

## CRITICAL COMMENTARY

# Who Decides Now? Protecting and Empowering Vulnerable Adults Who Lose the Capacity to Make Decisions for Themselves

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### Summary

The implementation of the 2005 Mental Capacity Act in England and Wales heralds a new era for social work practitioners and researchers. Protecting and empowering vulnerable adults—an important element of adult-care social work—relies on a legal framework that attempts to balance adults' rights with the desire to protect them. The new Act is part of that framework, addressing the fundamental issue of when and how decisions can be made on behalf of people who lose decision-making abilities ('capacity'). The Act encompasses the meaning of incapacity and best interests, advance directives concerning treatment, managing people's affairs and making decisions for them, overseeing the delegation process, and research. In explaining how the Act addresses some of these challenges, the article alerts practitioners and researchers to the key areas in which the Act will make a major impact.

**Keywords:** social work and law, adult care, vulnerable adults, mental capacity, consent, protection, research ethics

### Background

The passing of the 2005 Mental Capacity Act represents a significant landmark in the development of legislation relating to vulnerable adults. At last, there is

consolidating legislation addressing the needs of those who have lost, or may lose, the ability to make informed decisions, or may not be able to manage their own affairs. This article alerts practitioners and researchers to the key issues that will arise with the implementation of the Act from April 2007. It is not intended as a comprehensive guide, but rather to promote reflection on the implications of the new legislation.

The whole issue of protecting the most vulnerable who are unable to make decisions about care, treatment and property rights has a long history. The courts, in the UK and elsewhere, have long acknowledged that particular groups need protection, often invoking the assumed powers of the state under the doctrine of 'parens patriae'—the notion that the state has a duty to citizens who cannot speak for themselves. Thus, in the UK, the High Court has exercised its rights to wardship jurisdiction in relation to children by reference to this notion. Nonetheless, courts now prefer to rely on common law, namely law derived from history and precedent and not written-down statutes, to argue that doctors can treat adults who are incapable of giving consent. The proviso is that such treatment must be necessary to save life or improve or prevent the deterioration of physical or mental health, following precedents redefined in *Re. F (mental patient sterilisation)* ([1990] 2 A.C. 1, [1989] 2 W.L.R. 1025, HL). The common law principle of 'necessity' also allows doctors to treat patients who are temporarily unable to consent. An unconscious patient would thus be treated on the basis of the doctor's assumptions about need, explicit consent not being required providing there is no known objection and treatment not being 'more extensive than is required by the exigencies of the situation' (Mason and Laurie, 2005, p. 351). However, extension of this principle of 'necessity' to cover detention in a psychiatric hospital has now been ruled by the European court as contravening Article 5 of the European Convention on Human Rights (*HL v. United Kingdom* [2004] All E.R. (D) 39 (Oct)). In this context, the European Court held that compelling someone to remain in hospital as 'accommodation' in their own 'best interests' under the common law doctrine of 'necessity' was stretching the ambit of unwritten law too far. There were insufficient safeguards and the common law powers too imprecise.

Constantly shifting power relationships between state, service users and health care and social work professionals have stimulated debates about circumstances in which protection and decision making need to be on a clearer legal footing, with the Law Commission (1993) initiating a process of review and consultations (Lord Chancellor's Department, 1997, 1999). Despite the consultations, the 2005 Mental Capacity Act ended up being rather a rushed affair, clearing the final hurdle of Parliamentary approval and Royal Assent just before the General Election of 2005. Consequently, some of the controversies aroused were not fully explored through public debate, and an opportunity to clarify the law so as to conform to the European court judgment cited above was lost. This has led to the odd state of affairs in which the Department of Health has been obliged to declare already that it intends to amend the Act

and its associated Code of Practice so as to achieve this objective (Department of Health, 2006a; Hewitt, 2006).

