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CHAPTER TEN

The Background to the Ethical Grid

AN ANALOGY

The Ethical Grid is not a conveyer belt. It does not deliver correct answers in neat packages – rather it is like a gardener's spade. Like a good gardener, the proficient Grid user understands the importance of keeping her tool clean and sharp. Whether the implement is a spade or the Grid, and whether it is employed on soil or persons, the good worker will recognise when to use it. Sometimes conditions are unsuitable – the ground may be waterlogged, or the law or a social policy clear and agreed (though even in these cases it is worth trying the Grid out, to see what it reveals). Furthermore, the end results of even the most masterful use of either tool are never entirely predictable. Even with the most conscientious practice there is no guarantee that a particular digging method (and there is a range of options open to gardeners) will produce the desired horticultural results, and it is equally possible that even the most painstaking use of the Grid may not spawn the best practical results.

WHAT IS THE GRID AND HOW DOES IT WORK?

On referring to the figure of the complete Grid (Figure 30, on p. 209) the following features will be noticed:

1. There are four different layers to the Grid, indicated by different colours (blue, red, green, and black).
2. Each of the boxes, whatever its colour, is self-contained and detachable.
3. The Grid can be seen in more than one way. It is possible to use it as if the coloured layers have to be addressed in a set order. For instance, a user might think the most significant principles are those contained in the blue boxes at the centre of the Grid, and that the outer boxes are of decreasing importance as one steps (or spirals if that is the preferred method) to the outer limit of the Grid. But this use is not necessarily always the most appropriate.

   Alternatively a user might follow a spiral running from the outer limit of the Grid into the blue core, or might always begin with a consideration of consequences, or might always consider – as a start – four specific boxes, one taken from each coloured layer.

The Grid can also be seen as either a two- or three-dimensional object. If it is envisaged in three dimensions the four sides of the pyramid might be considered in turn. However, there is no special relationship or association between the boxes on each side.

Even if the Grid is seen in two dimensions it need not remain static on the page. It can be flexible in the user's imagination. For instance, it is possible to imagine an invisible cord at its centre which can pull the Grid (as if written on a piece of rubber) either towards or away from the viewer. The direction of the pull will depend upon the importance a user wishes to accord to the various layers. In this way the Grid can remain in view and in mind as a whole, though it should be noted that this use has less pliancy than regarding each box as detachable.

4. The Grid has to be applied to practical cases for it to come to life.

WHY IS THE GRID COMPOSED OF DIFFERENT COLOURED LAYERS?

First of all it must be explained that the Grid is an artificial device, and the separation of boxes into apparently airtight compartments is also artificial. Nor is it suggested that the Ethical Grid is an exact representation of the mental processes that make up moral reasoning, which is by no means as precise a process as the Grid might make it appear. However, in order to provide health workers with a practical and accessible route into moral reasoning, the layers have been distinguished by the use of colour. Given time and experience it ought not be necessary to refer to the Grid at all – it is certainly not a substitute for moral reasoning. Yet even the most seasoned moral thinker might find it useful to refer back to the Grid from time to time, to remind herself of the elements that should be part of a thorough deliberation.

The Grid is presented in four layers to show that at least four aspects are necessary to comprehensive ethical analysis. A deliberation which examines only the consequences of actions, or only the law, or only duties might happen to produce good results, but it will not have been carried through with integrity. Furthermore, *health work deliberations should, if the resulting actions are to be health work at all, refer to at least one box from the blue layer.*

It is not suggested that before every intervention the health worker pulls out his 'pocket Ethical Grid' and selects boxes until he is satisfied he has the right combination. This would be quite impractical. Nor is it claimed that the Grid is an indispensable advance in ethical reasoning. But it does make some of the processes of moral reasoning clearer for those unfamiliar with this way of thinking, and as such it is an aid both to understanding and to confidence. The thoughtful health worker can first become familiar with the Grid and its use by practising on hypothetical cases, and then by applying it to cases in practice where there is sufficient time. Proficiency in moral reasoning will improve with practice.

The Ethical Grid has been constructed with health professionals in mind, but it could also be used by people who are not paid to work for health. Work for health in its richest sense is work every member of a society can be involved in.

THE BLUE LAYER

The blue layer (Figure 26, on p. 204) is set at the centre of the Grid because it is its core rationale. Its four boxes represent – in the most basic manner – the key components of the foundations theory of health.[1,5] The Ethical Grid should be seen as a practical manifestation of this theory.

CREATE AUTONOMY

What is Autonomy? (brief answer)

Why is the creation of autonomy a central part of work for health? This question may be answered quickly in two complementary ways: by focusing on practical tradition, and by studying other theories of health.

The Historical Tradition

Whatever the means, whether through a personal regime of living or a medical and health professional intervention, practical work for health has always been carried out with the intention of creating autonomy. If treatments are not designed with this end in mind there is little point in making them at all.

A broken arm is a physical impediment to autonomy, and also an obstacle to biological development. Unless it is excruciatingly painful a broken arm does not undermine autonomy completely – a wide range of choices and possibilities will often remain – but it does restrict personal possibility to a degree. An intervention to mend a broken arm is obviously carried out in order to remove the obstacle to normal biological development, but this is not the only reason; it is also carried out in order to enable the person to move on in life without the obstacle. In other words the health intervention is done in order to allow a person the maximum degree of autonomy. The whole point of humane treatment is to enable full persons to flourish as much as possible.

The principle of autonomy has, as a matter of fact, always inspired health work.

All Plausible Theories of Health Equate Work for Health, in Some Way, with the Creation of Autonomy

In a previous work[1] a variety of theories of health are presented and discussed. Among the most influential are: the theory that health is an ideal state, the theory that a person is healthy if she can function in a socially useful role, the theory that health can be bought or given as if it is a commodity, and the theory that health is an ability or strength to adapt to the changing challenges and circumstances of life. Though these theories do not share a common view of health, each makes good sense up to a point – and each incorporates the idea of autonomy to some degree. For instance, the World Health Organisation's 'ideal state' is one in which a person is physically, mentally, and socially well, has a satisfying life, and can be economically productive – all notions which require a good level of autonomy. Autonomy is obviously required to carry out a socially useful role (although the level needed will vary dependent upon the role and the society), and the giving or selling of medical commodities – though done for a variety of reasons – is nevertheless valuable in direct proportion to the increased autonomy brought about in the receivers or purchasers of the commodities. Finally, the ability to adapt to life's changing circumstances is actually a general definition of autonomy, according to which health just is personal autonomy, and work for health the creation of an ability to thrive (or at least persevere) whatever trauma is suffered.

(Note: readers who wish to learn the content of the other three blue boxes and the remaining layers of the Ethical Grid directly, should turn to p. 202. But for a detailed, practical account of the importance of autonomy, read on.)

What is Autonomy? (detailed answer)

Several ethical principles have been hailed as health care's primary inspiration. 'Being just', 'not doing harm', and 'doing positive good' are all candidates.[77] At times each can assume temporary precedence over competing notions, even when some forms of autonomy are at stake. For example, when a resource is scarce not all 'autonomy claims' can be met and just distribution must be the priority. Nevertheless, autonomy is the pivotal health care notion.

Autonomy is Basic to Health Care

To say autonomy has no importance in health care is a contradiction in terms:

1. Under Western law consent is essential in any health care intervention which involves touching a competent person. Without consent, touching is a civil or criminal offence. In order for a person to consent to an operation he must have sufficient knowledge to understand the implications of what is proposed. To put it another way, his level of autonomy must be sufficient to give him command of the decision.
2. There is no difference in kind between the problem of disease and other problems of life – there is difference of degree only. All problems affect an individual's autonomy – when a person has a problem her autonomy is lessened by definition, at least in the part of her life where the problem exists. Because disease is not radically different from other problems, health workers have no special obligation or right to fight it. Any justification of work against disease must refer to the creation of autonomy, since this is fundamental.
3. Work for health is work to liberate enhancing human potentials. This enhancement is necessarily the creation of autonomy. Health work can diminish only when this diminishing avoids worse harms.
4. Unless an arbitrary distinction is made between physical and mental mobility, if autonomy is a priority then physical and mental autonomy matter equally.

These four points make most sense once a distinction between different understandings of autonomy is grasped. There is Understanding A – *autonomy as being able to do* – and Understanding B – *autonomy as being able to have one's expressed wants*. These categories are explained during the course of this section.

Autonomy is not health work's only inspiration. In complicated situations extensive deliberation is required (the Ethical Grid is meant to support precisely this). However, interventions which make no attempt to increase autonomy are not health work.[78]

THE RICHNESS OF AUTONOMY

In most medical ethics literature an 'autonomous person' is said to be 'self-determining' – to have control of her destiny. Autonomy is taken to involve personal wants – an autonomous person can determine what she desires and if her autonomy is respected no one will stand in her way. But this is Understanding B only. It fails to grasp the depth of autonomy's meaning.

There are at least three different ways of thinking about autonomy.

AUTONOMY AS A SINGLE PRINCIPLE

On this understanding autonomy is a principle that 'the wishes of individuals ought to be respected'. Critics of the use of this principle[79] point out that 'autonomy is not the only ethical imperative'. Such commentators are quite correct to say that in some circumstances other considerations take precedence over the desires of individuals (for instance, if a person has irrational desires, or if his desires will cause avoidable harm to others) but wrong to believe they have therefore exposed the limitations of the concept. They have not, because autonomy should be thought of more broadly.

