

<p>Institution: University of Cambridge</p>
<p>Unit of Assessment: UoA4</p>
<p>Title of case study: From research into mental capacity to clinical practice via Parliamentary statute: informing and implementing the Mental Capacity Act 2005</p>
<p>1. Summary of the impact (indicative maximum 100 words) In the context of Law Commission reports on legislation in mental capacity, in 1999, Tony Holland published a ground-breaking review on capacity and an empirical study of the capacity of people with mental disorders. Through Holland's role as one of two expert advisers to a Parliamentary Pre-legislative Scrutiny Committee in 2003, this work directly informed the Mental Capacity Act 2005 and the Code, both of which remain current. With full implementation of the Mental Capacity Act in 2007, Holland's studies from 2008 refined concepts of capacity and best interests for clinical practice; and have examined other aspects of the Mental Capacity Act including advocacy, the Mental Capacity Act in different clinical settings, and the Deprivation of Liberty Safeguards.</p>
<p>2. Underpinning research (indicative maximum 500 words) Previous studies by the clinico-legal research group led by Holland (Department of Psychiatry from 1992; and Professor of Learning Disability Psychiatry from 2002) applied the legal definitions of mental capacity, as defined in case law and the Mental Capacity Act, to clinical practice. From 2002 to 2008 his group investigated different decisions in various settings made by people with learning disabilities; and those with dementia, schizophrenia or by those who self-harmed. The aims were to refine capacity assessment processes, investigate individual factors associated with incapacity, and demonstrate how specific strategies could improve decision-specific capacity. These projects demonstrated that capacity can reliably be assessed and strategies developed that improve a person's capacity to make the decision in question, thereby directly informing a key principle enshrined in the Mental Capacity Act - the responsibility to optimise capacity. Studies from 2008 extended this work focussing on the concept of 'best interest' in social care settings for people with learning disability; the development of the Independent Mental Capacity Advocacy service; and the Mental Capacity Act in the context of safeguarding proceedings. Other studies by Holland's group informed changes in the Mental Health Act and, as initially suggested in a conceptual paper by Zigmond and Holland in 2000, proposed that any future Mental Health Act should be based on similar principles as the Mental Capacity Act. In support of this, they published a comparative study of mental health legislation across Commonwealth countries contrasting those findings with the present gold standards of the WHO and Council of Europe (Fistein et al, 2009).¹ Whilst legislative changes in Northern Ireland have taken this approach, it has not been accepted by other UK jurisdictions. These studies were in collaboration with an academic lawyer (Professor Michael Gunn, Nottingham Trent University at that time) ensuring the integration of legal and clinical concepts and publication in academic legal and clinical journals.^{1,2,3,4} This joint approach was extended to the most recent study of the Deprivation of Liberty Safeguards (DoLS) funded by the Department of Health, work that forms part of the NIHR Collaboration for Leadership in Applied Health Research and Care. Since the Mental Capacity Act has been in force it has become apparent how important and far reaching this is in both health (such as hospital wards and ITUs⁵) and social care settings.⁶ In a published ethnographic study by Dunn et al⁶ the subtle effects that influence support workers judgements about 'best interests' were demonstrated. Work led by Holland recently undertaken by Fistein has also shown similar complex and perhaps unexpected influences on Responsible Clinicians and Approved Mental Health Practitioners when using the Mental Health Act. Both the Mental Capacity and Mental Health Acts are concerned with complex ethical and clinical issues that are central to good clinical practice.</p>
<p>3. References to the research (indicative maximum of six references) 1. Fistein, E.C.; Holland, A.J.; and Gunn, M.J. (2009). A comparison of mental health legislation from diverse Commonwealth jurisdictions. <i>International Journal of Law and Psychiatry</i> 32, 147-155 2. Jacob, R., Clare, I.C.H., Holland, A.J., Watson, P.C., Maimaris, C. and Gunn, M. (2005). Self-harm, capacity, and refusal of treatment: implications for emergency medical practice. A prospective observational study. <i>Emerg. Med. Journal</i> 22:799-802</p>

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3. Wong, J.G., Clare, I.C.H., Holland, A.J., Watson, P.C. and Gunn, M.J. (2000). The capacity of people with a 'mental disability' to make a particular health care decision. *Psychological Medicine* 30: 295-306.