Unsurprisingly, addressing the needs of those who lack capacity is not an issue unique to the UK. In both Australia and Canada can be found examples of state-funded independent bodies specifically set up to manage the affairs of vulnerable adults and protect them from abuse: for example, the Office of the Public Advocate in Victoria, Office of the Public Guardian in New South Wales, Office of the Public Guardian and Trustee in Ontario.

### **Case study**

Susan, aged twenty-five, was involved in a serious road accident, as result of which she suffered a brain injury which has left her with an impairment of her ability to reason and make judgments. Her brother is her only remaining relative. After receiving hospital treatment, she moves to residential care, where she receives the twenty-four-hour care she needs because of her extensive disabilities. There is a well grounded fear that her physical and mental condition may well deteriorate. She receives a very substantial sum from the insurance company to compensate the loss of her livelihood and provide for future care.

This case study raises a number of ethical and practical issues. Consideration of some of these may facilitate an exploration of the 2005 Mental Capacity Act.

### **Capacity and best interests**

The 2005 Mental Capacity Act applies to anyone over sixteen who lacks capacity to make their own decisions as a result of 'an impairment of, or a disturbance in the functioning of, the mind or brain' (section 2). The common law principle, that all adults are competent to make decisions unless it can be demonstrated otherwise, is restated. The legislation uses the word 'capacity', and it is the assessment of capacity which effectively determines the degree of autonomy that the individual will have. Capacity to make decisions means understanding the information relating to the decision, being able to retain that information, evaluate it and communicate the decision (section 3). The 2005 Mental Capacity Act itself does not state who is responsible for the assessment of incapacity, but its important underlying principle is that consent has to be decision-specific. Furthermore, the draft Code of Practice identified the assessor as the 'person who wishes to take some action in connection with the person's care or treatment or who is contemplating making a decision on the person's behalf' (Department for Constitutional Affairs, 2006, p. 3.42), hence the conclusion that the 'burden to demonstrate that a person lacks capacity lies with the health professional' (Leyshon and Clark, 2005, p. 130), although, in many contexts, for 'health professional', social worker must surely be substituted. Although it is clear why often decisions might be primarily medical, a significant number of

decisions or actions contemplated would be care-related, and therefore involve social workers. Here, social work assessment skills would be crucial.

In the case study, this means that Susan would not simply be declared to be 'brain injured' and therefore unable to make any decision in the circumstance; rather, a capacity to make decisions will be related to specific decisions that she needs to make as and when these arise. Consequently, assessment and reassessment may need to be made with each decision, with 'all practicable steps' (section 1) taken to help her make a decision. Although a laudable principle, this has substantial implications for professionals involved in cases such as Susan's, not least in terms of time.

Section 1 also requires that incapacity cannot be assumed simply on the basis of making 'unwise' decisions, and that all actions and decisions made by other people should be in the service user's 'best interests'. Clearly, this will be consistent with social work principles of empowerment, although the Act is silent about what exactly constitutes 'best interests'. It is worth noting, though, that the Act implies a right to make choices which may not be in service users' own long-term interests. Thus, Susan's decision to spend a significant proportion of her weekly income on chocolate and cigarettes may be decidedly unhealthy, and therefore contrary to her long-term interests, but cannot be overridden simply on these grounds. By contrast, the decision taken for her that the majority of her substantial insurance company payout should be invested has to be one that is demonstrably in her best interests. Those who take over decision-making powers *are* under an obligation to make wise decisions; service users *are not*.

Alongside the best-interest obligation stands a requirement for decision makers who act on someone else's behalf to adopt the least restrictive approach, not in the sense of curtailing liberty, but in the context of limiting the sphere within which they make those decisions. In short, those who take on responsibility for other people must maximize the service user's rights to choice and freedom. This is elaborated on in section 4, which requires the assessor to take into account 'all the relevant circumstances', ignoring appearance, age and other factors that may lead to assumptions being made. Furthermore, the assessor must consider the person's expressed wishes, their values and beliefs, and, where 'practicable and appropriate', the views of carers and those with a clear interest in their well-being. This section of the Act is, reassuringly, heavily imbued with social work principles and values.

