

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.)

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Autonomy and safeguards in people with impaired decision-making abilities

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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

handicap) have a diminished ability to make reasoned decisions. However, it is important to recognise that in any given situation there should be an assessment of the person's ability to make a reasoned decision and assumptions not made for convenience's sake. Even people with substantial intellectual impairment are capable of making some decisions.

The Law Commission's paper (1989) states that the law recognises the difference between incompetent and vulnerable people. It is not clear how valid or practical such a distinction is as many people who are competent will also be vulnerable. It may be more sensible to view competence as a continuous variable and that the person's ability to make a particular decision will be a function of his/her competence and the nature of the decision required.

A simple model can be postulated whereby one plots the person's decision-making ability against the complexity or importance of the decision, (See Fig. 1). The shaded area under the graph represents the times when one requires help in a particular decision. People with impaired decision-making abilities will clearly require more help with less complex problems than the average person.

The position with adults who have impaired decision-making abilities is less satisfactory because it is only partially addressed by separate pieces of legislation. This has led to various pressure groups calling for particular reforms but these reforms seem over-concerned with legal structures and are based on extreme cases.

Let us consider for example the case of Paul.

Paul is a 42-year-old man with Down's syndrome. He has a moderate mental handicap and lives at home with his parents. He also suffers from epilepsy for which he receives medication. The professionals who have assessed Paul's needs feel he would benefit from attending a local Resource Centre during the day, but his mother feels it is too risky and likes Paul to be at home some of the time in any case. His seizures are not particularly well controlled and doctors would like to assess this further by Paul staying for a short period in a home run by a Health Authority. The parents will not agree to Paul staying away from home. His parents make all decisions for him although occasionally Paul is able to make some decisions such as which tapes he would like to listen to. It is assumed that the parents have this responsibility and that this is not in any way able to be challenged despite evidence that some of their decisions may not be in his best interests.

Existing practice

The practice at the present time in this area is a mixture of *ad hoc* arrangements and pieces of legislation. Much of the legislation and recent discussion have centred around health-care decisions, for example consent for operations, even though for most people these represent only a small percentage of their total number of decisions they might make.

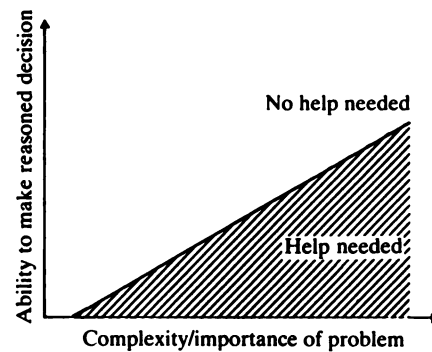


FIG. 1. Autonomy and safeguards in people with impaired decision-making abilities.

One can divide somewhat arbitrarily the different types of decisions:

(a) **Everyday decisions**

For most people with an impaired decision-making ability such everyday decisions are made by their carers. However, in recent years there has been a growing awareness of people's ability to make simple decisions, and encouragingly this happens more frequently. For many it is still the family who have continued to care for the disabled person but for others it is likely to be the paid carers of an organisation such as the Social Services Department, Health Authority, or voluntary body. There is no specific legal framework that covers this arrangement but assumptions are made that families and carers are able to make decisions on people's behalf.

(b) **More important decisions**

Many of these are likely to be taken by the carers on the person's behalf. However, it is more likely that a wider spectrum of professionals, lay people and family may be consulted before the decision is made than if it were an everyday decision. Such decisions are often brought up in client review meetings but again there is no specific legal framework.

(c) **Financial matters**

Those individuals claiming social security benefits or pensions and are still capable of managing their affairs can appoint agents to collect their benefits. The agent is not allowed to keep or spend the money without the consent of the claimant. Another person (often relative or paid carer) may apply to the DSS to become the nominated appointee to look after the benefit because the claimant is unable to do so.

The power of attorney arrangement can also be utilised but the person is required to be able to appoint the attorney – some people clearly cannot.

The power usually relates to financial matters but can be more general. The Enduring Powers of Attorney Act (1985) enables the power of attorney to be created which can survive any subsequent mental incapacity, although at the onset the person must still be capable of appointing the attorney.

