

Institution: University of Birmingham		
Unit of Assessment: UoA 18, Law		
Title of case study: Transforming Understandings of Intellectually Disabled People's Rights to Enjoy Legal Capacity in Law, Policy, and Practice		
Period when the underpinning research was undertaken: January 2014–present (research ongoing)		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Rosie Harding Dr Ezgi Taşcıoğlu Magdalena Furgalska	Professor of Law and Society Research Fellow Research Assistant	1/9/2012–present 1/2/2017–31/1/2018 1/3/2018–31/12/2018
Period when the claimed impact occurred: January 2016–31 December 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact <p>Professor Harding's work has resulted in significant improvements in law, policy, and practice relating to legal capacity and supported decision-making by people with intellectual disabilities. Specifically, her research has:</p> <ol style="list-style-type: none"> 1. Changed the course of the Mental Capacity (Amendment) Act reform of the Deprivation of Liberty Safeguards, and influenced the implementation of this law; 2. Co-produced new legal guidance for the application of mental capacity laws, better safeguarding the rights of intellectually disabled people; 3. Informed the Law Commission's law and policy recommendations on statutory wills, and shaped its policy on supported will-making; 4. Transformed professional practice, particularly of care-workers and psychiatrists, through shaping the training programmes and delivery of CPD relating to supported decision-making; 5. Improved public awareness and understanding of disability and human rights; 6. Influenced legal argument and case law about sexual intimacy and legal capacity in everyday life. 		
2. Underpinning research <p>Harding's interdisciplinary research addresses how the law should respect and support the autonomy of persons with intellectual disabilities. Article 12 of the UN Convention on the Rights of Persons with Disabilities (the 'Convention') establishes the equal right to enjoy legal capacity. To implement this right, the Committee on the Convention has called for the abolition of substituted decision-making systems that include third parties making objective "best interests" decisions and their replacement with frameworks based on "supported decision-making". Harding's research interrogates how to operationalise this international legal obligation, within domestic (English) law. Since 2014, she has found that:</p> <p><i>Current domestic law is inadequate in safeguarding disabled people's rights because:</i></p> <ol style="list-style-type: none"> (i) Judicial interpretations of the objective best interests rationale underpinning "statutory wills" (where a court makes a will for a person who lacks testamentary capacity) in the Mental Capacity Act 2005 ('the Act') conflict with intellectually disabled people's rights under Article 12 of the Convention [R1]. (ii) Legal reform of the best interests approach is required in order to prioritise individuals' wishes and preferences in many areas, including deprivation of liberty [R1, R2, R5]. (iii) The Mental Capacity Act 2005 Code of Practice needs revision to provide more detailed examples of supported decision-making to ensure compliance with the Convention [R3]. 		

Existing domestic efforts to provide supported decision-making are inadequate in safeguarding rights because:

- (i) Although the concept of “mental capacity” is well understood and embedded in health and social care practice, there is very limited awareness of the concept of legal capacity [R3].
- (ii) Supported decision-making in health and social care practice focuses only on everyday choices (what to wear, what to eat). Intellectually disabled people receive far less help from care professionals to make complicated life-affecting decisions (e.g., about relationships, education, employment) [R3–R5].
- (iii) Entitlements to informal support, and independent advocacy can be short term [R6], even though intellectually disabled people prefer to be supported by people they know and trust [R3, R4]. The development of a formal nominated supporter scheme offers the optimal balance of support and supervision to enable intellectually disabled people to exercise legal capacity [R6].
- (iv) The lack of a duty to provide accessible legal information hinders support for intellectually disabled people’s legal capacity and access to justice. This could be remedied by the introduction of an accessible information standard for legal services, akin to the duty that exists for health and social care services [R6].
- (v) There is an on-going lack of support for intellectually disabled people to develop intimate lives and sexual relationships. Those supporting intellectually disabled people’s sexuality are often forced to navigate the risk of criminal liability arising from efforts to regulate sex work [R4].