## Advance decisions

What some call 'advance directives' or 'living wills' the 2005 Mental Capacity Act terms 'advance decisions'. The English courts' assumption that written declared wishes about treatment and care should always be respected, as in *Re. AK (adult patient)(medical treatment consent)* ([2001] 2 FCR 35, [2001] 1 FLR 129, [2000] Fam Law 885), is now enshrined in sections 24–26 of the Act. This

provision applies to anyone over eighteen, and is relevant to adults who lose capacity so long as they made their future wishes known at a time when they did have capacity. If they did not, decisions are made in the person's 'best interests' in accordance with common law and previous court decisions, particularly *Airedale NHS Trust v. Bland* ([1993] 1 All E.R. 821), in which the court authorized discontinuation of a life-support machine.

Advance decisions relate exclusively to refusal of certain kinds of treatment; if they concern life-saving treatment, they must be in writing and witnessed (section 25). Advance decisions cannot be used as a way of demanding particular forms of treatment or securing services. They therefore cannot be used as a 'backdoor' route to euthanasia, since that would require active intervention to terminate life. In practice, there are further limitations. For example, it is not possible to preclude forms of compulsory treatment under the 1983 Mental Health Act, since a decision to detain someone who meets the criteria and treat them against their wishes in accordance with that Act would override any advance instructions to the contrary (section 28).

One disadvantage of advance decisions is that not all situations can be anticipated, and while practitioners might conclude that specific instructions given in advance are mandatory, what happens if the advance directive says nothing about the particular form of treatment or care now considered appropriate? Here, the 2005 Mental Capacity Act provisions for delegating wider powers may be useful.

### Delegating decision making

The provision for delegating the full range of decision making breaks new ground, although built on the existing Enduring Powers of Attorney which become Lasting Powers. The new Lasting Power is all-embracing, extending the general, primarily property-related provisions of Enduring Powers of Attorney into consent to medical treatment and, critically for social workers, consent to care and provision of services. As with all powers of attorney, it has to be arranged while the person wanting to delegate powers still has the capacity to do so, but it has the advantage that it gives the proxy (or donee of the power) a general power to make decisions and to put into effect the donor's known wishes. To be effective, the Lasting Power must be in a prescribed format and registered with the Public Guardian (sections 9–11 and 22–23 of and Schedule 1 to the 2005 Mental Capacity Act). So, in the case study, it might be appropriate for Susan to appoint her brother to act on her behalf. If she did not have confidence in him, she could choose a friend or indeed anyone else she trusted. This raises the possibility in exceptional cases of people wanting to nominate a named social worker and practitioners may need to be prepared for this eventuality, although the Draft Code of Practice (Department for Constitutional Affairs, 2006, p. 6.35) advises against paid carers taking on this role and notes in passing that attorneys cannot nominate substitutes or successors—surely two strong reasons for resisting this task.

Note, in addition, that there is new provision for nominating Independent Mental Capacity Advocates for people who have no family or friends. NHS bodies or local authorities are obliged to appoint advocates where serious issues, such as intrusive medical treatment or change of residence, are being canvassed (section 37). This would certainly include decisions related to closing residential homes, for example.

If Susan were able to make some decisions for herself some of the time, she might well decide that it is appropriate to appoint a proxy to act for her on those occasions when she cannot. The advantage of the Lasting Power of Attorney is twofold. First, it can be comprehensive. Second, the extent of the power delegated is determined by the service user ('donor'). Once having decided the extent of the proxy's powers, the expectation is that these will be exercised once the donor loses capacity, but only when they do so; the arrangement must then be registered with the Public Guardian. From then on, decisions are made in the person's best interests (section 4), except that they cannot countermand previously expressed wishes articulated at a time when someone had capacity (section 11). One practice dilemma would arise if periods of incapacity were sporadic or intermittent—what happens in those circumstances?