The mistaken devaluation of autonomy is common within the pages of some medical journals, particularly in papers on 'ethics in medicine' by doctors who lack philosophical education. For example, a paper in the *Journal of the Royal College of General Practitioners*[80] asked doctors to say what they would do in brief vignettes about control of information in 'unhealthy lifestyle'. The authors chose to offer 'patient welfare' and 'patient autonomy' as contrasting reasons for action. But by separating welfare and autonomy like this the authors assume 'autonomy' means nothing more than 'patient control of decision-making'. If so the only question is: does the principle of autonomy apply in this case, or is it better that the doctor decides? Not only is this a very crude representation of clinical reality (where education, conversation, coercion, guilt and recrimination often subtly combine) but it reflects little of autonomy's real meaning. In fact, as we shall see, concern for patient welfare is itself a central part of autonomy creation.

AUTONOMY AS A RIGHT

The view that autonomy is a principle has led many writers to claim that autonomy is a right. To assert the right to autonomy is to declare that people capable of self-determination ought not be manipulated, even if others believe this is in their best interest. This is a plausible view of autonomy, but again it is too simple. It regards autonomy as a single type of thing (like life or property – which you either have or have not) which everyone – apart from those whose thought processes are disabled for one reason or another – should have.

This makes perfect fighting sense where people are repressed, where human beings are not allowed self-determination and creative self-expression, and where they might be freed. In such cases to speak of the right to autonomy can be a powerful and emotive weapon. In these circumstances one might justly scream – these people have a right to autonomy! But although this may be politically effective it is impossible to demonstrate that moral rights exist. We have many legal rights, but laws are invented. No one can show conclusively that 'human rights' exist in any form other than human convention. We do not have an objective right to life, we merely have life. Despite volumes of writing on the subject,[81] to cast argument for change in rights language is philosophically unhelpful. To speak of autonomy as a right is to do nothing more than to say 'I believe that the human ability to choose should be acknowledged and personal choices respected'. However often this is said, and by however many people, autonomy does not move one jot nearer to becoming an objective right. To speak of autonomy as if it is a right is to perpetuate the myth that autonomy is a single state and something that can be attained or ceded.

AUTONOMY AS A QUALITY

Autonomy is essentially a quality, not a disembodied principle or a right partially separate from human beings. It is utterly wrong to think of autonomy as something that is entirely lost if a right to choose is denied.

Rather autonomy is an intrinsic personal quality. At its most basic, *to be autonomous is to be able to do – to be able to do anything rather than nothing*. Autonomy, thought of in this way, is a matter of degree – the better the quality of the autonomy the more a person is able to do. A person becomes able to move more extensively in her life as her level of autonomy rises.

This view of autonomy is more complicated than the other versions, and requires detailed explanation. The remainder of this chapter is devoted to this task. By thinking of autonomy as a quality it is possible to move forward on several fronts. It becomes possible to:

1. Make a clear distinction between *creating autonomy* and *respecting autonomy*.
2. Show conclusively that respecting autonomy in the sense of 'agreeing to the wishes of others' (a derivative of Understanding B) is a weak idea without reference to the creation or increase of autonomy (Understanding A). When autonomy is conceived of as a basic quality essential to human dignity, which can be enhanced or diminished dependent upon what happens to or is done to people, then work to increase autonomy becomes work to raise the level of human possibility. More prosaically, in a medical context it may be that a doctor considers he is abiding by the principle of autonomy and respecting a patient's right to autonomy in full so long as he is neutral and does not place undue influence upon him. It is not uncommon to hear doctors argue that a *laissez-faire* approach shows sufficient regard for autonomy – 'the main thing is to let the patient make up her own mind'

and 'it's not always up to me to tell the patient everything about his condition – if he wants to know he will ask'. But without additional help this may not be enough – the patient may not have a high enough level of autonomy. Her autonomy may not yet be of a quality good enough to enable her to exercise a reasoned choice.

Indeed, if doctors think respecting autonomy merely means saying 'over to you' whenever there are hard clinical decisions to be taken, they have things badly wrong. Superficially it may seem as if a patient's 'right' to exercise the 'principle' is respected if she is left alone to decide to have treatment or not. Certainly she will not be under pressure to do what clinicians would like, but without advice, support and education – and especially if she is upset and anxious – she may have little or no autonomy to exercise.

3. List ways of enhancing autonomy and contrast these to diminishings or constrainings. In this regard it is important to recognise that the quality of autonomy can be improved or worsened by factors internal to a person – factors at least partly within the power of individuals – and also by external factors.
4. Demonstrate that in health work there is a crucial point at which efforts to create autonomy (Understanding A) – efforts to improve the quality of a person's autonomy by trying to enhance what that person is able to do – become secondary to a duty to respect autonomy in the sense urged by talk of principles and rights (Understanding B). It can be shown that an *autonomy flip* can occur, where work to create autonomy must give way to respect for autonomy.
5. Begin to consider solutions to a seemingly intractable dilemma. This occurs whenever it is felt more important to provide for a person's welfare (creating autonomy in line with Understanding A) than to respond to a person's expressed wants (respecting autonomy in line with Understanding B). One trivial example of this dilemma occurs when a decision is made to deny fat children sticky buns even though they want them. A perhaps more serious example confronts doctors who work with people who experience problems with illicit drug use. Should doctors provide the drugs cheaply and safely – which is what many drug users want – or should they insist on detoxification out of concern for their welfare? Which policy has most regard for autonomy?

(Note: It is true to say that if it is argued that autonomy is a quality, and that this quality ought to be increased, then this belief could be translated into a principle. Equally, if health workers have a duty to enhance this quality in others, then it might be argued that this implies a right to have one's autonomy increased.

The first suggestion is undoubtedly true – we create principles and there is no reason why we should not create this one. However, we must remember that the principle is not a thing in itself but originates from admiration of a complex human quality.

The second recommendation is a little more complicated. If it is meant to imply an objective right, then it is wrong. The duty to create autonomy stems from health workers' decisions to commit to work for health, and does not exist before this pledge. Furthermore, a health worker does not have an indefinite duty to create autonomy, but is limited by her understanding of health. No one has an absolute right to have her autonomy increased.)

AUTONOMY AS A HUMAN QUALITY

The view that autonomy is a human quality stems from the foundations theory of health,[1,5] according to which work for health is supposed to remove obstacles in the way of human potential. Not all of these can be eliminated by cutting away. Some can be removed only through the provision of something else. For instance, ignorance is an obstacle that can be remedied only by giving information. Work for health, thought of in this sense, is work to enable, work to provide a stage on which to perform. The greater a person's stage the more movement in life she will have.

This view of health must explain autonomy as a quality. Because health is directly related to the freedom of body and mind, and not necessarily associated with freedom from disease and illness, autonomy does not just mean the ability of a person to command her physicians. According to the foundations theory of health autonomy makes full sense only when it means being able to do in the widest sense.

There are degrees of autonomy as a quality – it is not something one either has or has not – and it is a complex notion. A person may be highly autonomous in some respects and incompetent in others. Autonomy is not, however, necessarily related to the amount of options available. Much depends upon context. A physically disabled child living in poverty with an uncaring family – a child living in conditions which disadvantage him on top of his handicap – will have a lower level of autonomy than a physically fit, loved, exceptionally talented Eton schoolboy. However it does not always follow that wealth, age, or fitness are connected to levels of autonomy. For example, a 5-year-old child will not have the same range of options as a 30-year-old middle-class insurance executive – he will not usually be able to do as much as freely – but the child will still be able to exert some control in the aspects of his life which matter most to him. For instance, he will probably be able to choose which toys he plays with, and which books he reads – within a range of options. Realistically, taking account of the different contexts of the two people, their levels of autonomy – the quality of what they might do – can be said to be roughly equivalent.

Whoever we are, whatever circumstances we live under, we are all (unless permanently comatose) able to do some things – able to move freely in some areas of life – and constrained in other aspects. These constraints can be internal to us (for example, limit of talent, limit of willpower) or external (for example, restrictions created by the desires of others, or no resources to allow us to travel widely).

Thus it makes good sense to see autonomy as the ability to do, a quality almost all of us possess to some degree, and a quality which can frequently be enhanced in a great range of ways. This insight shows it is possible to work to increase autonomy without having to be a docile pawn in the game of another person. It is possible to work for autonomy in this broad sense without always having to do what another person requests. And this turns out to be a very important distinction.

Creating autonomy – enhancing the human quality of doing – is basic to health care. It is possible to represent the basic ground of work for autonomy in this way. Autonomy increases as a person moves towards the right of the spectrum.

