

## John as a utility and 'utility'

K. NADESALINGAM, Consultant Psychiatrist, Services for People with Mental Handicap, Church Hill House, Crowthorne Road, Bracknell, Berkshire RG12 4EP

John is a 30-year-old man suffering from severe mental handicap (IQ:30) and epilepsy, without other physical deformities or illness. He is sociable, would initiate social interaction (physical), enjoys a cuddle and going out on trips. He has no communication skills but is able to understand basic commands like 'open your mouth', 'sit down' and so on. He has been a long-term in-patient in a mental handicap hospital for the past 15 years. He is from an affluent family and had been admitted because of his family's inability to cope. He has visits from his mother once a month, and from his father less frequently. A few months ago his mother left a verbal instruction to the ward staff to make arrangements to donate his organs and to ask me, as responsible medical officer, to leave written instructions to inform the local Organ Transplant Team before his death, whenever it becomes imminent, so that the Organ Transplant Team can remove the necessary organs on his death.

One cannot comply with her request without asking the following questions. Has not John got the choice, like a person of normal intelligence, although he cannot express his choice? Should we assume his choice by proxy consent which is usually given when the person's authorisation is lacking because of his incompetence? A person's interests, well-being and welfare comprise the basis for proxy consent. The consentor is expected to make an assessment of whether the proposed procedure is going to benefit the incompetent or not. On occasion the person's interests may conflict with the proxy's interests so the 'best interests doctrine' may not serve the best interests of the patient. So it cannot be strictly said that the consent given or withheld is that of the incompetent. As doctors we often use the 'best interests doctrine' when making decisions to treat a mentally incompetent person without his consent. An extreme example would be surgical amputation of a limb of a mentally handicapped adult when his life is under threat.

In the case of John the 'doctrine of best interest' is not justified because the suggestion is not going to bring him any good so the concept can be discounted and the possibility of proposing the 'doctrine of substituted judgement' explored. "Here the guardian is expected to enter into the person's point of view and give consent to preserve the patient's integrity" (Kleinig, 1985); in other words, give consent on

behalf of the mentally incompetent for what the incompetent would have done if competent. Here again the question arises whether John's mother can effectively be a substitute judge. What is the need at this stage, when he is alive and well, for this substituted judgement? Has John's mother got any other interest to make this request? Substituted judgements are usually used to benefit the individual concerned or to benefit a known close relative; for example, donation of bone marrow to a relative by an incompetent person or the donation of a kidney to a relative by an incompetent person when no other compatible donor could be found. Under these circumstances, in the case of John, the doctrine of substituted judgement, too, could be discounted.

The other aspect of this case is whether John is different from the others, and is his mental handicap making him less of a person – a non-autonomous person? Because of the involvement of moral philosophers and the Human Rights Organisation, the concept of autonomy has become extremely important in the health care profession. Although the concept of autonomy has been given such importance in recent years, this was the principle on which John Stuart Mill wrote his essay on 'Liberty'. "The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of others, to do so would be wise or even right . . ."

The concept of autonomy has been emphasised not only by utilitarian moral philosophers like Mill but also by deontologists, like Kant. "To the Idea of freedom there is inseparably attached the concept of autonomy, and to this in turn the universal principle of morality – a principle which in Idea forms the ground for all actions of rational beings, just as the law of nature does for all appearances . . ."

Since autonomy is given so much importance in ordinary life, and dealing with one's will, liberty, rights and individual choice, it is reasonable to assume that anything done to interfere or insult the autonomy of the person should be discouraged. People of normal intelligence can refuse organ donation at their death for various reasons, mostly

based on religious beliefs; for example, Muslims, Hindus and Jehovah's Witnesses believe the body is sacred, should not be mutilated and should be treated with respect. Others refuse to donate organs because they do not wish their bodies to be mutilated after death. John is mentally handicapped and not autonomous in all respects, but the line between autonomous and non-autonomous persons based on competence is arbitrary. Even though mentally handicapped, John can express his wishes against actions he does not like, e.g. the giving of an injection, refusing meals when he is not hungry, refusing to go out to the Adult Training Centre when he does not feel like it. Is he different from the rest of us who die without expressing a wish to donate organs?

Whatever our religious, cultural or social background we respect the dead. Yet we are prepared to mutilate their bodies to donate organs for the benefit of others when their wishes are not known. Are we not assuming that those who have not expressed their wishes, and those not competent to express their wishes, have no objection to organ donation? In some cases even if their wishes are known we do not care about their wishes because they are no longer persons. Extending this, could in future parents of mentally handicapped people decide to donate their offspring's organs and leave instructions years before death is anticipated? Could the Unit General Managers as the custodians of the Health Authority property, in the absence of any relatives, donate the organs of mentally handicapped people as the dead body becomes the property of the Health Authority? Could this come to include the mentally ill who have been previously competent and lost their competence because of their illness, who may have had definite views not to donate the organs when they were competent?

"Utility or the greatest happiness principle holds that actions are right in proportion as they tend to promote happiness . . ." (Mill) – the end justifies the means. "I must again repeat, what the assailants of utilitarianism seldom have the justice to acknowledge, that happiness which forms the utilitarian standard of what is right in conduct, is not the agent's own happiness but that of all concerned" (Mill). If one looks at the dilemma from a utilitarian angle there is no doubt that it would bring happiness to the greatest number of people – all those who are going to be recipients of John's organs, his family members and maybe some of the care staff – at the expense of John who has no choice or voice. So his happiness is immaterial. Perhaps I would be the only person who would be unhappy. Since each is counted as one in calculating the sum total of happiness according to utilitarian philosophers there is a convincing case to comply with John's mother's request. The same argument would apply even if John is not incompetent and has died or is dying. Utilitarian theory is

flawed in several ways. Taken to extreme, if it is going to benefit two or more people it assumes that it is not morally wrong even to kill a person and transplant his organs.