The Court of Protection may take control of a person's financial matters if it is satisfied (medical evidence required) that the person cannot manage their own affairs. It often appoints a receiver but despite efforts to simplify procedures can still be complicated, costly and is usually only applied to those people who have substantial capital. Many disabled people are still poor and only have income from their state benefit.

(d) Consent to health treatment

It has been recently clarified (case of F; TvT, 1988) that no-one can consent to treatment except the adult themselves. There are exceptions to this under sections of the Mental Health Act (1983). Where treatment is required and not controversial the doctor usually obtains the agreement of the next of kin and/or usual carers, acting in the 'best interests of the patient'. In emergencies the doctor acts using the 'principle of necessity' as he can not usually obtain consent, as in the case of someone unconscious. However, as Bicknell (1989) has pointed out, it is still not uncommon for doctors to seek out long-lost relatives for consent form signatures, perpetuating at best an irrelevancy and at worst misguided paternalism. The recent case of F and sterilisation has highlighted all the prejudices and inadequacies of the law in dealing with such controversial treatments.

Existing legislation

There are three pieces of legislation which I would like to mention which have some input on decision making and safeguards for people with impaired decision-making abilities:

(a) Mental Health Act (1983)

The Mental Health Act (1983) concerns "the reception, care and treatment of mentally disordered patients, the management of their property and other related matters". There is an implication that people should only be under the act when it is absolutely necessary and for treatment. Even the guardianship order which attempts to provide a community orientation to care and treatment has substantial limitations. The definition of mental impairment requires the person to be both intellectually impaired and seriously socially irresponsible or abnormally aggressive. Thus some people would not fulfil both criteria. The guardian has fairly circumscribed powers – deciding where a person lives, ensuring

a person attends a place for medical treatment, occupational training or education and ensuring a doctor/other person can visit the person. There are no financial powers nor can they provide consent to treatment.

The Mental Health Act acknowledges it is designed for a small minority of people and not really a system of ensuring autonomy and safeguards for the majority of adults who have impaired decision making abilities.

(b) National Assistance Act (1948) and Amendment Act (1951)

Under Section 47 of the Act power is given to compulsorily remove aged and other persons to hospital or other institutions providing they are suffering from grave chronic disease or being aged, infirm or physically incapacitated, are living in insanitary conditions and unable to look after themselves and are not receiving proper care and attention from other persons. The specific criteria mean that it is rarely used and it is applied to extreme conditions usually concerning elderly people.

(c) Disabled Person's (Services, Consultation and Representation) Act (1986)

This Act addresses some of the issues I have raised and I discuss this in more detail later. It has only been partially implemented at the present time.

In summary, decisions are currently made in an *ad hoc* way without clear recourse to general principles. The existing legal principles are based on extreme cases and not ethically relevant to most ordinary situations. Thus while people have recognised the existing shortcomings and proposed solutions, these again have often relied on the extension of legislation based on extreme cases. The issue here then is that important ethical and social principles that affect all decisions are not being applied.

Future directions

Having described the present arrangements, I would like to consider how we might begin to provide a meaningful framework.

Principles

When considering services (and help in making decisions should be part of this) it is important to have an agreed set of values. Wolfensburger (1983) has put forward the Social Role Valorization theory and this has been taken up particularly vigorously for services for people with a mental handicap. He has argued that the major role of services is to provide opportunities for an individual to have a valued

social role in a society. This has been further elaborated by O'Brien (1987) who has detailed five essential accomplishments for services – community presence, choice, competence, respect and community participation. This then sets the framework for helping people to make choices and how it can be safeguarded. It is clear that those individuals who can make reasoned decisions should be allowed to do so – this has not been the case for many. For those whose ability is impaired, any decisions that are made need to take account of the outlined framework, as do the safeguards.

Legal and social framework

I would like now to consider how we might begin to build up a legal and social framework which would provide the basis of ensuring that people with impaired decision-making abilities are able to make decisions where possible and, where this is not so, that their interests can be safeguarded.