3. References to the research

- R1.** Harding, R. (2015) ‘The Rise of Statutory Wills and the Limits of Best Interests Decision-Making’, *Modern Law Review* 78(6): 945–970. DOI: [10.1111/1468-2230.12156](https://doi.org/10.1111/1468-2230.12156)
- R2.** Harding, R. (2017) ‘[Care and Relationality: Supported decision-making under the UN CRPD](#)’ in Harding, R., Fletcher, R., & Beasley, C. (eds) *ReValuing Care: Cycles and connections in theory, law and policy*, pp. 114–130 (Routledge ‘Social Justice’ Series).
- R3.** Harding, R., & Taşcıoğlu, E. (2018) ‘Supported Decision-Making from Theory to Practice: Implementing the right to enjoy legal capacity’, *Societies* 8(2): 25. DOI: [10.3390/soc8020025](https://doi.org/10.3390/soc8020025)
- R4.** Harding, R., & Taşcıoğlu, E. (2020) ‘[“That’s a bit of a minefield”: Supported decision-making in intellectually disabled people’s intimate lives](#)’ in Ashford, C., & Maine, A. (eds) *Research Handbook on Gender, Sexuality and Law*, pp. 255–269 (Edward Elgar).
- R5.** Harding, R. (2020) ‘[Challenging Capacity: Shifting Paradigms of Intellectual Disability across Law, Medicine and Society](#)’ in Jacob, M., & Kirkland, A. (eds) *Research Handbook for Socio-Legal Studies of Medicine and Health*, pp. 52–69 (Edward Elgar).
- R6.** Harding, R., Taşcıoğlu, E., & Furgalska, M. (2019) ‘[Supported Will-Making: A Socio-Legal Study of Experiences, Values and Potential in Supporting Testamentary Capacity](#)’.

4. Details of the impact

Harding has **directly shaped state law and policy on legal capacity**, including by drafting sections of key codes of practice that affect millions of lives (impacts 1–3). Her research has also been **used by professionals seeking to operationalise supported decision-making** (impact 4), **by civil society and self-advocacy organisations** (impact 5), and by **barristers** seeking to protect people’s rights to intimate lives (impact 6).

1) Changed the course of the Mental Capacity (Amendment) Act reforming the Deprivation of Liberty Safeguards and influenced the implementation of this law. Amendments to the Mental Capacity (Amendment) Act 2019 (‘the Bill’) were shaped by Harding’s research on legal capacity [R2, R3, R5; E3]. The Bill replaces the current Deprivation of Liberty Safeguards under the Mental Capacity Act 2005 (MCA) with the new Liberty Protection Safeguards (LPS). It is expected to come into force in 2022. While the Deprivation of Liberty Safeguards process applies to over 300,000 individuals, the new LPS process will apply to more people, as it includes care arrangements in the community as well in hospitals and care homes.

At consultation stage, Harding identified problems with the Bill including a proposed new

statutory definition of “deprivation of liberty”, an inappropriately expanded role for care home managers, and inadequate safeguards to protect against conflicts of interests. Harding submitted written evidence on the Bill to the House of Commons Public Bill Committee and provided a policy brief for members of the House of Lords. A section of this brief was quoted by Baroness Tyler in February 2019, during the Lords’ debates on the Commons amendments [E4]. At a private meeting with the Bill team in March 2019, Harding advised Peers on how to respond to Government amendments. According to Baroness Tyler, this **‘influenced Ministerial thinking’ and shaped the final form of the Bill** [E3], resulting in significant **changes including the introduction of additional safeguards against conflicts of interest and changes to how “deprivation of liberty” is defined in the new LPS**. Also, **the contested definition of deprivation of liberty was removed from the Bill**; instead the current definition in the MCA was retained, and this definition is now explained in the statutory Code of Practice to enable flexible interpretation and regular review [E4]. Finally, in November 2020, the Department of Health and Social Care announced that **the elements of the Bill relating to the role of care home managers would not be implemented**.

2) Co-produced new legal guidance for the application of mental capacity laws, better safeguarding the rights of intellectually disabled people

Harding (i) co-produced the new Liberty Protection Safeguards Code of Practice and (ii) revised parts of the Mental Capacity Act Code of Practice. She also advised that both codes be combined, to better protect the rights of people with disabilities.

(i) Crucial parts of the new LPS Code of Practice —that relate to the definition of deprivation of liberty (part 1 of the code) and “Keeping the Person at the Centre” of these processes (part 2) —were co-produced by Harding [E10]. As an invited member of the Department for Health and Social Care Liberty Protection Safeguards Code of Practice co-production group (2019), Harding helped draft chapters 4, 5, 6, 7, 8, 10 and 11 (Part 2) [E10]. For instance, Harding’s findings on supported decision-making [R3–R6] were used to develop guidance in draft Chapter 4 on supporting people to make decisions and express their views about residence and care plans [E10].

