Submission to the House of Lords' Committee considering the Mental Capacity Act 2005 (MCA) from the Cambridge Intellectual and Developmental Disabilities Research Group (www.CIDDRG.org.uk), Department of Psychiatry, University of Cambridge.

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1.0 Introduction
1.1 The Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG) comprises clinical academics working in the local specialist services for people with learning (intellectual) disabilities and academic researchers who have engaged in grant-funded research relating to the MCA both before, and after, its introduction. On the basis of early work undertaken by members of our group and our collaborators, Tony Holland was appointed as the psychiatric adviser to the Joint Houses of Parliament Scrutiny Committee of the draft Mental Incapacity Bill (chaired by the late Lord Carter). He has continued as an adviser to the Office of the Public Guardian, and, like Isabel Clare, acts as an adviser to third sector and statutory organisations. We have been commissioned by the Department of Health to undertake research on the introduction of IMCAs, on IMCAs and safeguarding, and the interface between the MCA's Deprivation of Liberty Safeguards (MCA-DoLS) and the MHA. All these reports are publicly available. While our principal specialism is that of learning disabilities, we have treated, supported, and/or carried out research with other groups of individuals who may be at particular risk of lacking capacity to make one or more decisions for themselves.

1.2 We welcome the opportunity to make this submission, which draws upon both our research and our experience as clinicians. Details of peer-reviewed academic publications, which have formed the basis of book chapters and other materials for trainees in our disciplines, practitioners in health and social care, carers, and managers and support workers in social care settings are attached as Appendix I. Other materials are available through our website or by contacting us.

2.0 Overview
2.1 We remain strongly of the view that the MCA, which sets out a legal framework encompassing a very broad range of decisions, is sound and innovative. It seeks to address issues that have often been, and will remain, contentious because they relate to individuals who, at that time, are vulnerable, and involve decisions that may be ethically challenging and about which there may be diverse and indeed opposing views. It seems inconceivable that there could be any return to the uncertainty of the case law or the potential abuses of guardianship
legislation. However, we believe that there are some conceptual and practical issues that the Committee may wish to consider. The most important are set out below.

3.0 Conceptual issues

3.1 The principle that adults have the right to make decisions about their own lives is accepted legally and ethically. However, there needs be some means for proceeding when an individual cannot understand the nature of what is being asked, make a decision about a course of action and/ or communicate her views by some means. An obvious, if extreme, example is that of the unconscious patient: if consent were to be required in order for treatment to take place, nothing would happen. The same may be true in situations in which a person is extremely intoxicated, or has advanced dementia, or is in severe pain. We accept that an individual with capacity has the right to refuse treatment or have life-sustaining treatment withdrawn. However, when a person lacks capacity to make such decisions, we do not think they should be made on her behalf without stringent safeguards; we must not deny her right to life. The MCA requires an appreciation of the need both to empower and to protect, and can involve balancing competing rights.

3.2 Concerns have been raised about the inclusion in the MCA of an 'impairment of, or a disturbance in the functioning of, the mind or brain' as a necessary, but not sufficient, factor for determining a person's capacity to make a particular decision. Its inclusion, it has been argued, is discriminatory, but the alternative is that decision-making might be challengeable at any time, perhaps for reasons that are spurious. We should not wish to see the return of a 'status' approach (for example, a diagnosis of severe mental health problems) as a lawful reason to limit adults' right to make decisions for themselves. The MCA’s principles state very clearly that the starting-point must always be the presumption of capacity. Moreover, the fact that the MCA may, under the appropriate circumstances (for example, following a car accident) apply to any of us rather than simply to a variety of groups with particular diagnoses (such as that of a learning disability) is, we believe a powerful argument against any charge that is discriminatory. Nevertheless, in order to avoid discrimination in practice, greater knowledge and understanding of decision-making in the general population is still needed; we must ensure that the threshold for capacity for those who are assessed under the MCA is not set too high.