Advocacy

(a) Independent advocates

One such safeguard is to appoint an independent advocate who could enable a person with impaired decision-making to make a decision or if this is not possible to make the decision for them. The advocate may of course wish to consult with others, including family members and other professionals before coming to a decision. This is not unlike the proposed Guardianship Order of Mind/Mencap (Carson, 1987).

The Disabled Person (Services Consultation and Representation) Act (1986) has partly addressed the issue of representation and advocacy. A disabled person may appoint a representative or, if unable to do so, the local authority can appoint such a person. The representative has limited rights – to attend meetings, have access to information and visit the disabled person – but only in relation to local authority services. Such granting of powers to independent advocates is clearly not without dangers and it is important to safeguard the interests of the disabled person by ensuring that the local authority has the appropriate authority to intervene if it feels an advocate was not acting in the best interest of the person.

This requires that the legal changes be made to incorporate the extended power of the advocate and of the local authority to intervene. Such changes need to be carefully considered and applied – under which legislation this might be achieved is beyond the scope of this article but there does seem to be a case for it to be incorporated into the Disabled Persons Act (1986) rather than the Mental Health Act (1983). The use of

independent advocates in the United Kingdom has been patchy, but there is good evidence that it can work given the right conditions (Sang & O'Brien, 1984).

(b) Professional advocate

A further safeguard is the use of professional advocates. People acting in such a capacity are not uncommon at the present time although they may not be formally acknowledged as acting in that capacity. Such a role has been more recently promoted under the guise of case managers or resource coordinators – one of the key concepts in the Government Community Care (1989) proposals. It would be envisaged that the independent advocate would liaise closely with the professional advocate.

(c) Families

Families often find themselves in a double-bind situation – acting both as services providers (care etc.) and independent advocates. This can on occasions create difficulties where there is a conflict. Currently it is tacitly assumed that the family has primacy in making decisions for adults who have impaired decision-making abilities. This paradox exists despite the recent legal clarification that this is *not* the case. One possible safeguard is to ensure that there is a separation of service provision and independent representation. Thus if the family has a caring role this should be seen as a contractual agreement with the local authority and the independent representation devolved to another person who would have the responsibilities outlined in the section on independent advocacy. Families may feel this is an infringement on their rights but it should be remembered that the purpose of this exercise is to ensure that the disabled person has a valued lifestyle.

It is clearly necessary in some instances to delegate day to day decisions to the carers as it is impractical for the independent advocate to be there all the time. Such delegation should however be made explicit and not covertly assumed as it is at present.

Paid carers

The same principles apply to paid carers as was discussed with families. Again, day to day decisions should be delegated to them if it is appropriate.

Further safeguards

However well developed and systematic any system of safeguards purports to be, there will probably always need to be a fail-safe mechanism. Much of the current concern has been over how effective the current fail-safe provisions have been and where tragedies have ensued they soon reach the media

(Beverley Lewis case). A recent survey has estimated that between 4–5% of mentally handicapped adults are abused (Cooke, 1990).

The essence of the fail-safe mechanism is that someone (probably the local authority) should have the right to intervene if it feels the person is at risk and all other means have proved inadequate. Such powers would need to include the ability to remove the person to a place of safety until proper alternative provision can be made. The details of such a provision needs to be specified and also the mechanism.

This should only need to be used in a very small number of cases – if it is used more frequently it probably indicates a poorly developed system of safeguards. Whether it should be incorporated into the Disabled Persons Act or the Mental Health Act is debatable and probably of lesser importance than ensuring it is appropriately constructed and used. I personally favour using the Disabled Persons Act as this may have less stigma.

The effect of the proposed changes in how decisions would be made can be illustrated in returning to the case of Paul.

Paul would be allocated an independent advocate who would have responsibility for enabling him to make decisions and also to make them on his behalf when necessary. Everyday decisions would most likely be devolved to the parents and they would have a 'contract' or agreement with the local authority to provide the care for him. Thus the family's role has been clarified and their advocate role redefined. Such decisions about his health care (epilepsy) would be made by the advocate based on the advice of the professionals and the feelings of the family. Likewise the decision as to whether he should attend the day centre could be made in a similar way.

I would argue that the framework I have put forward is more likely to result in decisions being

made with and for Paul which result in a more valued lifestyle than he formerly enjoyed.

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