

Institution: Cardiff University		
Unit of Assessment: Law (18)		
Title of case study: Strengthening rights and participation under mental capacity law		
Period when the underpinning research was undertaken: 2013-2020		
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:
Dr Lucy Series Professor Phil Fennell Dr Julie Doughty	Lecturer Emeritus Professor Lecturer	30/09/2013 - present 01/10/1975 - 31/08/2018 14/07/2003 - present
Period when the claimed impact occurred: 2013-2019		
Is this case study continued from a case study submitted in 2014? No		
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>The Mental Capacity Act 2005 (MCA) regulates whether the 2 million adults in England and Wales with mental disabilities can make key personal decisions for themselves. Of these, 300,000 people are deprived of liberty by care arrangements in hospitals or care homes. Cardiff University research was central to new Court of Protection (the MCA's specialist court) rules on the participation of people who may lack capacity in proceedings, as well as new guidelines for health and social care professionals on supporting those who may lack capacity to make or participate in decision-making for themselves. Cardiff research on the Court of Protection and liberty safeguards also influenced civil society debate and led to major changes to statutory amendments to the MCA in 2019.</p>		
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>The Mental Capacity Act 2005 (MCA) regulates fundamental rights to self-determination for those whose decision-making capacity is affected by conditions like dementia, intellectual disabilities or brain damage. The Court of Protection (CoP), a specialist court established by the MCA in 2007, has a growing jurisdiction over people who lack capacity, and can authorise deprivation of liberty in health and social care settings, allowing others to decide in 'best interests' over matters including living and care arrangements, medical treatment, and relationships.</p> <p>Although described by the House of Lords as 'visionary' for its time, the MCA has been criticised for failing to properly support people's decision making, protect their rights and respect their wishes [3.1, 3.2]. The Cardiff team [G3.1] gathered empirical data on the CoP, exploring transparency, access to justice, participation, cost and delay. Series' [G3.2] ongoing work further examined 'problems of empowerment' under the MCA.</p> <p>2.1 Court of Protection (CoP)</p> <p>The researchers examined a large sample (250) of CoP files for health and welfare cases and surveyed local authorities and NHS bodies (2014, 2015) in England and Wales to examine their involvement in CoP proceedings and associated costs and delays.</p> <p>The Cardiff team overcame significant legal and practical challenges in conducting this research because of laws prohibiting the reporting of proceedings held in private. They successfully persuaded the Ministry of Justice to change the CoP rules around reporting proceedings heard in private and were the first to gain access to court files for research purposes.</p> <p>This work established robust empirical evidence of difficulties with the operation of the CoP:</p> <ul style="list-style-type: none"> • Disabled people and their families had limited access to justice when conflicts arose with local authorities and/or healthcare providers over health and welfare matters [3.3]. • People deprived of their liberty under the MCA had serious difficulties exercising rights 		

of appeal against their detention [3.3].

- The CoP's jurisdiction has fundamentally changed since it was established: its proceedings can be very costly and protracted as it hears increased numbers of cases involving more complex welfare issues, entailing greater cost, delay and resources [3.3].
- People who are alleged to lack capacity rarely participated directly in proceedings, contravening the European Convention of Human Rights (ECHR). The researchers based this finding on an analysis of case law, the analysis of CoP files, and a 'participation' roundtable involving the judiciary, civil servants, experts and key stakeholders [3.3, 3.4, 3.5].

2.2 Supporting rights and decisions

Series contrasted the approach to supported decision making under the MCA with approaches associated with the UN Convention on the Rights of Persons with Disabilities (CRPD) and identified limitations in the MCA's respect for the person's 'wishes and feelings' and recognition of a person's preferred and trusted supporters [3.1, 3.2]. In comparison with other jurisdictions that have adapted their laws to reflect the CRPD, the MCA does not enable the person to nominate a designated person to support decision making, and the 'best interests' standard affords lower priority to the 'wishes and feelings' of the person.

2.3 Deprivation of liberty

The researchers further established that appeals to the CoP under the MCA's Deprivation of Liberty safeguards (DoLS) are costly, inaccessible (only 1% of the sample studied managed to exercise rights of appeal under the safeguards), and slow (8% of people died before getting a final determination). They recommended consideration of practices adopted by tribunals to support participatory and cost-effective appeals [3.3].