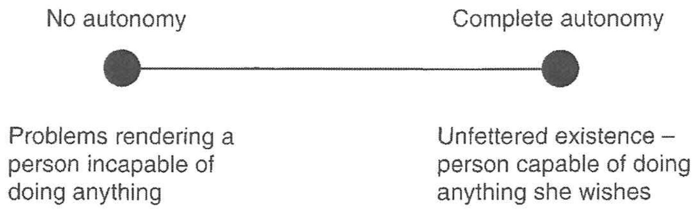

Figure 24 The basic autonomy spectrum

Work to create autonomy does not necessarily imply obedience to patient choice. It is true to say that the creation of choice is a primary goal, but in many cases work can be undertaken to create autonomy without direct reference to it. For example, it may be that a nurse believes a person's depression might be alleviated by a change in his social life. To a withdrawn and lethargic person such a change might not seem at all desirable. However, if the nurse feels change in the person's social life is genuinely worth trying (and the nurse would need to be able to point to evidence to support her proposal) then, in order to create autonomy, she would be justified in a range of attempts to involve the patient in group activity. Although the nurse would not be respecting personal choice immediately, her intent would be to enable the patient to do more, to be freer from the grip of his depression. Hand in hand with the achievement of this goal the patient would gain a higher level of choice. This is not to say that a health worker can force a person to do something against her expressed wishes, but if there is ambivalence then she may seek to create autonomy – but only with the specific aim of moving the person to a position where she is able to exercise a more fully reasoned choice (a choice free from depression in this case). The judgement about the point at which respecting autonomy (Understanding B) must take precedence over creating autonomy (Understanding A) is neither easy nor precisely measurable. Inevitably there will be a grey area in which there will be controversy about whether or not the autonomy flip (see p. 192) has occurred. It is unlikely any foolproof method exists to assist in this judgement, though the Autonomy Test outlined later in this section can provide some practical help.

In some cases, in cases where a person is severely mentally handicapped, or where a patient is suffering from a mentally disabling illness, the notion of respect for autonomy may have no part to play. However, this does not mean that the issue of autonomy disappears (as the standard medical ethics account has it). On the contrary, autonomy remains as important as ever. Such a degree of handicap means that a person's life will be subject to some very severe constraints – that the person's autonomy will be of poor quality. But if anything in these cases there is all the more reason to seek avenues which enable the person, even within the severe restrictions of circumstance which surround him. When there is very little of a good thing even the smallest addition can be precious.

In many cases there is a clear relationship between the creation of and respect for autonomy. For instance, it is not possible for a person to express a free wish unless she knows what her situation is, unless she knows the possibilities open to her. So if there are three types of surgery available, and the patient thinks there is only one, she may opt for it, but she will have done so with a lower level of autonomy than she might have had. In this way creating autonomy (as enabling mental doing) can be a prerequisite for respecting autonomy (conforming with informed requests).

The fact that wishing depends upon the achievement of a certain level of being able to do – on the provision of certain conditions both for life movement and choice – is even clearer in some other cases. For example, take the case of a frightened, anxious person entering hospital to discuss a future operation. It is possible to be in such a state of nervousness that one cannot think straight. The person may not even be able to comprehend realistically what is being said to him, never mind formulate a coherent view about what to do about his clinical problem. He may, after meeting the consultant in charge, agree to a particular procedure, but since he has not been able to think properly it makes very little sense to say this is what he wants. In order to have any autonomy (on Understanding B) to respect, autonomy (as being able to do – Understanding A) must be raised to a sufficient level. Looked at with reference to the continuum illustrated in Figure 24, the primary task of the health worker is to ensure that the anxious patient moves from A to B on the spectrum (Figure 25).

As a general guide, the impetus of all health care interventions should be first to try to move a person as far to the right of the spectrum as possible, and secondly to move a person past point B on the spectrum at the earliest possible opportunity. Although the exact position of point B is bound to be the subject of some controversy, and must be decided with reference to the particular facts of the case, this does not invalidate the guiding idea.

It must be said that not all health professionals think of their work like this. Those who do not are not working for health on the foundations theory. It is, to be sure, easier and often more efficient not to work as the first priority to move a person from A to B. For one thing the attempt is likely to be time-consuming. But if autonomy is seriously considered an essential goal of work for health, the effort must be made.

TWO CASES

Consider the following two cases. Both involve consent, although in subtly different ways. Consent might be defined as an expressed agreement to a procedure based on a level of information which would be sufficient to satisfy the giver of that information if he were to be on the receiving end. Bear in mind that consent must be based ultimately in autonomy as ability to do. That is, a person must already be at a certain point – past point B – on the autonomy spectrum to be able to give a consent.

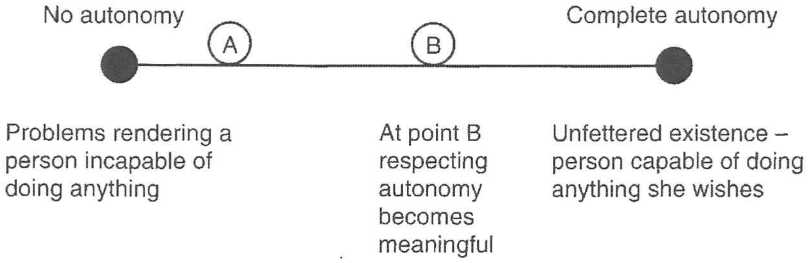

Figure 25 The autonomy spectrum indicating a point of 'autonomy flip'

19. CAROLE

Think about Carole, an unemployed, unhappy young woman. She is living in an apparently close middle-class family, which has profound tensions below the surface. Her father is terminally ill.

Carole's behaviour consists of intermittent lethargy, drunkenness and rebellion – but overall she is catastrophically miserable. She gets in trouble with the law, caught shoplifting a skirt from Marks & Spencer. Carole's parents decide enough is enough, and she is persuaded to see a psychiatrist, who makes a diagnosis but does not tell Carole or her parents what it is. All he will say is that she has an emotional problem she can be helped with. After a couple of weeks in hospital as a 'voluntary patient' Carole is treated as an outpatient. She is given an injection of a long lasting anti-psychotic drug (Modecate) and also another drug (Kemadrin – procyclidine) to counteract possible 'Parkinsonian side-effects'. She is not told what to expect by either the doctor or the nurse who administers the injection.

There are two key issues to consider in this case. *Does Carole give meaningful consent to her treatment, and in which direction is she moved along the autonomy spectrum?* These questions are crucial in the great majority of health care interventions. Before considering answers in Carole's case consider a little more detail. She is having many difficulties in her life, and clearly at a low ebb. Carole is immensely vulnerable. She is blamed by her family and some of her friends for causing most of her troubles – 'Everybody has problems, why does it always have to be you who over-reacts and makes things even worse?' For her own part she blames herself entirely for her calamity.

Carole desperately wants to be happier, to resolve this situation in which she is drowning. She is an intelligent young woman but drifted away from school before taking her final exams – for which she had not worked anyway. Carole has not studied or read anything other than the tabloid newspapers for the last three years: she can't be bothered to read anything else, she can't concentrate and can't see the relevance of any of it to her.

Carole becomes a 'voluntary patient' because she sees it as a way out. She has to do something to get out of the hole and she doesn't have many options left. In addition the pressure placed on her by her family is becoming ever more unbearable. She says she agrees to the drug treatment but she has very little idea what it will do to her, indeed whether it will benefit her in any way (although she knows the demonstration of compliance with her family's wishes might).

The point of this example is not to criticise psychiatry (although something very close to this situation actually happened, culminating in a bemused young person breaking out of a mental hospital through a kitchen window – to escape only to pass out and wake up in the early hours covered in frost) but to show how lack of a theory of health can diminish autonomy. There were clearly many other ways in which Carole's life might have been enhanced, even if the diagnosis had been correct. When disease, or at least perceived disease, is regarded as the priority, above other problems which might receive attention, then it is inevitable that other ways of improving a person's life will neither be spotted nor pursued.

20. EVELYN

The next example is again taken directly from life. It is discussed towards the end of this chapter and presented now as an exercise for self- or group-learning.

RESEARCH FOR HEALTH?

This case is based on the experience of Evelyn Thomas. Her words have been extracted from an article which appeared in the *Observer* (UK). The reports of the feeling and motivation of the chief researcher are imaginary. The justification offered by the actual researcher can be found elsewhere.[82]

This exercise describes the feelings of two characters. The situation is that a woman who has had a mastectomy has discovered that she has been involved in clinical trials without her consent. The *first trial*, which took place simultaneously in different centres around Britain, involved the testing of preventive hormonal treatment. Evelyn's treatment was compared with that of other women cancer sufferers who were receiving either no further treatment or different drugs.

The *second trial* was to test the effects of post-operative counselling. Evelyn was not counselled yet other patients were. Their 'psychological adjustment' was compared.

We might call the doctor Alan Hughes since the position for which he argues is not unique to the researcher in question. The view advanced below is a paraphrased amalgam of the beliefs of several doctors. It is not intended to represent accurately the opinion of the Professor in real life.

DR HUGHES explains:

'I have been a clinical researcher and consultant surgeon for over 20 years now, and been in medicine for 10 years before that. My experience allows me to balance, in the broadest perspective, long-term human gain against possible short-term individual suffering. I would emphasise my choice of the word "possible". The whole point of research is that the answer is not known. It may turn out that the subject of a controlled trial might have benefited more from a treatment from which she was excluded, but equally she might not have done. We simply do not know for sure, which is why we need to experiment.

'I know that this patient, and you could say the same of others in the past, feels hurt and perhaps abused by what I have done, but I stand by my actions and refuse to change my practice. If this patient had been informed that she was in either trial it would have rendered her inclusion scientifically invalid. We do not know the precise relationship between mental state and physical well-being, and this might have affected our results. This is particularly obvious in the case of the post-operative counselling. We were searching for very specific information, and only this information. This made it necessary for us to control as many variables as possible.

'I think there are three main points to consider here: first of all each research proposal has to be passed – approved – by an ethics committee. These are committees made up of highly experienced, eminent, honourable people. Ethics committees make sure that no research proposal which is at all unethical is passed. They did not consider that I needed consent for my research because they weighed up the costs and benefits, and appreciated the considerable amount of good that potentially could be achieved by the work.