(ii) In February 2020, Harding was directly consulted by the Ministry of Justice (MoJ) Mental Capacity Policy Division on parts of the MCA Code of Practice that relate to research with people who lack capacity (Chapter 11). For example, Harding provided the MoJ with amendments incorporating legal changes since the 2007 publication of the Code of Practice, and detailing what should happen if a participant loses capacity during a research project. In addition, she drafted practical scenarios on how to involve intellectually disabled people in research. These amendments and scenarios will form part of the revised MCA Code of Practice [E5].

Harding argued strongly for a combined Code of Practice for the MCA and LPS in her response to the MoJ consultation on the MCA Code of Practice. In February 2020, the Department for Health and Social Care announced its decision to integrate both Codes of Practice. Over two million people with limitations to their capacity are directly impacted by the separate codes, but the combined Code will also affect the much wider group of those caring for, supporting, and conducting research involving intellectually disabled people. The combined Code will be published for consultation in Spring 2021, having been delayed by the coronavirus pandemic.

3) Shaped law reform and policy development on wills at the Law Commission of England and Wales (the ‘Commission’)

Harding influenced the Law Commission’s consultation on wills, particularly the operation of the best interests principle in the making of statutory wills, and shaped its provisional policy on supported will-making.

This impact followed discussion with the Commission at a 2016 private meeting, after which Harding’s research [R1] was positioned in the Commission’s consultation paper on wills as the leading critique of the current rationale for statutory wills, and operation of the best interests

principle [E1]. The Commission engaged with Harding's arguments that the courts take an incoherent approach to the making of statutory wills, and that statutory wills require reform [E1, E2]. Law Commissioner, Professor Hopkins stated: 'While we ultimately reached the provisional conclusion that reform is not required to the "best interests" rationale, Professor Harding's article "The rise of statutory wills and the limits of best interests decision-making in inheritance" [R1] was influential in our consideration of the issue and is referred to extensively in Chapter 3 of our Consultation Paper' [E2].

Harding's work on supported decision-making [R3] led to further collaboration with the Commission on policy development related to **supported will-making**. In particular, Harding was commissioned by the Commission to conduct empirical research into the experiences of intellectually disabled people when making wills [R6]. The Commission publicly acknowledged this as having influenced its policy decisions on improving support for intellectually disabled people to make a will [E1]. Law Commissioner, Professor Hopkins, stated the research 'provides important insights into the experiences of people with intellectual disabilities in making wills and, when we resume our work on wills, will provide an invaluable evidence-base to the Commission in assessing a potential scheme for supported will-making and in determining how a scheme could work' [E1, E2]. It was key in the Commission's recognition of a need for supported will-making and will shape the Commission's proposals on supported will-making and testamentary capacity in their forthcoming report on the law of wills [E1, E2]. **These changes to the law will make a difference to the lives of over three million people with impaired capacity in England and Wales, enabling more intellectually disabled people, and people living with dementia, to express their testamentary wishes.**

4) Transformed professional practice and engagement with the right to legal capacity and supported decision making

Professional and civil society organisations have changed their practices and training relating to supported decision-making as a result of Harding's research. Examples include:

- directly influencing the training programmes of civil society organisations. For example, Harding was consulted by CHANGE, a learning disability charity, and Advonet, an advocacy charity, to input into a training programme for people with learning disabilities and for health and social care professionals in how to support decision-making [E9];
- designing and delivering sessions on supported decision-making for advocates supporting people making decisions in their lives (National Advocacy Conference, 2018) [E9] and for best interests assessors (CPD training day, 2018) [E9];
- contributing to a CPD webinar for Finders International on supporting vulnerable clients which was viewed by over 300 private client legal professionals (2020);
- giving guidance to practitioners via prestigious lectures, including: a keynote address at the Head First conference (2018) with a mixed audience of over 500 attendees working in the field of brain injury as well as those directly affected by brain injury; a plenary presentation at the National Mental Capacity Forum Action Day (2018) with 300 attendees [E9]. Audience feedback highlighted the importance of empirical, socio-legal research for professional practice development [E9];
- engaging extensively with civil society organisations and self-advocacy groups to increase their knowledge and understanding of rights to legal capacity and supported decision making. In particular, Harding participated in workshops for organisations including Mencap, Headway, People First, and the Down's Syndrome Association (DSA). She also contributed an accessible version of her research findings to the *DSA Journal* (2018) [E9];
- collaborating with health and social care professionals, for example through co-authoring a CPD contribution for *BJPsych Advances*, a professional journal for psychiatrists, on legal developments in testamentary capacity and statutory wills [E9].