4. Wong, J.G., Clare, I.C.H., Gunn, M.J. and Holland, A.J. (1999). Capacity to make health care decisions: Its importance in clinical practice. *Psychological Medicine*, 29 (2): 437-446.

5. Redley, M., Keeley, H., Clare, I.C.H., Hinds, D., Luke, L. and Holland, A.J (2011). Respecting patient autonomy: understanding the impact on NHS hospital in-patients of legislation and guidance relating to patient capacity and consent. *Journal of Health Services Research and Policy*, 16 (1), pp. 13-20.

6. Dunn, M.C., Clare, I.C.H. and Holland, A.J. (2010). 'Living a life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 54, 2, pp. 144-160.

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

In the 1990s, high profile case law and the reports of the Law Commission highlighted the gap that existed in English law with respect to substitute decision-making; and specifically the principles that should guide when other adults can and should make decisions on behalf of another and how such substitute decisions should be made. These issues were illustrated in cases such as those of *Re C* (1993) and *Re MB* (1997) and also in contentious situations such as requests to sterilise adults with learning disabilities (e.g. *Re F* 1990; and *Re A* 2000). Holland was involved in the case of *Re A* and also as a psychiatric expert in a particularly high profile case that highlighted the need for the additional safeguards in addition to those provided by the Mental Capacity Act (HL vs. the United Kingdom 2004 – generally known as the *Bournewood* case). This case led to the UK being found at fault in 2005 by the European Court of Human Rights resulting in the later introduction of the Deprivation of Liberty Safeguards in 2009. Holland's report is quoted in the 2004 European Court of Human Rights judgment setting legal precedent in case law that remains relevant today - see para A19 of corresponding document in the British and Irish Legal Information Institute's database.¹ Early in this legal debate his group became concerned as to how legal principles that were emerging in case law, and later in draft legislation, would work in clinical and social care settings where the issues of competence and capacity are often ambiguous and not easily defined with the precision that operates in law. In terms of respect for an individual's autonomy, Holland expressed strong support for the Law Commission's ideas on the functional and decision-specific concepts of mental capacity, and on the need to optimise capacity where possible.

Findings from early projects within the research group directly informed the then Mental Incapacity Bill through a Joint Houses of Parliament Pre-legislative Scrutiny Committee from 2003 (chaired by the late Lord Carter) with Holland appointed as one of two advisors.² Recommendations that directly arose from this committee and remain very relevant included provision for the involvement of people lacking capacity in research, the need for advocacy in specific situations, and refinements about end-of-life decisions. When the Mental Capacity Act was eventually passed in 2005, Holland submitted evidence to the Department of Constitutional Affairs with respect to the Code of Practice, meeting directly and advising the Minister, at that time, Baroness Ashton.

The way that this research informs policy and practice is perhaps less direct than in other areas of clinical research. It is the clarification of key concepts and the integration of legal, psychiatric and psychological expertise that Holland's group was able to achieve with different members (Michael Gunn, Isabel Clare and Tony Holland; and later Marcus Redley) contributing to different audiences informed by the interdisciplinary discussions that had taken place.^{3,4,5} During the implementation phase from 2007 Holland was the advisor for the Royal College of Psychiatrists on the Mental Capacity Act working, closely with the British Psychological Society to produce early guidance.⁶ He was also on a working group set up by the Intensive Care Society - that guidance being adopted; and he was also part of a workshop held by the Office of Fair Trading (OFT) on the Mental Capacity Act and banking – guidance later published by the Office of Fair Trading. As clinical and

forensic psychologist and sociologist in the group, respectively, Isabel Clare and Marcus Redley later led a commissioned study on the early Independent Mental Capacity advocacy service, reporting directly to Lucy Bonnerjea⁷ at the Department of Health. This evidence helped reshape the Government's ideas on the Independent Mental Capacity advocacy services and their statutory role arguing, for example, that these should be available in safeguarding proceedings (see papers 2008 to 2011). After 2007 when the Mental Capacity Act came into force, Holland served on an advisory group for the Social Care Institute for Excellence and, since 2010, has been a member of a strategy group advising the Office of the Public Guardian.⁸