'This raises the second point: if clinical research is permitted only if patients are informed, then we would not have the benefit of many scientific advances. It is vital that we advance our scientific understanding for the benefit of all future patients, and any one of us might be future patients. It must also be said that most people included in research trials do not suffer. In this case no worse treatment was given to the patient. We believed that both drug treatments were roughly equivalent.

continues

continued

'As for the counselling trial, the patient received the highest standard of care possible from our doctors and nursing staff. It is true to say that she did not receive this particular form of intervention – but at the time we had no idea whether she would benefit from it or find it to her disadvantage. In any case different people respond in different ways to all forms of medical treatment: medicine is the most uncertain of all sciences – there are always exceptions to all forms of treatment, always people who recover when they seem to have no chance of doing so.

'It is also very pertinent to consider what it means to be working at this level in medicine. I cannot just sit still and rest on my laurels. I have to achieve, I have to compete. Some of my younger colleagues – men still in their forties – have published over 300 scientific papers and I have just over 150. I am ambitious and it is expected of me – it is an integral part of the profession that I am involved in. It is unrealistic to expect me to stop doing what so many of my peers are doing: it is part of the profession. Why should I challenge this practice, especially since I regard it to be morally quite justified?'

Evelyn Thomas explains her point of view. These are her own words as reported in the *Observer*:

'When I was found to have breast cancer I had high expectations of the medical profession. Like most patients I believed the doctors observed strict ethical codes. I placed absolute trust in those treating me and assumed that our relationship was based on openness and frankness. I assumed that my treatment was the only option.

'I now know that I assumed too much. Patients with breast cancer presenting themselves to my surgeon in the early 1980s had their treatment determined, without their consent, by computer randomisation. My consultant's role was to diagnose, establish eligibility for entry into clinical trials, withhold information, ensure randomisation and thereafter monitor progress. My rights to have information and to choose, and my responsibility for my own body were denied. My trust was abused. I am both deeply hurt and bitterly disappointed to have been so misused by members of the medical profession.

'In retrospect, the first indication that I was in a trial came a few days after my mastectomy. The mastectomy patient in the next bed had been seen by a counsellor and given helpful information. The counsellor avoided me, and a breast prosthesis was given to me by a male fitter more used to fitting artificial limbs.

'It took several years to obtain confirmation that I had been in a trial. The first trial compared post-operative counselling with no counselling; the availability of counselling was not mentioned to those randomised not to receive it.

'The second trial compared three chemotherapy regimes and no treatment; the regimes were tamoxifen tablets, cyclophosphamide injections and a combination of both. Patients were again randomised – to one of the four choices – without any alternative being offered.

'The administrators at the hospital had confirmed that I was entered into these two trials without my knowledge. Since a trial of lumpectomy versus mastectomy was also in progress at that time I suspect that I may have been in that trial since I was offered no alternative to mastectomy.

'I believe that these trials were wrong for several reasons. At the very least they were unkind. It is unkind not to offer available alternatives to total breast amputation; it is unkind not to offer available counselling to all patients following breast surgery; and it is unkind not to offer to patients an alternative to cyclophosphamide with its side-effect of hair loss that is dreaded.

'Withholding information about the trials may also have invalidated them. It was forgotten that patients, unlike laboratory animals, can move around and communicate

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with each other. Treatments are discussed and unexplained differences discovered. Inevitably these cause worry, and patients may become confused and resentful. Such feelings, and the stress produced, may be the very factors which affect health and well-being . . .

'Secret trials demean patients. By depriving patients of opportunities to make informed choices, doctors appear to assume that we are unintelligent, immature and irresponsible.

'Finally, I believe that such trials are unethical. I agree with the principles laid down in the Nuremburg Code for experiments on humans, which state that "the voluntary consent of the human subject is absolutely essential" and that the person involved "should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understood and enlightened decision".

'Some doctors violate these ethical principles. They argue that patients cannot cope with full knowledge of their disease or uncertainties in its treatment, so that it is kinder to say nothing. Such arguments are wrong, because it is the patient or family who has to cope with an incurable and progressive disease.

'I am not arguing against scientific medical research or randomised clinical trials (RCTs). As a patient I have the most to gain from progress. As a scientist who has herself carried out physiological research on human subjects, obviously I approve of scientific methods in medicine. But RCTs must only be used with the informed consent of the participating patients. If investigators cannot convince patients that each arm of an RCT carries equal chance of risks or benefits then they must respect those patients' decisions not to participate.

'My experience shows that doctors can no longer assume that secrecy in their dealings with patients can remain undetected. Yet once I did start asking questions of my consultant and hospital, the response continued to be secretive. Relevant questions about my treatment have been met with prevarication and half-truths. Approaches to various organisations such as the Community Health Council and the General Medical Council have produced little progress in getting the information, explanation and discussion that I sought. Indeed the only advice offered by the President of the GMC was that I should take legal action – a sorry reflection on the body that has a statutory duty to control the conduct of doctors.

'It is good practice for such trials to be authorised before they start by the hospital's ethical committee, to see whether they are ethically acceptable. The existence of these secret trials therefore raises awkward questions about the committee's role. A letter I received last year from an administrator at the hospital said that informed consent had initially been required for the comparative trial of chemotherapy, but that after a few months the ethical committee had changed its mind. The administrator explained why:

> The reasons for this decision were that the study was being carried out on a National and European level and that other participants on the trial had not felt it appropriate to seek informed consent because of the specifically humane treatment offered in each of the arms of the study. More importantly, the experience nationally and locally was that many patients found it intensely stressful to have to face up to not only consenting to mastectomy but very shortly afterwards to have to consider the true nature of their disease and the uncertainty surrounding its management. The decision-making involved in getting informed consent was considered harmful for the welfare of some patients.

'Such reasons are not adequate to explain why the ethical committee chose to ignore the Nuremburg Code and many subsequent guidelines on the ethical conduct of research.'

Evelyn Thomas's argument was first published anonymously by the *Bulletin of the Institute of Medical Ethics.*

EXERCISE

Either imagine that you are Doctor Hughes – and that you have read Evelyn's account – and a junior colleague asks you to lead a new research project which requires the diseased patients to be ignorant that they are subjects of research.

Or imagine that you are Evelyn and the information has been leaked to you by a sympathetic hospital worker that the research has been proposed, and that it has been put to Dr Hughes that he might like to become involved in it.

Where might Dr Hughes picture himself within the Rings?

Imagine that the doctor and Evelyn both know how to use the Ethical Grid. Imagine a conversation between the two, with the Grid on a table between them. How do you think the discussion would go?

MISUNDERSTANDING THE IMPORTANCE OF AUTONOMY

The above example shows a doctor placing other values above both the promotion of individual autonomy and respect for choice. There is little question that the motives of researchers in such cases are complex, and often honourable in that the work is directed towards a general increase of human good. But their research is misguided because the importance of autonomy is underestimated.

In the example the researchers place the notions of not causing harm (referring to the stress that might be caused to patients by asking them if they consent to being in a medical experiment), patient welfare (in the sense of not unnecessarily impeding the attempted clinical cure), and the well-being of future patients (who will presumably be helped by advances in the understanding of drug therapies) above that of autonomy (understood in either way). But while it is right to say that autonomy should not always be the primary health care drive, it should not be overridden so lightly. However politically pleasing many might find the view that medicine should work essentially with communities it remains a fact that individuals suffer the disabling problems we call diseases, and that a doctor works most closely with individual patients. Consideration of patient autonomy (in the broadest sense) must always be the starting point for interventions which seek to work for health.

This was obviously not the case in the above example. Three further errors were committed by the medical professor. Briefly, the first was to think of autonomy as a single principle, the second was to commit a category mistake (wrongly supposing that work for health is the natural concomitant of work to counter disease), and the third was to have left Evelyn at a point unnecessarily near the left of the autonomy spectrum when he might – without harm to anybody else – have moved her further to the right. The professor was not working for health in this case. No genuine health work can regard people only as means, even if they are thought to be means towards greater ends.

THE AUTONOMY FLIP

Before the Autonomy Test is outlined it is important to consider how the notions create and respect autonomy might be ranked in order to guide practical interventions.

RANKING IDEAS WITHIN AUTONOMY

By attempting to rank these two ideas, an apparently unyielding health care dilemma is again brought to the fore. It is this: to what extent should a person's welfare (autonomy as 'being able to do' – Understanding A) take precedence over a person's wants (autonomy as 'being able to have one's choices' – Understanding B)?

Should welfare ever take precedence over wants? All experienced health carers will be familiar with the frustration of watching a person do something to himself which the health carer thinks is foolish, or tragic, or just 'bloody stupid'. Perhaps the person is eating too much or too little, smoking, drinking, engaging in unprotected sex with several partners or injecting heroin. If the person is indulging in any of these habits, a concerned health carer might well consider that this is not good for him – that it cannot possibly be in his interest even though he thinks it is. Understandably a health worker might think it his task to ensure the person changes his ways.

In such cases there can be a strong temptation for some doctors to be paternalistic – in other words for doctors to give their perception of the person's welfare (often referred to as 'health') a higher priority than his choice.

