Respect for autonomy can be regarded as establishing a stalwart right or authority to control one’s personal destiny, that is to say, the right to control one’s goals on the basis of one’s desires and plans. However, this is not to say that respect for autonomy is the only source of moral obligations and rights, nor that it is absolute or lexically superior to other principles such as expressions of beneficence, where doctors act to promote the welfare of patients. Many other moral rules including truth telling, promise keeping, confidentiality, and consent, can be derived from respect for autonomy. An expression of respect for autonomy includes treating people in such a way as to enable them to act autonomously. The new Mental Capacity Act 2005 deals with decisions relating to people who temporarily or permanently lack mental capacity and therefore are unable to act autonomously. Its starting point is that all people have the capacity to make healthcare decisions and their decisions, and more importantly their autonomy, must be respected. It emphasises that unwise decisions do not automatically invalidate autonomous judgements. Respect for autonomy is most evident when unwise or indeed capricious decisions are accepted as valid and binding.

Provenance of the Act

The Act aims to clarify a number of legal uncertainties and to reform and update the current law where decisions need to be made on behalf of others. It governs decision-making on behalf of adults, both where they lose mental capacity at some point in their lives, for example as a result of dementia or brain injury, and where the incapacitating condition has been present since birth. It covers a wide range of decisions on personal welfare as well as financial matters, substitutes decision-making by attorneys or court-appointed ‘deputies’, and clarifies the position where no such formal process has been adopted. The Act includes new rules to govern research involving people who lack capacity and provides for new independent mental capacity advocates to represent and provide support to such people in relation to certain decisions. The Act provides recourse, where necessary and at the appropriate level, to a court with power to deal with all personal welfare (including healthcare) and financial decisions on behalf of adults lacking capacity.

The Act introduces a principle of equal consideration in relation to determinations of a person’s capacity. It makes it clear that such determinations should not be made on the basis of a person’s age or appearance, nor should unjustified assumptions about capacity be made based on the person’s condition or behaviour. The implication is self-evident – preconceptions and assumptions held by a person making the assessment of capacity must have no input into the assessment. This point should hardly need making. Decisions about capacity must be based solely on the assessments with respect to particular situations. In other words, tests of capacity are situation specific.

As Shickle writes in this journal, the Act has been widely welcomed. Concerns such as those of the Christian Medical Fellowship need to be in the public domain. They remain concerned that serious medical treatment may be withdrawn ‘in the best interests of the patient’ and that the Act will make possible sterilisation of those with learning disability. The real anxiety appears to be that the Act, under the guise of best interests, will facilitate decisions that devalue life, leading to outcomes such as euthanasia. There is also a feeling that there has been a missed opportunity to integrate the provisions of the Mental Capacity Act 2005 with those of the Mental Health Act 1983. The Mental Health Act 1983 is currently under review and Zigmond has argued that there is little reason to believe that a self-standing Mental Health Act is required. Indeed, the expert committee reporting on the reform of the Mental Health Act 1983 recommended that assessment of capacity be the organising principle of the new Act. This recommendation was rejected by the Government.

The new Lasting Power of Attorney (LPA) extends the previous enduring power of attorney beyond property and finances to personal welfare, including medical treatment. The powers that may be covered under ‘matters of personal welfare’ include:

- deciding where the donor is to live, eg whether a person with dementia should be moved to a nursing home
- prohibiting a named person from having contact with the donor
- monitoring medical care
- giving direction that a doctor should pass medical care to another doctor.
It is important that the donor be aware of the full extent of the powers that are being transferred to the donee. Although the powers will be monitored by the new Court of Protection and the Public Guardian, the anticipated risks are the potential for conflicts between the best interests of the donor and the interests of the donee who has the LPA.

Research on vulnerable subjects

The Mental Capacity Act 2005 regularises research on people lacking mental capacity. This is an important subject. Research involving human subjects is potentially important for society as a whole because of the possibility of advancement of knowledge. Strictly speaking, research on human subjects is only justifiable if there is a reasonable prospect that the study will generate the knowledge that is sought, that there is a need to use human subjects and that the selection of subjects is fair. It is also important that the benefits to the individual and to society outweigh the risk to the individual. Research on human subjects who lack mental capacity is potentially morally perilous because of the temptation to use the subjects simply as means to the ends of society as a whole. One of the cornerstones of the conceptualisation of autonomy in the tradition of Kant is that all persons must be treated as ends in themselves, that is as human subjects with dignity and value and not merely as means or objects.7

The Willowbrook case exemplifies the risks. The Willowbrook State School was an institution for mentally disabled children in New York. A number of these children, with the consent of their parents, were exposed to strains of an infectious hepatitis virus in order to study the period of infectivity. The aim was not immunisation. The justification was that they were likely to be infected in any case because viral hepatitis was endemic in the institution. One of the criticisms of this study was that the children were unlikely to benefit directly from the study and that the investigation was not aimed at furthering knowledge about the children's current medical conditions. In the light of the potential moral risks of using persons who lack mental capacity in research, the provisions of the Mental Capacity Act adequately balances these risks against the potential benefits.

The Act will come into effect in 2007. In the intervening period it is imperative that doctors and other agencies become fully aware of the provisions within the Act and also that training be widely available on the implications of the Act for clinical practice. Psychiatrists have been the resource in many hospital settings for the assessment of capacity in patients refusing treatment. There is no doubt that in the new dispensation, doctors of all specialties will have to become confident about their assessments of mental capacity. Clinical judgements on capacity as well as the physical status of patients must become uniformly routine judgements in all areas of medicine.

References

2 The United Kingdom Parliament. www.publications.parliament.uk
4 Christian Medical Fellowship. www.cmf.org.uk/index/mental_capacity_act.htm