A Lasting Power of Attorney will also cover managing money, property and associated financial affairs: buying and selling property, operating bank and building society accounts, claiming benefits, receiving income, making payments, investing money, and so on. These extensive delegated powers could be overseen by arrangements within the Lasting Power of Attorney itself or, failing that, through referral to the Court of Protection if abuse were suspected, since that Court can adjudicate on disputes or revoke the Lasting Power (sections 22–23). This supervisory role is important, although it raises questions about who would know about the abuse and who would have responsibility for referring the matter to the Court.

### **Enforced delegation**

If someone loses capacity without having made prior arrangements, this then becomes a matter for the Court of Protection and Public Guardian. The former can appoint Deputies who can take decisions on welfare, health care and financial matters (but cannot refuse consent to life-sustaining treatment). The Court itself can make a wide range of decisions on property, health and welfare. Experienced adult care social work practitioners may well be familiar with the role of this court, which, in future, will have a wider range of responsibilities. To aid those who are not, the Public Guardianship Office (2006)—the 'administrative arm' of the Court of Protection—offers an informative website.

The Public Guardian will have day-to-day oversight of the implementation of the Court's directions and other cases in which people act with powers delegated by people who have lost 'capacity'. Thus, there is extensive provision for accountability and supervision, but practitioners need to bear in mind that

there is a cost to service users, since the Public Guardianship Office levies charges which can be in addition to the professional fees charged by Deputies.

## Research involving people who cannot consent

The Act provides certain safeguards for 'intrusive' research where people without decision-making capacity are involved as subjects. The word 'intrusive' is interpreted rather widely, meaning any research that normally requires informed consent (section 30) which, in effect, means nearly all research. It would certainly include social work research which assessed the effectiveness of particular forms of care, for example, or explored the implications of particular policies, or even conducted an analysis of where particular groups of service users lived by using personal data. One constraint is that the research must be 'connected' to the 'impairing condition' that affects the subjects themselves, or to the 'treatment' for people who share the same 'condition'. In addition, the use of subjects can only be justified if there is some reason why it cannot be confined to people who can consent (section 31). It is debatable how far, in practice, this may circumscribe some kinds of social work research. Making the connection with the impairment may not be quite as problematic as the implication that researchers need to seek out people who could give informed consent.

Space does not permit a debate here about the rights and wrongs of this limitation, but it may be worth noting the formalization in statute of what many would consider to be sound research ethics. Therefore, the impact of the legislation may not be as great as a first reading of the legislation might suggest. Taken together with the 2004 Medicines for Human Use (Clinical Trials) Regulations, which make consultation with representatives of people unable to give full consent compulsory, the 2005 Mental Capacity Act completes the cycle by applying the same principles to other kinds of research. Thus, the 2005 Mental Capacity Act requires, for instance, that there is consultation with carers and no interference with the subject's freedom of action or privacy (sections 32–33). One questionable aspect of the legislation, however, is that the Act lays the duty to be satisfied that the research meets all the requirements of the Act on an 'appropriate body' that may not be wholly autonomous, since the Department of Health (2006*b*) has declared its intention to use existing research ethics committees rather than establish a totally independent body (Griffith, 2006). However, that may offer reassurance to researchers fearful that the Act would venture into new territory.

## Conclusion

The 2005 Mental Capacity Act consolidates and extends provision for people who lose capacity to make decisions for themselves. By setting out clear legal

authorities and safeguards, the legislation aims to empower and protect a specific group of vulnerable adults and, in many respects, the legislation is to be applauded. However, there are a number of issues that may arise in practice, particularly in relation to the need to assess decision-making capacity in the light of each decision and circumstance rather than generally. Researchers need to familiarize themselves with restrictions on investigations that include people unable to give full informed consent, and all practitioners should consider the implications of the Act for their own work.

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