3.3 We have made some particular recommendations in our report about the MCA-DoLS and its interface with the MHA. While some of the practitioners who took part in our research recognised the benefits of the DoLS in care homes, the conceptual point we wish to make here is that in hospital settings, and particularly in psychiatric hospitals, there seems to be limited understanding of its human rights implications. Among many practitioners, the MCA-DoLS was viewed as providing as a legal framework to justify depriving individuals of their right to freedom of movement; there was limited consideration of the way in which modifications to the person's social and physical environment might avoid the imposition of a deprivation of liberty.
3.4 While we recognise that the timing of the progress of the Bournewood case through the Courts and of what is now the MCA through Parliament meant that the Government had no opportunity to address the violations of Art. 5 of the ECHR as part of the ‘parent’ legislation, the DoLS part is practically, as well as conceptually, complex: the procedure is cumbersome; applications for authorisation are dependent on Managing Authorities; the legislation is not sufficiently closely linked to the principles of the MCA leaving uncertainty about its relationship to the MHA; there is a gap for young adults because the Safeguards apply only to those aged 18 years of more; the Safeguards apply to care homes and hospitals but not to supported living; and, perhaps worst of all, our findings suggest that the Safeguards may not protect the very people (assenting patients in hospital who lack capacity to make decisions about the arrangements for their care and treatment) for whom they were designed. We think the MCA-DoLS require further consideration. We believe that they should, however, remain as part of the MCA. While the MHA has a more robust review system, the MCA applies to anyone with an ‘impairment of, or a disturbance in the functioning of, the mind or brain’, not just those with a ‘mental disorder’, and has a focus on the concept of decision-making capacity and is based in very sound ethical principles.

3.5 While Articles 5 and 8 of the ECHR have received considerable attention in the context of the MCA, little has been made of Article 6. Under Art. 6, individuals must have access to the courts for decisions about civil obligations. The judgement in the Neary case rekindled concerns dating back to Bournewood, where, if Mr HL had not had paid carers who were willing to challenge his care and treatment, his admission to hospital might never have been subjected to scrutiny. As Neary illustrates, even where family members or others believe that some course of action taken under the MCA is not in fact in the best interests of the person who lacks capacity, concerns about the removal of support or some other adverse outcome may result in their being reluctant to consider any legal challenge. The point we wish to emphasise is that a person whose capacity is so compromised that she is unable to make the relevant decisions for herself is unlikely to know of her right to challenge and to be able to exercise this right. At the same, family members who may wish to submit a challenge on her behalf may be reluctant to do so, because of concerns about the consequences for their relative. The MCA needs to be incorporate a robust system of review and, if necessary, challenge, without being burdensome.

4.0 Practical issues

4.1 From the perspective of members of this group with responsibilities for training, our impression is that considerable progress has been made since the introduction of the MCA. Today’s junior doctors, and their colleagues in other disciplines, are much more attuned to the concepts of capacity, decision-making, and best interests than their predecessors. Nevertheless, there is more to do.

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1 *HL v United Kingdom (45508/99) (2005) 40 E.H.R.R.*
2 *London Borough of Hillingdon v Steven Neary and Mark Neary [2011] EWHC 1377 (COP)*
In some places, there remains a lack of awareness of the full scope of the legislation and a continuing belief that it is limited to people with learning disabilities or dementia. The setting in which the MCA most often needs to be considered is in the Accident and Emergency (A & E) departments of general hospitals, where many patients who are admitted are in a state of shock or are confused, intoxicated, or unconscious. As we have shown (Jacob et al., 2005) engagement with these patients, where it is possible, can support them to gain or regain capacity to make their own decision about the recommended treatment for their condition. As a result, they are more likely to consent to, rather than resist, that treatment.

4.2 On occasion, judgments about an individual’s capacity to give or withhold consent may need to be made immediately. Much more often, however, there is at least some time and, if there is uncertainty about the person’s capacity, there are opportunities to enhance her knowledge and understanding of the relevant information, her ability to make a choice, and/or her communication. Sometimes, this may involve simplifying, or breaking down the decision into smaller steps, or making it as concrete as possible; at other times, it will involve more general development of her skills and confidence in making her own decisions and experiencing, in a safe way, their consequences. We wish to emphasise the principle that ‘all practicable supports’ must be offered to assist an individual to gain, or regain decision-making capacity. In some situations, capacity assessments merge into best interests decision-making in that, in seeking to establish someone’s person’s capacity to make a specific decision, her wishes and feelings, beliefs and values, will become evident.

4.3 We are concerned, however, that there are times when a person’s capacity to make a decision for herself is used by service providers to abrogate their continuing responsibilities. This may particularly be the case in demanding settings such as A & E departments in general hospitals or social care settings where support staff are concerned they might be blamed for any adverse consequences to the person or others. ‘It’s their choice’ is a refrain that we hear too often. Health and social care practice in mental health, intellectual disabilities, services for older people and other settings in which people with complex needs inevitably involves a delicate and nuanced balance between supporting decision-making and protection from harm. The fact that someone who may be vulnerable and at risk of harm to herself or others has made an apparent reckless but capacitous decision places an even greater responsibility on services to seek to provide support, however difficult that might be.