Such a policy assumes this ranking of the two notions of autonomy:

FIRST: CREATE AUTONOMY

SECOND: RESPECT AUTONOMY

The expression create autonomy refers to basic work to enable a person (Understanding A), to work to provide adequate conditions of welfare – conditions for a way of life where a person is able to realise fulfilling possibilities. For instance, educating a person about the effect of medication on her body, and ensuring that an extremely stressed person takes a rest, are both actions which would qualify as work to create autonomy.

Create autonomy ought to take precedence over respect autonomy when a person clearly faces disabling problems, and makes no objection to the health worker addressing these problems. However, at a point which varies – dependent upon circumstances and the individuals concerned – the two notions 'flip over' like this:

FIRST: RESPECT AUTONOMY

SECOND: CREATE AUTONOMY

The ultimate aim of work to create autonomy is to move a person to a position where she is so unfettered that she is able to exercise an informed choice about what she would like, and be able to get it. It should be self-evident that:

> Education for health is work for wholeness. It is not just to do with physical functioning, it is at least equally to do with the mental life of a person . . . work for health in its full and proper sense is work towards laying the foundations for full human flourishing.[1]

Human beings are distinguished from most animals by our facility to think – to reflect, to introspect, to plan our actions. Not to pay particular attention to this human asset when working for health is absurd.

The central ethical problem in health care occurs when a carer wants to carry on creating autonomy (as welfare) while the subject believes he has reached a level of autonomy sufficient to permit a reasoned choice, and wants his autonomy respected. This may mean that the subject wishes to have further autonomy created, but in a way unacceptable to the health worker.

Consider a case from practice. Take the example of a person said to be 'abusing heroin'. While create autonomy is ranked first, the health worker can justifiably seek to push the person to the right of the spectrum. So, if the drug taker seeks help whilst intoxicated the health worker might offer facilities for treatment, might educate about the risks of heroin injection, might counsel, might review the person's life circumstances to see if a changed life-style might be preferable (and possible) as an alternative to heroin-taking, might show the safest ways of injecting, and might argue for whatever point of view she believes in (so long as she does not present this as the only worthwhile possibility, so long as she does not take advantage of the person's vulnerability to put forward propaganda).

However, once the autonomy flip has occurred work to create autonomy can continue but must always be implemented so as to take the fullest possible account of the wishes of the subject of health care. So, if the drug taker says something to this effect, 'I have listened to all you have to say, I have learnt from you, but I do not wish to stop my habit, and I do not wish you to try to make me stop anymore', and it is clear that he has the capacity to understand and has made an informed choice, then this wish must be respected.

Of course the duty to respect autonomy is not absolute in all cases. For instance, it is inappropriate if a parent insists 'I wish to continue inflicting unnecessary suffering on my children'. Autonomy ought not be respected if a person's choice will deliberately harm others, and the harm is avoidable. Equally, it might be the case that a health worker has to take wider considerations into account, that to respect individual autonomy in all cases might be to go against what might loosely be described as the 'public interest' (perhaps if the doctor were not to report a chronic epileptic patient seen driving a car).

Neither is it an implication of a commitment to respect autonomy that whatever a person wishes should be provided. It does not follow that because a patient wants ampoules of heroin on prescription a doctor has a duty to oblige. But what is implied is that once choice is possible, once the human faculty of reason is present, then the doctor should not positively prevent this choice unless respecting the wish would cause harm to others, or seriously undermine the subject's welfare and the subject does not recognise this.

THE AUTONOMY TEST

The Autonomy Test applies only to health care and only to individuals.

In the arena of urgent practice, images and models may seem nothing more than a diversion from reality. Such decision-making tools require time to think through and apply, and this time is not available to most health workers. If Paradigm Y is not to remain an optimistic hope something immediately applicable is needed.

On many occasions in health care decisions have to be made quickly, even though there are no simple rules available. What is required in these circumstances is a 'litmus test', a speedy way of obtaining a provisional indication whether a proposed course of action ought to go ahead or not, or if it ought to be modified.

Although many health care decisions are perennially debatable, some policies are clearly wrong. The Autonomy Test is of most value in its ability to help expose these cases. It also helps to clarify options for creative progress by focusing on practical ways of moving a person to the right of the autonomy spectrum.

WHAT IS THE AUTONOMY TEST?

The Autonomy Test is a basic means of checking the appropriateness of plans, and of 'brainstorming' for better possibilities for care. However, the Autonomy Test is also a result of a systematic account of the nature of health, and to use it is to concede many implicit assumptions.

The Autonomy Test – Annotated

The Autonomy Test consists of a number of simple questions, and requires the health worker simply to list various possibilities.

ONE

Will physical or mental autonomy not be increased when it might have been? Will it be diminished in any way?

This is a very demanding question. Only rarely in the context of medical interventions will it be possible honestly to answer NO to this question. It is very strict. The question requires that if a drug is prescribed with 'side effects' which diminish, or a person has to stay in hospital, then the response must at this stage be YES. If there is doubt about whether or not an intervention is one which acts to diminish then, if possible, seek the opinion of the subject.

If the answer is genuinely NO then go to SIX. If the answer is YES, or if there is any possibility that it might be YES because a factor has been overlooked, then go to TWO.

continues

continued

TWO

List the way(s) in which autonomy will be increased and the way(s) in which autonomy will be diminished by the proposed action:

Increases in Autonomy	**Diminishings of Autonomy**

Note: At this point it is inevitable that there will be disagreement about what things count as increases (enablings) and what as decreases of autonomy (diminishings). It is likely that there will be particular debate over the question of long-term and short-term autonomy. Some will take the view that although autonomy (either in the sense of being able to have wishes fulfilled, or in the sense of being able to move unfettered) is diminished in the short term, this is justified by the probable long-term increase. (This position is sometimes asserted when people are detained – in their perceived best interests – under Mental Health Acts.)

THREE

Are each of these diminishings absolutely necessary?

If NO, then STOP

Reconsider the proposed action. Consider a fresh policy.

If YES, then go to

FOUR

Will these diminishings have the effect of increasing the autonomy of the patient (according to either Understanding A or B) in the future?

If NO, then STOP. Reconsider the proposed action. Consider a policy which might work for health instead.

If YES, then go to

FIVE

Are the patient's reasoned wishes being overridden?

If NO, and the intent is to move the person to the right of the autonomy spectrum as soon as possible, then proceed to SIX.

If YES, then either STOP – a *category mistake* will be committed if disease is challenged at the expense of human choice – or show how this overriding of reasoned wants can be justified in another way. Possible justifications might include:

continues

continued

1. The individual's wishes will harm me or others unnecessarily.
2. The individual is reasoning erroneously – he may be thinking illogically – he may be deriving false conclusions, or he may have false beliefs (but, if so, then an attempt must be made to move him as soon as possible to the point where the *autonomy flip* can occur).

Note: At this point in the Autonomy Test it is very important to bear in mind the distinction between physical autonomy – the freedom that a person has to live without physical obstruction – and mental autonomy – the freedom that a person has to make decisions and act on them. It is usual for short-term physical autonomy to be decreased in health care in order to increase long-term physical autonomy – restraining an arm in a sling, or prescribing drugs which cause drowsiness in order to cure infections, or injuring a person during surgery: all these are reductions in short-term physical mobility. So long as these diminishings are not imposed against a person's wishes, they are not problematic. But here the insidiousness of the category mistake becomes truly apparent. Although it is a genuine mistake which implies no intent to harm, the mistake can be dangerous. It is one thing to stop a broken leg moving by slapping plaster of paris around it, yet quite another to prevent a person acting on her choice to drink 'too much' or to have 'too many boyfriends', by classifying her as ill and administering long-lasting tranquillisers. The reduction of mental autonomy, even in the short term with the goal of promoting long-term gain, is far harder to justify in the case of any rational person (whether child or adult) who can understand the implications of what she proposes to do.

Justifications have been attempted, but they smack of the miserliness of spirit – just as a financial miser will be forever saving, waiting just a little longer until he spends. For example, it has been argued that breaking a confidence (in other words not respecting a person's choice) is justified so long as this results in greater autonomy for that person in the long term. But it is hard to see the purpose of this. If the person is in a position to choose, then he should be permitted this. Otherwise, on the next occasion that the person with the power to deny choice disagrees with that choice, she will be able to justify its denial by saying that the patient is not yet autonomous enough.

What such an argument basically says is this: although you do have the capacity to choose for yourself, either you are making the wrong choice deliberately, or you cannot see that by choosing this choice you are shutting a great many doors that would otherwise be open to you. Thus, for the sake of your future capacity to choose – which should be as great as possible – I override your present capacity – and I do it for your sake.

Naturally many kind and experienced people do pursue policies such as this with those they feel could benefit from their 'hidden' support. However, it is always open to such well-meaning closet paternalists to explain in the fullest possible terms why they believe that the other person is making a mistake. There is the danger that since there is no theoretical cut-off point – no binding rule to tell the paternalist when he has gone too far, or continued for too long – that he will, using exactly the same justification time and time again, continue to override personal choice.

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The Autonomy Test is clear on this. To satisfy the Autonomy Test the flip should occur just as soon as the person can weigh up the problem, review the options, and assess the implications. A free society does not wait until some ideal inspired moment – people must be free to make mistakes.

SIX

Consider the list of the ways in which autonomy might be increased (the ways in which latent enhancing human potentials might be made actual). Decide, if at all possible in partnership with the patient, the order of priority in which this list of possible potentials might be achieved.

Weigh these against any potential costs.

SEVEN

Once decided and agreed – initiate proposed action.