In 2018-19, Series' legislative analysis highlighted serious problems with the proposals for the DoLS' successor, Liberty Protection Safeguards, and the subsequent Parliamentary Bill based on the Law Commission's proposals. These issues included [3.6]:

- Provision for independent scrutiny of care arrangements.
- Weakened access to justice through poor rights to information, advocacy and appeal.

3. References to the research (indicative maximum of six references)

[3.1] L Series, 'Relationships, autonomy and legal capacity: Mental capacity and support paradigms', 2015, 40 *International Journal of Law and Psychiatry* 80 DOI: 10.1016/j.ijlp.2015.04.010

[3.2] L Series, 'The Place of Wishes and Feelings in Best Interests Decisions: Wye Valley NHS Trust v Mr B', 2016, 79 *The Modern Law Review* 6, 1101 DOI: 10.1111/1468-2230.12233

[3.3] L Series, P Fennell and J Doughty, *Welfare cases in the Court of Protection: A statistical overview*, 2017, Cardiff University, Report for the Nuffield Foundation. Available on request from HEI

[3.4] L Series, 'Legal capacity and participation in litigation: Recent developments in the European Court of Human Rights', 2015, in Quinn G, Waddington L and Flynn E (eds), *European Yearbook of Disability Law* (Martinus Nijhoff). Available on request from HEI.

[3.5] L Series, P Fennell and J Doughty, *The Participation of P in Welfare Cases in the Court of Protection*, 2017, Report for the Nuffield Foundation, Cardiff University. Available on request from HEI.

[3.6] L Series, 'On detaining 300,000 people', 2019, 25 *International Journal of Mental Health and Capacity Law* 2 DOI: 10.19164/ijmhcl.v2019i25.952

Selected grants:

[G3.1] PI: Phil Fennell, Co-I's: Lucy Series, Julie Doughty, Luke Clements 'Personal welfare disputes in the court of protection' Nuffield Foundation (2013-2017). Initial grant (pilot study): £88,737; Follow-on study grant: £130,825

[G3.2] PI: Lucy Series, 'Empowering whom? The mental capacity act 2005 and the problem

of empowerment' Wellcome Society and Ethics Research Fellowship (2017-2021), £237,868

4. Details of the impact (indicative maximum 750 words)

Cardiff research benefited a broad range of stakeholders concerned with and/or regulated by the Mental Capacity Act (MCA), including people who may lack capacity to make decisions, policymakers and parliamentarians, and health and social care professionals among numerous others. It directly influenced reforms to the Court of Protection (CoP) Rules, national guidance on supported decision-making, and major legislative reforms for the MCA Deprivation of Liberty Safeguards (DoLS).

4.1 Facilitating participation in Court of Protection (CoP) proceedings

Since 2011, the CoP has experienced a yearly increase in applications concerning welfare and deprivation of liberty, with 5,219 applications made in 2019 (UK Family Court statistics, 2020). Cardiff research [3.3, 3.4, 3.5] shaped a rule change to increase participation in these cases [5.1].

Alex Ruck Keene, barrister and member of the Ad Hoc Rules Committee for the Court of Protection, stated that Cardiff's research was important in *"showing the fact that we really did need to do something in order to say with a straight face that this regime is compliant [with the European Convention on Human Rights]"* and *"crystallising what the court should then do to secure the participation of the person"* [5.2].

Ruck Keene cited Series' research in a paper for the Rules Committee on the necessity of a rule change, subsequently resulting in changes made in March 2015 and came into force in 2017 [5.1, 5.2]. He continued: *"Every single judge now, at the beginning of every single case, has to expressly consider how the person concerned participates – which is completely different to the position before"* and *"there has been a marked increase in the number of times when the judges have gone to see the person and/or the person has come to court"* [5.2].