5. Improved public awareness and understanding of disability and human rights

Civil society organisations used **information and tools provided by Harding to protect the rights of intellectually disabled people**. For example:

- Harding supported a West Midlands charity (Changing Our Lives) and its employees to understand capacity law and Court of Protection practice, and assisted their work as

advocates for intellectually disabled people seeking to move out of long-term segregation in hospital units. As Trustee Harding has shaped the charity's strategy on deprivation of liberty and the right to legal capacity by widening the evidence base of its (confidential) work on the NHS 'Transforming Care' agenda [E6].

- Harding set up the Capacity Law and Rights Information to You (CLARiTY) project to provide accessible legal information [R6] and address the unmet legal needs of disabled people and family carers during the coronavirus pandemic. This project involves Wolferstans solicitors, Bringing Us Together (a community interest company led by family carers of disabled people), and a leading disability consultant. CLARiTY facilitated two interactive accessible legal information sessions for people with learning disabilities and family carers (October–December 2020), covering lockdown rules about visiting family and friends in care homes and hospitals (Session 1) and supported decision-making, best interests decisions, do not resuscitate notices, and support with developing relationships (Session 2). Attendance was limited to 50 per session to enable inclusive and accessible discussion, but summaries were published online. Participants commented on how useful the sessions were, in particular the 'supportive environment' and 'people's stories that brought the law to life' [E7]. By 31 December 2020, the online summaries had been accessed by 893 unique visitors, with traffic to the site as a whole increasing from 138 unique visitors per month in September 2020 to 2,493 unique visitors per month in December 2020 [E7].

6) Influencing legal argument and case law about sexual intimacy and legal capacity in everyday life

Leading barristers have challenged the constraints placed on care professionals who support intellectually disabled people to develop intimate relationships by utilising Harding's research [R4]. This impact arose following the decision in *Lincolnshire County Council v AB* [2019] EWCOP 43 that care workers should not support intellectually disabled people to access sex workers for public policy reasons. Harding offered access to a pre-print of R4 on social media, providing a timely and accessible analysis of the interaction between the Sexual Offences Act 2003 and the MCA 2005, and warning of the potential for oppressive precedents which treat disabled people differently from non-disabled people. 14 requests for the piece were received from barristers, solicitors, and social workers. Two barristers who requested the pre-print cited it in their skeleton argument [E8] in a December 2020 Court of Protection case before Justice Hayden (Judgment pending). They were arguing on behalf of an intellectually disabled man who has capacity to consent to sex, and to purchase sex, and who wished to access sexual services through a charity. The question for the court was whether care workers offering support with choosing an escort or with accessing money to pay for sexual services would be committing a criminal offence under the Sexual Offences Act 2003. The two arguments from R4 cited in the skeleton argument concerned the constraints posed by the Sexual Offences Act 2003 relating to care professionals supporting intellectually disabled people in developing intimate relationships.

5. Sources to corroborate the impact

- E1.** Law Commission (2017) *Making a Will* Consultation Paper 231 and press release.
- E2.** Testimonial from Professor Nicholas Hopkins, Property, Trusts and Family Law Commissioner, Law Commission of England and Wales.
- E3.** Testimonial from Baroness Tyler, member of the House of Lords.
- E4.** House of Lords Hansard 26 February 2019 Vol 102, Col 106; House of Commons Hansard 2 April 2019 Vol 657, Col 963–969.
- E5.** Email consent to contact MoJ, Mental Capacity Policy Team for corroboration
- E6.** Testimonial from CEO, Changing Our Lives
- E7.** Feedback on sessions, website user logs for legalcapacity.org.uk 2017–2020.
- E8.** Section of the skeleton argument of barristers
- E9.** Portfolio of engagement with professional practice.
- E10.** Testimonial from Department of Health and Social Care