of help is an obstacle since the applicable legislation does not permit any contact to be made by social service employees without the consent of the person concerned. It is speculated that "a variety of regulated, assisted decision-making functions" is required to take account of people's varied circumstances and contexts. Reverence for an individualised sense of self may trump a person's acute need for care and yet fails to take account of our dependency on others.

Amanda Keeling deals specifically with, "The Problem of Influence: Autonomy, Legal Capacity and the Risk of Theoretical Incoherence." Although substituted decision-making is prohibited by the Committee for the CRPD, the intricacies of our social relationships are such that it is implausible to ignore their influence in decision-making. In advancing a decision-maker's view of a person's best interests, it is acknowledged, "...that for many adults, what will be happening is a *best interpretation* of the individual's will and preferences...a form of decision-making *for* someone which is led as much as possible by what we know they want, or would want in the relevant situation" (p42). This interpretive difficulty is the spanner in the works because legal frameworks create legal boundaries setting out where the state may and may not intervene. However, if autonomy may be fostered through our networks and social environments, then the enduring model of *self-governance* should be curtailed and *relational autonomy* embraced. Clearly however, not all relationships foster autonomy. While an individualised conception of autonomy may result in a person being left to make decisions alone, it is accepted that "intense support" is difficult to separate from influence.

How people are supported in their legal capacity is moot, most particularly if this is considered in the context of government policy. For example, England's Department of Health and Social Care's "Building the Right Support" (2022) concerns the support of people with learning disabilities whose behaviour is described as challenging. It states:

“Where, exceptionally, admissions to an inadequate hospital setting occur, this will be with the involvement of the patient (where they have capacity or based on a best interest decision-making process⁴ where they do not) and their carer or family. It will also be based on an assessment of the risks and benefits that concludes this is the most favourable option for that individual patient. Additional mitigations and safeguards will be put in place to monitor their safety, wellbeing and treatment.”

Such state intervention challenges conceptions of legal capacity.

In “Putting the Pieces Together: Article 12, ‘Safeguarding’ and the Right to Legal Capacity,” Margaret Hall frames the debate as “a deadlock in which one side insists on non-interference with the exercise of legal capacity (achieved through supported decision-making) while the other insists on the unjust consequences of doing so” (p276). The possibility that any decision-making authority will be misused is not new. Similarly, separating the capacitated from the incapacitated is hardly an exact science. Both facts are nested in social, political and professional contexts, in custom and in practice. Margaret asserts that “because traditional safeguards have been created, interpreted and applied with ‘capable’ persons only in mind they require more focused development to become more inclusive of all persons...” (p276-277). She proposes that fairness-based legal safeguards have much greater promise than mental capacity based discrimination in which substituted decision-making is justified.

So there you have it. I did not read “Supporting Legal Capacity in Socio Legal Context” in the order in which the editors perhaps envisaged: from the conceptual contours of capacity law, to framing and interpreting legal frameworks to supporting legal capacity in our daily lives. I behaved as I do with collections of short stories, that is, “that’s an interesting title/pathway...that touches a nerve...that’s too far beyond my radar tonight.” I could not have read it in a single day since there is such rich detail in each chapter. Each one combines proximity and distance: close attention to the experience of the individual(s) whose decision-making is under scrutiny to the sometimes remote professionals tasked with resolving the inherent tension-tangles. The book’s title aside (just a thought, but perhaps something along the lines of “Up close and personal decision-making: global perspectives”?) there is much to applaud in this valuable collection and resource. I recommend it highly.

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29 November 2022

⁴ How may it be proposed that it is in a person’s “best interests” to be placed in “an inadequate hospital setting?”