4.2 Informing NICE guidelines on supported decision making

The National Institute for Health and Care Excellence (NICE) guidelines are considered a gold standard of evidence-based practice within the UK and internationally. The Cardiff research is central to new NICE guidelines published in 2018 to improve supported decision making in clinical practice. Series gave expert testimony – as one of five expert witnesses, and the only academic – to NICE [3.1, 3.2] arguing for a stronger emphasis on *how* the person wishes to be supported and respecting their wishes [5.3, page 15]. In the published guidelines [5.3]:

- Series is cited over 40 times (the second most cited expert appears nine times);
- her evidence solely informed 17 provisions, including finding out how the person wishes to be supported, improving continuity of support, and providing accessible information about assessment;
- her evidence is the sole citation for a number of recommendations including overarching principle 1.4.12 'Practitioners must take all reasonable steps to minimise distress and encourage participation' [5.3, page 23].

Cardiff's research was also cited in other guidance in the UK and internationally, with citations including the Law Commission in recommending a new framework enabling people to nominate their chosen supporter [5.4a]; Mental Welfare Commission for Scotland guidance on supported decision making [5.5a]; and the Supreme Court of Victoria, Australia in emphasising 'the fundamental importance of relationships, context and support for the effective exercise of legal capacity' for disabled people [5.5b].

4.3 Influencing major legislative reforms to the Deprivation of Liberty Safeguards

The Mental Capacity (Amendment) Act 2019 replaced the deprivation of liberty safeguards (DoLS) with the Liberty Protection Safeguards (LPS). These are due to come into force in 2022. They affect at least 300,000 people in the UK, including around 200,000 in care homes. A Baroness in the House of Lords worked with Series throughout the passage of the LPS Bill and noted that, prior to the legislative reforms, the *"DoLS were poorly understood and not implemented properly, and thousands of people who should have been benefitting from it were*

not” [5.6].

Cardiff research [3.3, 3.5, 3.6] was instrumental in influencing changes to the DoLS as follows:

a. Influencing initial calls for reform to the DoLS (2015-2018)

Cardiff research showing serious problems with access to justice and the cost of CoP proceedings [3.3, 3.5] helped shape the debate on reforming the DoLS and underpinned Parliamentarians’ and policymakers’ recommendations for reform. For example:

- the final report of the House of Lords Select Committee on the Mental Capacity Act and reform of the Deprivation of Liberty Safeguards cites Series and Fennell seven times. Their research explicitly underpins Recommendation 31 on access to justice [5.7a];
- Series gave evidence emphasising problems with rights of appeal to the House of Commons and House of Lords Joint Committee on Human Rights, highlighting the need to reform the Safeguards [5.7b];
- the Law Commission cited the research findings on the Court of Protection in its consultation paper, impact assessment, and conclusion that the existing system was unworkably costly and failing to deliver effective rights of appeal [5.4a-c], leading to its recommendations to reform the DoLS and supported decision-making [5.4c].

These outcomes led to the Law Commission’s proposal for a new framework, the Liberty Protection Safeguards, which were adapted by the UK government and included in the Mental Capacity (Amendment) Bill [HL] 2018.

b. Improving civil society and parliamentary engagement with the draft Bill (2018)

The Baroness stated that the draft Mental Capacity (Amendment) Bill (2018) “watered down the legislation and didn’t include any of the protections for individuals that the Law Commission had recommended” [5.6]. She further noted that the research “helped us to understand that the proposed Bill was a seriously harmful stripping away of rights for individual people and their families...including poor provision for independent scrutiny of care arrangements, and weakened access to justice through poor rights to information and appeal” [5.6].

As there was no further public consultation on the Bill, Series used her blog (10,000 monthly visits during the consultation on Bill), Twitter (6,000 followers), and correspondence with civil society organisations (including Liberty, Mencap, Age UK) to highlight the issues raised in her research [3.6]. She also produced a series of research briefings on the Bill, which highlighted possible negative impacts of the Bill, including [3.6]:

- care home owners would have been able to decide whether or not somebody needed or got access to an advocate to help them challenge their placement or any restrictions;
- detained people and their families would have no statutory right to information about their rights;
- including the person being a danger to others as grounds for detention would be problematic as mental capacity legislation should not extend into public protection [5.6].