4.4 More generally, we have some concerns about how judgments are made with respect to best interests. We are very supportive of the basic framework set out in the MCA and its Code of Practice, but would like to raise two main issues. First, there seems to be some confusion about the priority to be given to different factors in considering a person’s best interests in relation to a particular decision. These factors include not only the ascertainable views of the adult who lacks capacity but also those of others who care for or about her. In contrast with most situations in which someone has the relevant decision-making capacity, its absence means that the person’s views are not determinative. Instead, according to the MCA, her views, as far as they are ascertainable, must be balanced against other factors. There have been examples where, we believe,
the right balance has not been achieved. For example, in the Neary case, very limited, if any, consideration appeared to have been given to Mr Steven Neary’s wish to return home. At the very least, his views should have been acknowledged, with an account of the reason that acting on these views would not be in his best interests and could not be followed. A second example, which has been addressed in a Court ruling, but may still be contentious, relates to the person who lacks the capacity to consent to life-saving treatment and whose carers believe would resist that treatment. In such a case, some judgment needs to be made about the value to be placed on the person’s putative resistance. We believe that there is an obligation to seek ways to make the intervention possible. Decision-makers in these complex situations need to recognise the tension that may exist between the person’s right not to be subjected to treatment that is degrading and her right to life. In such a case, as in many others, establishing best interests is a process, rather than a decision to be made at a single meeting. People do not always respond in the way that is predicted by those who know them well and their responses can sometimes be ascertained only through trying out one or more particular courses of action.

4.5 Secondly, and relatedly, we have concerns about the judgments made about the best interests of men and women with lifelong and severe disabilities who may always have lacked capacity to make some or most decisions for themselves. Research we carried out in social care settings (Dunn et al., 2010) suggested that support workers used their own conception of a ‘good life’ as the starting-point for making decisions on behalf of people with severe learning disabilities. We believe that these staff should be encouraged to think more critically and reflectively about the well-being of those whom they support and how best it might be enhanced. While we are critical of the MCA-DoLS, one of its reported benefits was that, in care home settings, it provides some opportunity for support workers and their managers to consider with other practitioners how the environmental modifications might alleviate limits to the freedom of individuals who lack capacity in relation to decisions about the arrangements for their care and treatment.

5.0 Conclusions
1. We support the MCA. While there is still a good deal of progress to be made, the legislation and the programme of dissemination with which it was accompanied have brought about a cultural sea-change in the lives of adults who lack capacity to make one or more decisions for themselves.

2. We are supportive of the MCA-DoLS from the perspective that some legislation is needed to protect the rights of vulnerable people and to prevent a deprivation of liberty that is not in an individual’s best interests or authorised by some other means, such as the use of the MHA. The difficulties in hospitals settings largely reflect the different principles of the MCA and the MHA. We believe that there is a case for the MCA to be used to address all matters relating to decisions made on behalf of people who lack capacity to make one or more decisions for themselves. The MHA might then be reserved, and arguably

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3 DH NHS Foundation Trust v PS [2010] EWHC 1217 (COP)

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limited to forensic settings, for treatment of a mental disorder in individuals who have the capacity to consent but withhold that consent. If such a radical approach were to be considered, the protections enshrined in the MCA could be enhanced so that, in certain situations (e.g. where a person was being deprived of her liberty and it was proposed to that she should receive serious medical treatment), a review system would be activated. However, we recognise that such radical reform is unlikely. Given our view that a deprivation of liberty is as important for individuals as serious medical treatment, we believe that an immediate improvement, which would involve some amendments to the MCA-DoLS procedure, would be to provide IMCAs under s. 35 to all those who lack capacity to make a decision about arrangements for their care and treatment and for whom an application is made for authorisation of a deprivation of liberty.

3. With respect to best interests, we believe that there needs to be a better understanding of the way in which the different factors that need to be considered might best be balanced, with more concerted efforts to enable individuals to gain or regain capacity to make the relevant decision for themselves as far as possible. We also believe that clinicians and other practitioners would benefit from greater understanding of best interests decision-making, limits to freedom, and their responsibilities towards individuals who make reckless but capacitous decisions within a context that, while consistent with the principles of the MCA, is broader and promotes the well-being of the men and women whom they treat, care for and/or support.

We hope these comments are of some value to the Committee.

Anthony J. Holland, Health Foundation Chair in Learning Disabilities; Hon. Consultant Psychiatrist
Isabel C.H. Clare, Consultant Clinical & Forensic Psychologist; Affiliated Lecturer
Marcus Redley, Senior Research Associate.


Correspondence please by email or post to:
Professor Tony Holland ajh1008@medschl.cam.ac.uk (after 1st October);
Dr Isabel Clare: ichc2@medschl.cam.ac.uk (before 30th September)

Cambridge Intellectual & Developmental Disabilities Research Group,
Department of Psychiatry, University of Cambridge,
Douglas House, 18b Trumpington Road, Cambridge CB2 8AH
Appendix I

This submission has been informed by interdisciplinary research undertaken by our research group and our collaborators over many years. Listed below is a selection of peer-reviewed publications.