Whilst initial publications were primarily in the academic press, versions were later published in professional and practice-based journals (see below) and led to guidance (published by the British Institute of Learning Disabilities in 2007) on the assessment of financial decision-making capacity by people with learning disabilities.⁹ Once the Mental Capacity Act came into force in 2007, Holland was involved, often together with Paul Gantley from the Department of Health, in presentations on the Mental Capacity Act to professionals, support workers, families and user groups.¹⁰ This included Learning Disability Today events (users with learning disabilities), social care provider meetings (e.g. Hft,¹¹ a provider for people with learning disabilities), Royal College of Psychiatrists conferences, and local clinical groups. Holland prepared two continuing professional development on-line training modules for the Royal College of Psychiatrists in 2007 on the Mental Capacity Act; these have received very positive feedback, and are still available. In 2008, Holland worked with the social care provider Hft to produce a carer/family friendly DVD on the Mental Capacity Act sponsored by a grant from the Department of Health; helped prepare web-based material for the Prader Willi Syndrome Association (PWSA), also advising in his capacity as psychiatric advisor to the Association;¹² and as advisor on ageing and dementia to the Down's Syndrome Association (DSA).¹³ Following the Deprivation of Liberty Standards amendment a consultation event organised by Holland with the Department of Health in November 2011 explored findings with key stakeholders from the Deprivation of Liberty Standards study. In 2013 the report from the study was accepted by the Department of Health and has recently been quoted in evidence at a House of Lords Committee hearing. Holland and colleagues have submitted evidence to this Committee.

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

1. British and Irish Legal Information Institute's database.
<http://www.bailii.org/eu/cases/ECHR/2004/720.html>
2. Tony Holland's involvement in the Parliamentary Scrutiny Committee is a matter of public record. <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>
3. Redley, M., Clare, I.C.H., Luke, L. and Holland, A.J. (2010). Mental Capacity Act (England & Wales) 2005: The emergent Independent Mental Capacity Advocate (IMCA) service, *British Journal of Social Work*, 40 (6), 1812-1828.
4. Redley, M., Platten, M., Clare, I. C. H., & Holland, A. J. (2008). *The Involvement of Independent Mental Capacity Advocates (IMCAs) in Adult Protection Procedures in England*. London: Social Care Institute for Excellence.
5. Clare, ICH, Redley, M., Keeling, A, Wagner, A., Wheeler, J., Holland, A, and Gunn, M. Understanding the interface between the Mental Capacity Act- Deprivation of Liberty Standards and the Mental Health Act. Department of Health, 2013
6. Letter from then Chair Parliamentary Cttee, Royal College of Psychiatrists
7. Letter from National Lead on the MCA, Department of Health.
8. Contact; Chief Executive and Public Guardian, Office of the Public Guardian, Ministry of Justice
9. Institute of Learning Disabilities (ILD) Financial decision-making: guidance for supporting financial decision-making by people with learning disabilities. <http://www.ild.org.uk/our->

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[services/books/practical-support-for-better-lives/financial-decision-making/](#)

10. Letter from then Implementation Manager Mental Capacity Act (at Department of Health 2005-2011)

11. Letter from Strategic Director of Innovation, Hft.

12. Prader Willi Syndrome Association: <http://www.pwsa.co.uk/index.php/what-is-pws/186-publications>

13. Down's Syndrome Association : <http://www.downs-syndrome.org.uk/information/familiescarers/adults-18/ageing.html>