These “fantastic briefings” [5.8b] were used “extensively by peers throughout the House of Lords”, according to the Baroness, to understand, scrutinise, and amend the complex Bill in a tight timeframe [5.6]. They were also used throughout the passage of the Bill by parliamentarians [5.8b] and reproduced and cited by the Joint Committee on Human Rights [5.8a]. The Baroness noted: “There are very few people who understand the law in detail but who also have the experience to translate that knowledge to lay people in a way that is easily understood without dumbing down. Dr Series’ unique role in doing this throughout the passage of the Bill was extraordinarily helpful to those campaigning for change, and a really powerful influence which helped us to secure the eventual changes to the legislation.” [5.6]

Series’ research also “played a unique role” in uniting civil society to campaign for key changes [5.6]. For example, she worked with Inclusion London, which supports over 70 Deaf and Disabled people’s organisations. Svetlana Kotova, Director of Campaigns and Justice, stated: “I can absolutely guarantee that without Lucy and her research we would not have had capacity to draft such detailed or comprehensive amendments.” [5.9]

Series also translated the main proposals into easily digestible documents [5.9] and worked on an engagement exercise with members, which produced “a powerful document to use in lobbying as the voices of the people we represented, and who would be directly affected by the legislation, were highlighted and brought to the fore” [5.9].

c. Securing changes to the legislation (Liberty Protection Safeguards, 2019)

The final Bill included changes that directly reflected Cardiff research [3.6]:

- “care providers will not be able to veto access to independent advocacy for detained persons” [5.6, also Amendment 1 5.10];
- detained people and their families have the right to accessible information about the Safeguards and their rights [5.6, also Amendment 3 5.10];
- the Safeguards will not extend authority to detain under the Mental Capacity Act into the arena of public protection [5.6];
- expanded provisions for independent reviews [5.6, also Amendment 4 5.10];
- a government definition of ‘deprivation of liberty’ that conflicted with domestic and international legal authorities was removed from the Bill [5.6].

The Baroness noted; “the original Bill was a serious reduction and watering down in the rights of vulnerable individuals and their families. It was from this basis that everything that we did became important. Dr Series enabled us to restore some of the original protections that the Mental Capacity Act was intended to ensure in law, particularly for vulnerable people in care homes” [5.6].

5. Sources to corroborate the impact (indicative maximum of 10 references)

[5.1] The Court of Protection (Amendment) Rules 2017 SI 2017/1035.

[5.2] Testimonial: Alex Ruck Keene, Member of the Ad Hoc Rules Committee of the Court of Protection

[5.3] National Institute for Health and Care Excellence, NICE Guideline NG108 Decision-making and mental capacity (3 October 2018)

[5.4] Law Commission citations to reform DoLS: **a.** Law Commission, *Mental capacity and deprivation of liberty: A consultation paper* (Consultation 222, 2015) **b.** Law Commission, *Impact Assessment: Mental Capacity and Detention* (2015) **c.** Law Commission, *Mental Capacity and Deprivation of Liberty* (Law Com No 372, 2017)

[5.5] International citations **a.** *NJE v Mental Health Tribunal and Bendigo Health* [2018] VSC 564 (Supreme Court of Victoria, Melbourne) **b.** Mental Welfare Commission for Scotland, *Good Practice Guide: Supported Decision Making* (2016)

[5.6] Testimonial: from Baroness, Member of the House of Lords

[5.7] **a.** House of Lords Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: post-legislative scrutiny* (HL Paper 139, 2014) **b.** Joint Committee on Human Rights, *The Right to Freedom and Safety: Reform of the Deprivation of Liberty Safeguards* (HC 890, HL paper 161, 2018)

[5.8] Citations in MCA (Amendment) Bill debates: **a.** Joint Committee on Human Rights, *Legislative Scrutiny: Mental Capacity (Amendment) Bill, 2018* **b.** House of Lords debates on the Mental Capacity (Amendment) Bill 16 July 2018, 11 December 2018, 15 January 2019

[5.9] Testimonial: Svetlana Kotova, Inclusion London

[5.10] Mental Capacity Act - Amendment Act 2019 (Liberty Protection Safeguards)