The Autonomy Test – Unannotated

ONE

Will physical or mental autonomy not be increased when it might have been? Will it be diminished in any way?

If the answer is genuinely NO, then go to SIX. If the answer is YES, or if there is any possibility that it might be YES because a factor has been overlooked, then go to TWO.

TWO

List the way(s) in which autonomy will be increased and the way(s) in which autonomy will be diminished by the proposed action:

Increases in Autonomy	**Diminishings of Autonomy**

THREE

Are each of these diminishings absolutely necessary?

If NO then STOP. Reconsider the proposed action. Consider a fresh policy.

If YES, then go to

FOUR

Will these diminishings have the effect of increasing the autonomy (according to either Understanding A or B) of the patient in the future?

If NO then STOP. Reconsider the proposed action. Consider a policy which might work for health.

continues

continued

If YES then go to

FIVE

Are the patient's reasoned wishes being overridden?

If NO, and the intent is to move the person to the right of the autonomy spectrum as soon as possible, then proceed to SIX.

If YES, then either STOP – the *category mistake* will be committed if disease is challenged at the expense of human choice – show how this overriding of reasoned wants can be justified in another way. Go to SIX.

SIX

Consider the list of the ways in which autonomy might be increased (the ways in which latent enhancing human potentials might be made actual). Decide, if at all possible in partnership with the patient, the order of priority in which this list of possible potentials might be achieved.

Weigh these against any potential costs.

SEVEN

Once decided and agreed – initiate proposed action.

APPLYING THE AUTONOMY TEST

Although the Autonomy Test is crude and open to interpretation, it is nevertheless a guideline that health workers might choose to adopt. It is enlightening to apply the test to various cases in real life. This will usually give clear answers. It is not necessary to go into detailed ethical analysis of most of these cases since the Autonomy Test makes no claim to depth – it is a litmus test, a traffic light: Should I stop or should I go? For instance, if Carole's case (see p. 187) is put to the Autonomy Test there is a swift result.

The Test Applied – Carole

ONE

Will physical or mental autonomy not be increased when it might have been? Will it be diminished in any way?

Answer Yes, unequivocally. Carole is an intelligent and able girl, yet she does not have enough information about her diagnosis and her treatment. Perhaps even more importantly no work is being done to help her *picture* what is happening to her, to help her conceive of the set of unfortunate circumstances which currently surround her – to help her map out her world. Carole desperately needs to recognise that all her problems are not her fault, that failure is just one map out of several possibilities, and that all maps have routes into each other – we can and will all fail at some things.

continues

continued

TWO

List the way(s) in which autonomy will be increased and the way(s) in which autonomy will be diminished by the proposed action.

Increases in Autonomy	Diminishings of Autonomy
	(Note: not increasing autonomy where it would be possible to do so is taken to be diminishing)
Possible alleviation of psychotic symptoms	Things done to Carole without her understanding
	Family not involved in any therapy
	No counselling – no picturing for Carole
	No attempt to help Carole to find a purpose in her life

THREE

Are each of these diminishings absolutely necessary?

Answer No. Reconsider the proposed action. Consider a fresh policy.

EXERCISE

Apply the Autonomy Test to the example highlighted by Evelyn Thomas, outlined earlier on pp. 188–190. Address this proposal: Dr Hughes wants to carry out an identical research programme on human subjects. Consider your response with reference to one of the potential subjects, Pauline Johnson.

THE LIMITATION OF THE AUTONOMY TEST

There is much that the Autonomy Test cannot do. There are many cases where what counts as an increase or decrease in autonomy is too open to interpretation for the test to be decisive. To resolve such cases more extensive ethical analysis is necessary, although the Autonomy Test will hardly ever be entirely redundant.

For instance, consider the following difficult case:

> LAW REPORT
>
> **Sterilisation of mental patient not unlawful**
>
> A sterilisation operation on a mentally disabled adult patient is not unlawful by reason only of the patient's inability to consent if it is carried out in the best interests of the patient.

The facts

F., who was born in 1953, has the verbal capacity of a two year old and the general mental capacity of a four to five year old. She has been a voluntary inpatient at a hospital since 1967, where she has formed a sexual relationship with a male mental patient. The evidence was that she had physical enjoyment from sexual intercourse with him and that she was not being sexually molested.

F. has the fertility of any other woman of her age, and her mother applied for a declaration that it would be lawful for F. to be sterilised, notwithstanding that she was incapable of consenting. Mr Justice Scott-Baker granted the declaration (Guardian Law Report 3 December 1988). The Official Solicitor, who was given leave to intervene, appealed.

The decision

Lord Donaldson referred to the case of Re B[1988]AC199 in which the House of Lords held that in the case of a mentally handicapped minor the court could, acting in its wardship jurisdiction, consent to the sterilisation of the minor if it was in her best interests. This raised the stark issue of whether the law treated adults who suffered from a disability differently, and on one view less favourably, than it treated children suffering from a similar disability. In the absence of consent all, or almost all, medical and surgical treatment of an adult is unlawful, however beneficial such treatment might be.

F.'s disability was such that she would never be mentally competent to appreciate the issues involved and to consent to sterilisation or to any medical treatment. The court had no power either under the *parens patriae* jurisdiction or under any statutory jurisdiction to dispense with F.'s consent or to give consent on her behalf.

The common law right of body inviolability save with consent was subject to two exceptions: first, emergency medical treatment, and second, physical contacts which are inevitable or at least are a usual feature of everyday life, such as the jostling on public transport, or generally acceptable standards of conduct. A doctor faced with an unconscious accident patient is lawfully entitled and probably bound to carry out such treatment as is necessary to safeguard the patient's life and health, although the patient is in no position to consent.

It would therefore not be surprising if the common law rule were subject to a further qualification in relation to those who by reason of disability are unable to consent. There is a clear and logical connection between the position of an adult who through an accident is temporarily deprived of the power of consent – the emergency treatment case – and the case of an adult who through permanent disability is equally unable to consent. The difference is largely, although not entirely, one of scale.

But the law should not regard adults as permanent emergency cases. In an emergency a doctor had little time but in this case the doctor had more time, and far more was required of him.

The test which the court did, and the reasonable adult should, apply was, 'what course of action is best calculated to promote my true welfare and interests'. What constituted true welfare and interests often gave rise to very difficult questions, but that did not affect the validity of the test . . .

Lord Justice Neill said the answer lay in considering the public interest. Provided that the operation was necessary within properly defined limits and appropriate safeguards were prescribed, there was no reason in principle why a patient who could not give consent should be deprived of the right to receive the treatment required.

'Necessary' in that context meant that which a general body of medical opinion in the particular specialty would consider to be in the best interests of the patient in order to maintain his health and secure his well-being. Unanimity was not required, but it should be possible to say of an operation which was necessary in the relevant sense that it would

> be unreasonable in the opinion of most experts in the field not to make the operation available to the patient.
>
> Lord Justice Butler-Sloss concurred.
>
> The appeal was dismissed, and leave was granted to appeal to the House of Lords.[83]

The problem for the Autonomy Test in these circumstances is that the autonomy flip can never occur. F. will never be able to have a sufficient level of autonomy created for her to enable her to consider her situation, and to express a wish.

The judges decided to apply a 'best interests test', but what one person might consider to be in her 'best interests', another might not. For example, a critic of the judgement argued:

> There are a number of deeply disturbing features about this case. It is not clear that the court had the jurisdiction to make the order that it did. And it is not clear that the order made was legally correct. To equate the sterilisation operation, as the judge did, with the extraction of a tooth, the repair of a hernia or the administration of an injection, fails to recognise the enormity of the invasion and injury which the proposed sterilisation represents. It fails to distinguish between the obvious therapeutic advantages in the supposed analogies and the dubious benefits which sterilisation offers. And it fails to acknowledge that sterilisation involves major abdominal surgery requiring general anaesthesia . . .
>
> As troubling, however, are the assumptions being made about the sexuality of women with a mental handicap, the risks to which pregnancy exposes them, and the response of courts to the interests of what the judge in one place calls 'mental defectives'.[84]

For the judges and the author of this quote the list of increases and diminishings is not the same. A judgement has to be made about who gives the most appropriate list in regard to the creation of F.'s autonomy, and this is not finally decidable. An analysis deeper than the Autonomy Test is required for this, but at least the Autonomy Test offers guidance in setting limits, and compels the listing of possibilities.

Clearly there is a difficulty with the ranking of dwarfings. Since a dwarfing must be avoided, unless to do it will prevent a worse dwarfing, it must be possible to state in general terms how one thing is worse than another. But how can subjective preferences be assessed in an objective way? Often this cannot be done – people's preferences are not the same. In such cases, the only way forward is to find out, in individual context, what the person wants. This is where the autonomy flip is useful – and where one must respect the liberty of other people. Where the autonomy flip cannot occur, great care must be taken that clearly avoidable dwarfings do not happen – and this judgement must rest on a deeper analysis and weighing of the potential and probable harms.

EXERCISE

Re-read **The Operation** in the Introduction pp. 12–19. Imagine that you are the surgeon (a) during the initial consultation and (b) as he meets the patient on the morning of the operation. Use the Autonomy Test and base a moral policy on its results.

RESPECT AUTONOMY (brief explanation)

The requirement to respect autonomy is also part of the core rationale of health work (the blue boxes), but as we have seen is significantly different from the necessity to create autonomy. The creation of autonomy requires the provision of the physical and mental wherewithal for enhanced movement in life, whereas respecting autonomy requires that the person's chosen direction should be respected, whether or not the health worker approves of it.