On the other hand the deontologists would argue, "The goodwill is not good because of what it effects or accomplishes – because of its fitness for attaining some proposed end"; ". . . that is, as one which is to have influence on the will; its true function must be to produce a will which is good, not as a means to some further end but in itself"; ". . . we are concerned not with actions we see but with their inner principles which we cannot see" (Kant). In other words means (actions) should be good in principle irrespective of their ends (effects). It can be argued that to assume that those incompetent to express their wishes and those who have not expressed their wishes have no right to refuse and deny the right to refuse organ donations to a person is morally wrong. So long as the inner principles we cannot see are wrong whatever actions we see, however much benefit it brings to the others, are immaterial.

One does not need to look upon moral philosophers to discount John's mother's request. One could look at the Hippocratic Oath, "I will follow that system of regimen which, according to my ability and judgement, I consider for the benefit of my patients and abstain from whatever is deleterious and mischievous".

There are several definitions of harm. Some are broad, including set-backs to reputation, property and liberty, and under this definition not respecting one's autonomy could be considered harmful. The other definitions are narrower, to include only set-backs to physical or moral interest. In health care ethics, doing no harm is known as non-maleficence. One does not need to do anything intentionally active to be non-maleficent whereas doing good, or benevolence, involves a positive act which includes promoting good but also preventing and removing harm.

Whatever definition one uses, one could argue that by complying with John's mother's request we are not doing any beneficial act to John but that the benefit it brings to others is immaterial and, on the contrary, we are doing harm to him by complying with this request. This is a maleficent act.

We say justice is done when someone gets what he deserves and query what kind of justice is this when someone gets something he does not deserve. We respect the wishes of people who are known to have ideas against organ donation and do not remove their organs at death. On the other hand we remove the organs of people whose wishes are not known. Is this just or is it just not to remove organs from these people to prevent an injustice being done to the many who may have ideas against organ donation, and the many incompetent to express such an idea (not to donate)?

One way of finding an answer to this dilemma is to go before the Courts which consider the legal and moral issues and give their judgement, often using the principle of 'substituted judgement'. In recent years some cases before the Courts involving mentally handicapped people and moral issues have been conflicting and controversial – Alexandra, where the Court ruled to subject a Down's syndrome baby to undergo an operation for a life-threatening condition where the parents refused consent; Dr Arthur, where the Court did not find him guilty of manslaughter when he prescribed only nursing care, water and DF 118 to a Down's syndrome baby, which was rejected by the parents, and enhanced its death; and Janet, where the Court gave a ruling in favour of a mother who wanted a mentally handicapped girl to be sterilised. The Court ruling may be legally binding but may be reversed by a higher Court. Therefore it need not be morally right.

In a nutshell, complying with John's mother's request is a maleficent act, over-rides his autonomy and is not just. Therefore it is morally wrong. This also includes removal of organs from people who die without making their wishes known, whether they are competent or not. There has been enough publicity by the media and almost everyone is aware of the good organ transplant would bring to others by letting someone receive their organs. It is rational to expect people to opt in by carrying a donor card or making their wishes known by some other means if they want to help someone when they die. We should restrict ourselves to removing organs only from

people who have opted in and should not expect or ask for consent from relations of a dying person to donate his or her organs when the dying person's wishes were not known, or even if the consent is given without request we should not remove the organs to avoid a moral wrong-doing, because among these people (who have not opted in or not made their wishes known) is the most vulnerable group of our society – the mentally incompetent. Is this too much to ask from a civilised society?

(I declined to make any such entries in John's case notes, but advised his mother that on John's death the body would become the property of the next-of-kin and the next-of-kin could donate his organs if he or she wishes. Anyone who reads this should not go away with the impression that I am against organ transplantation [I do carry a donor card]. I am only against the principles involved in this particular case.)

### References

- KANT, I. (1964) *Groundwork of the Metaphysics of Morals*. (ed. J. S. Paton). First edition. London: Harper Torch Books.
- KLEINIG, J. (1985) Psychosurgery and the mentally retarded. In *Moral Issues of Mental Retardation* (eds. R. S. Laura and A. F. Ashman). Beckenham: Croom Helm.
- MILL, J. S. (1986) *Utilitarianism*. (ed. M. Warnock). First impression. London: Fontana.

---

*Psychiatric Bulletin* (1990), 14, 603–607

## Autonomy and safeguards in people with impaired decision-making abilities

JOHN MORGAN, Consultant Psychiatrist Mental Handicap, Slade Hospital Resource Centre, Horspath Driftway, Headington, Oxford OX3 7JH

In everyday life we all make choices and decisions with regard to ourselves and our environment. Such decisions may be quite trivial, for example which pair of trousers we should wear, or major, for example to move home. The freedom to make such decisions may be called the right to self-determination or autonomy. For adults, such a right is recognised by

the law, either explicitly as in USA or more implicitly as here in the United Kingdom. Such a right is also partially acknowledged in children although if the child or young person is not capable of making a reasoned decision then the parent or guardian may make the decision on their behalf. Some adults through mental disability (mental illness, mental