This idea is bedevilled with controversy. Many of the really hard cases in medical ethics hinge upon whether or not 'respect autonomy' should be invoked. Some of these controversies can be settled with intelligent use of the grid, but there are no binding guidelines about how far personal (or group) autonomy ought to be respected. A strong (though not immutable) reason not to respect autonomy arises when the autonomous decision will harm other people. Beyond this, the issues must be resolved by personal judgement and comprehensive and appropriate moral reasoning.

RESPECT PERSONS EQUALLY

The requirement to respect persons equally when working for health follows from the requirement to create and respect autonomy in everyone. We regard people as valuable not only because of what each can do, but because of what each is. The cardinal aspects of personhood – being able to value one's life and having the potential for future choices – are shared equally by all persons.

The extent to which the box 'respect persons equally' should be employed is a matter of judgement. However, as with the other blue boxes, if this box is to be superseded firmly convincing reasons are required. If persons are not respected equally, perhaps because resources are scarce, then this is discrimination between beings who are fundamentally equal. If such discrimination is condoned by a health service for unjustifiable reasons then there are dangerous implications for that society as a whole. If it is all right for a health service to discriminate on grounds of age, race and economic worth, then other social institutions have *carte blanche* to do the same.

SERVE NEEDS FIRST

This element of the core provides a grounding for the other three. It gains its authority firstly from the fact that a true health service must – before any other task – provide for the basic needs of all it seeks to serve, and secondly from an underpinning association between work for health and justice as fairness. Since those who have made a commitment to work for health are obliged to create autonomy and treat persons with equal respect it follows that they must also want to ensure that everyone's basic needs are met. So, if there are people who have no shelter, or no food, or no purpose in life, or a very limited general education, while in the same society there are people whose material wants are being over-fulfilled then this is a system in which full health is not being achieved. It is a system in which there is a lower degree of morality than there otherwise might be.

All human beings have needs that are part of a shared human condition. Though they are never absolute,[58] they may be said to be factual. Rights vary over history and between contexts, and although it is argued by some that through hard work some people deserve more benefits in life than those who do not work so hard, it seems fundamentally unjust for such rewards to be enjoyed at the expense of basic human needs (though it must be admitted that despite millenia of philosophical labour, no one has yet succeeded in demonstrating that this is *necessarily* so).[5]

But what is so important about medicine and health work is that this principle has so often been followed in practice. In wartime medics do not (or should not if they are health workers) treat only the wounded from their army, and medical treatment is commonly offered to criminals regardless of what crime they have committed. Within health work it seems there is an elemental humanising principle at work. While some pains and some diseases may be socially caused and avoidable, many are not. A person unlucky enough to become unwell needs help and needs it unconditionally. When it is so given it is a pure moral donation – a giving based on sympathy and a desire to create better possibilities for others. By contrast, if a hospital turns away one person with a broken leg whilst admitting another, on the ground that the first person is a bank robber and the second a bank manager, health workers have no difficulty in recognising that the action of the hospital is morally superficial.

IN SUMMARY

A REVIEW

Why Are the Blue Boxes Core?

The Devil's Advocate Speaks Again

> All that is going on in this writing about health and ethics is a cleverish word game based on a set of improvable assumptions that you take for granted. You have decided what health is, and now, by the use of sophistry more than anything else, you attempt to deceive us into thinking that you are uncovering truths. But you are doing nothing of the sort. You are not a detective, you are an inventor. In order to defeat your position one need only refuse to accept your assumptions and make alternative ones instead – perhaps premises more acceptable to a person of a different political persuasion. For instance, one might just as well include these (or any other) boxes within the core 'health rationale': manipulate clients, create dependency, discriminate between individuals according to their social worth, and act to provide a service for those who, through their own efforts, can pay for it, and do so before you pay any attention to the worthless needy.

Harsh words, but they are from an exasperating devil's advocate who has not understood the argument of this book (and companion texts).[1,5] The point of these works is to provide a firm theoretical footing for a true health service, a health service which aims as its first priority to increase the degree of morality in the world through the interventions made in the name of health. It is undeniable that assumptions about

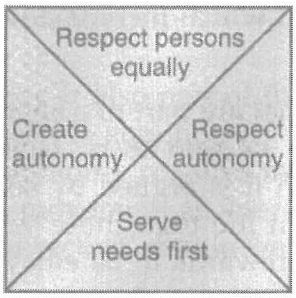

Figure 26 The blue boxes

what a 'true health service' is are just that – assumptions. They are preferences and cannot be empirically shown to define work for health. But on the other hand there is a rich and varied set of reasons behind them. These reasons are connected as threads in a tapestry. They begin and end in different places, but link together to present a compelling picture. Some of the threads the devil's advocate should see stitched together are:

1. It has been shown that work for health has a common factor – namely the removal of obstacles to people's biological and intellectual potentials.
2. The associated ideas of 'enablement', 'personhood', and 'enhancing potential' are (a) richer, more coherent and logically sound than the speculative alternatives of the advocate and (b) more likely to produce benefits that can be shared by all than any other option.
3. There is a clear relationship between ethics and health, demonstrated in these pages and elsewhere.
4. Certain actions can be considered to be immoral because they dwarf gratuitously. Those features vulnerable to the most serious dwarfing are precisely those which provide the basis for the equal treatment of persons.
5. The existing rationale of health work – in theory and in practice – cannot be ignored. Although things could be better and priorities reassessed, study of present health work practice shows that the principles outlined in the blue layer are already those that inspire much work in the name of health. The seeds of Paradigm Y are already sown in Paradigm X.
6. The practical consequences of the devil's advocate's idea are dreadful. How could a health service be organised according to these principles? Such a service would not be a legitimate health service because although it would seek to remove some obstacles to some potentials it would not do for all people equally, and some of the potentials – if achieved – would be debilitating, not enhancing.

Bear firmly in mind, before moving on, that in all but the most exceptional cases at least one blue box should be used during deliberations. A decision to ignore all four needs a massive justification. It is usually impossible to work for health without invoking a blue box.

THE RED LAYER

This level of the grid focuses on duties and motive. The boxes included are illustrated in Figure 27.

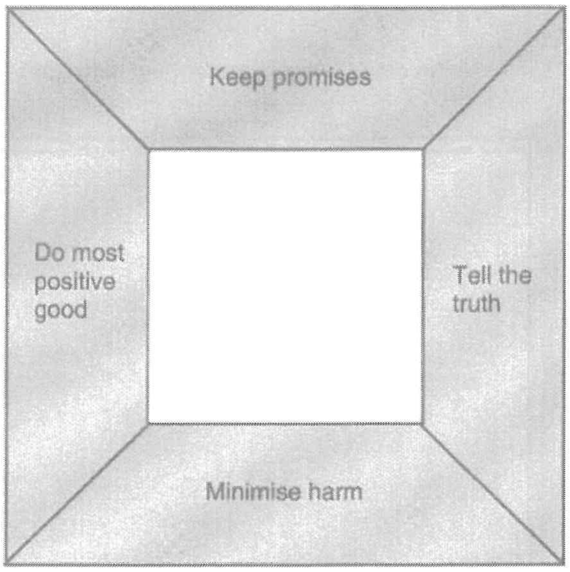

Figure 27 The red boxes

WHAT IS THE SIGNIFICANCE OF THIS LAYER?

The red layer corresponds with deontological outlooks, and contrasts with the green, consequentialist layer. It is meant to encourage consideration of obligations other than those immediately implied by a commitment to health work. The duties shown are not the only ones possible (*not killing, not causing unnecessary pain, being compassionate*, and *taking due care* are some of the alternatives) but are probably the most commonly recognised amongst health workers. Nor are these duties meant to be binding. They should never be dispensed with casually, but from time to time situations will occur where it is better that they are temporarily disregarded and excluded from use. However, when thinking about health work interventions it is important to bring moral obligations to mind and if one, more, or even all are to be disregarded then very good reasons must be advanced in justification.

THE GREEN LAYER

The green layer divides consequentialism into four key aspects in order to focus attention on outcomes of proposed interventions, and to encourage moral reasoners to clarify their priorities. Ethical confusions commonly arise between health professionals because they have failed to agree who 'the patient is'. It is often assumed that one's own target of concern is the same as everyone else's, when this is not so. In the same case a nurse may be seeking to maximise benefit for an individual, a social worker may see the family as the unit of care, a doctor may want to maximise benefit for all her patients, and so on. If these matters are not spelt out needless tensions can be created. Attention to the green layer will promote reflection about whether benefit (which must also be discussed and specified in advance) should be increased for humanity as a whole, for a particular group (perhaps a disadvantaged group such as the

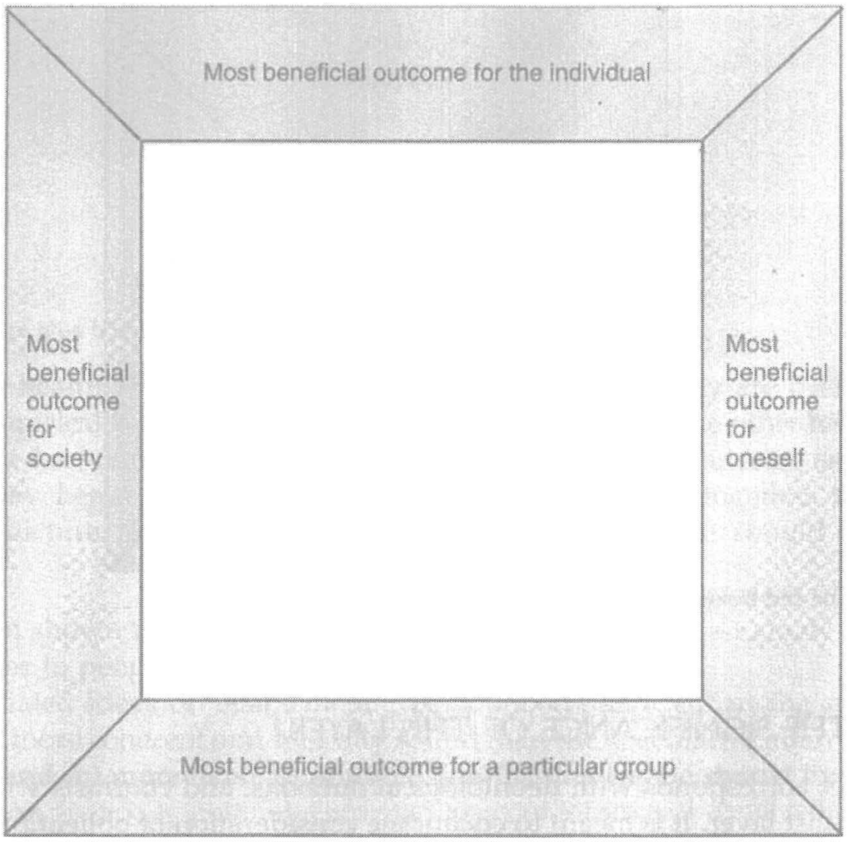

Figure 28 The green boxes

handicapped, members of the black community, people living in a particular housing estate), for an individual, or for the agent herself.

As with the other layers – and indeed the whole Grid – nothing is clear-cut. It may be that all the boxes of the green layer can be brought into play, or that only some can be used while others lie redundant, or it may be that a box will have to be chosen at the expense of other boxes.

For example, when considering an intervention it might be concluded that the interests of a particular group might have to be sacrificed in order to bring about an increase in social good. So it might be that renal physicians and patient groups get together to decide on the best use of scarce dialysis machines and kidneys, and in so doing agree a ranking of potential beneficiaries from 'essential' to 'inappropriate'. As they do this they will inevitably arbitrate in favour of the youngest and strongest recipients – placing the interests of a particular group (the oldest and sickest) as a lower priority.

But this is not necessarily the fairest or most morally desirable decision, and the green layer should be used only in conjunction with the grid as a whole.

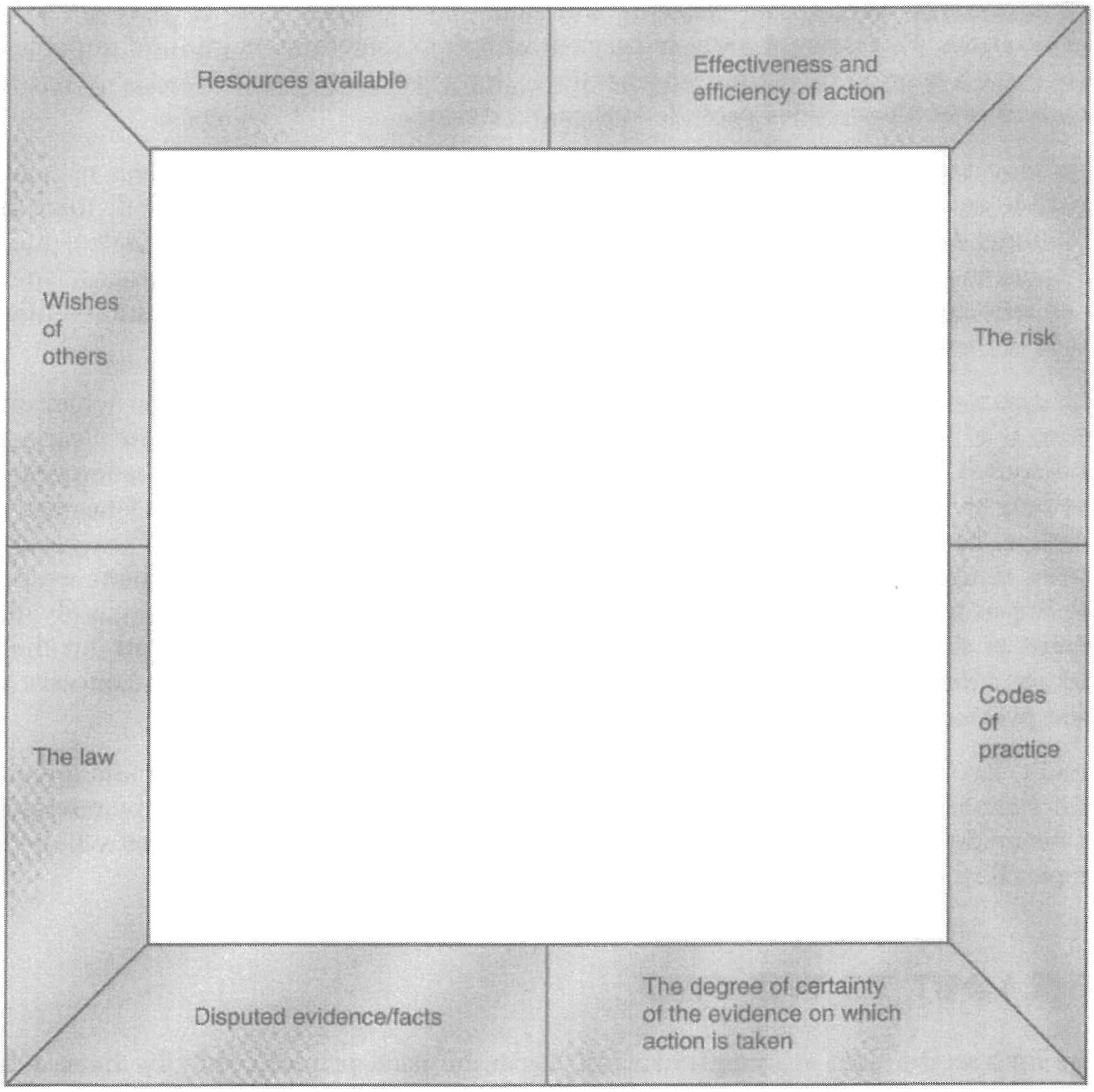

Figure 29 The black boxes

THE BLACK LAYER

The black layer is of great importance, yet includes factors often given insufficient attention by moral philosophers. The black layer is the level of external considerations. In many cases, in the hard world we live in, the black layer contains the most important factors. For instance, it may be that a person's legal right – say to receive advice or treatment – effectively takes any decision out of the hands of the health worker.

Ethics is not only a matter of deciding on principles, considering duties, and reflecting on likely outcomes in the abstract. Ethical intervention takes place in a perpetually uncertain world of limitations. Although it has been shown that law and morality do not necessarily correspond, existing law will have a clear part to play in some deliberations. Professional codes of practice, although sometimes vague and imprecise, may have a bearing on certain interventions, and it is for the health worker to decide when, if ever, these codes provide sufficient advice.

It is also necessary to assess an intervention's degree of risk, in whichever of many possible senses of risk are most relevant. Will physical harm occur? Will there be emotional damage? Is there a danger that an unfortunate precedent will be set? Is there a chance that the proposed intervention will produce unintended consequences? There is an associated demand on the Grid user to try to ensure that whatever intervention made is carried out with maximum efficiency and effectiveness.

It is also necessary to consider the degree of certainty of the evidence on which the action is to be taken, and to take account of those facts of the matter that are clear and undisputed. Not to do so would, by any standard, be foolish. Moreover, it is important not only to 'respect people' in the abstract, but to ascertain what their wishes are in practice. Since most professional health workers are in a position of some power and status, many clients may be overawed and have decisions imposed on them, even if the imposition is unwitting. Health workers should in every case try to clarify the wishes of those they are trying to help, and of those other people who care for them and are affected by what happens to them, and should try to help them conceive of their position and choices as plainly and accurately as possible.

Finally, there is an abiding responsibility (implied by the Grid as a whole) on anyone who intervenes in the life of another person to be able to justify all actions by reference to the evidence. Any person who has reasoned morally in a proper fashion will be in an excellent position to do this.

THE LIMIT TO THE GRID

The limit to the Grid is straightforward. It can be used properly only by those who honestly seek to enable people's enhancing potentials. The Ethical Grid can be used legitimately only by those who are consistently opposed to dwarfing, and devoted to the fight against it.

The Grid can be used as it is supposed to be only by people who have made a commitment to work for health, and are seeking to do so with integrity. If it is used insincerely, if the Grid is employed cynically – merely in order to further personal goals, for instance – then this is not a moral use, even though the outcomes might sometimes be the same as those which result from sincere use.

A CLAIM FOR THE GRID, AND WHAT IT CANNOT DO

The Ethical Grid is a tool, and nothing more than that. Like a hammer or a screwdriver used competently, it can help make certain tasks easier, but it cannot direct the tasks, nor can it help decide which tasks are the most important. The Grid can enhance deliberation – it can throw light into unseen corners and can suggest new avenues of

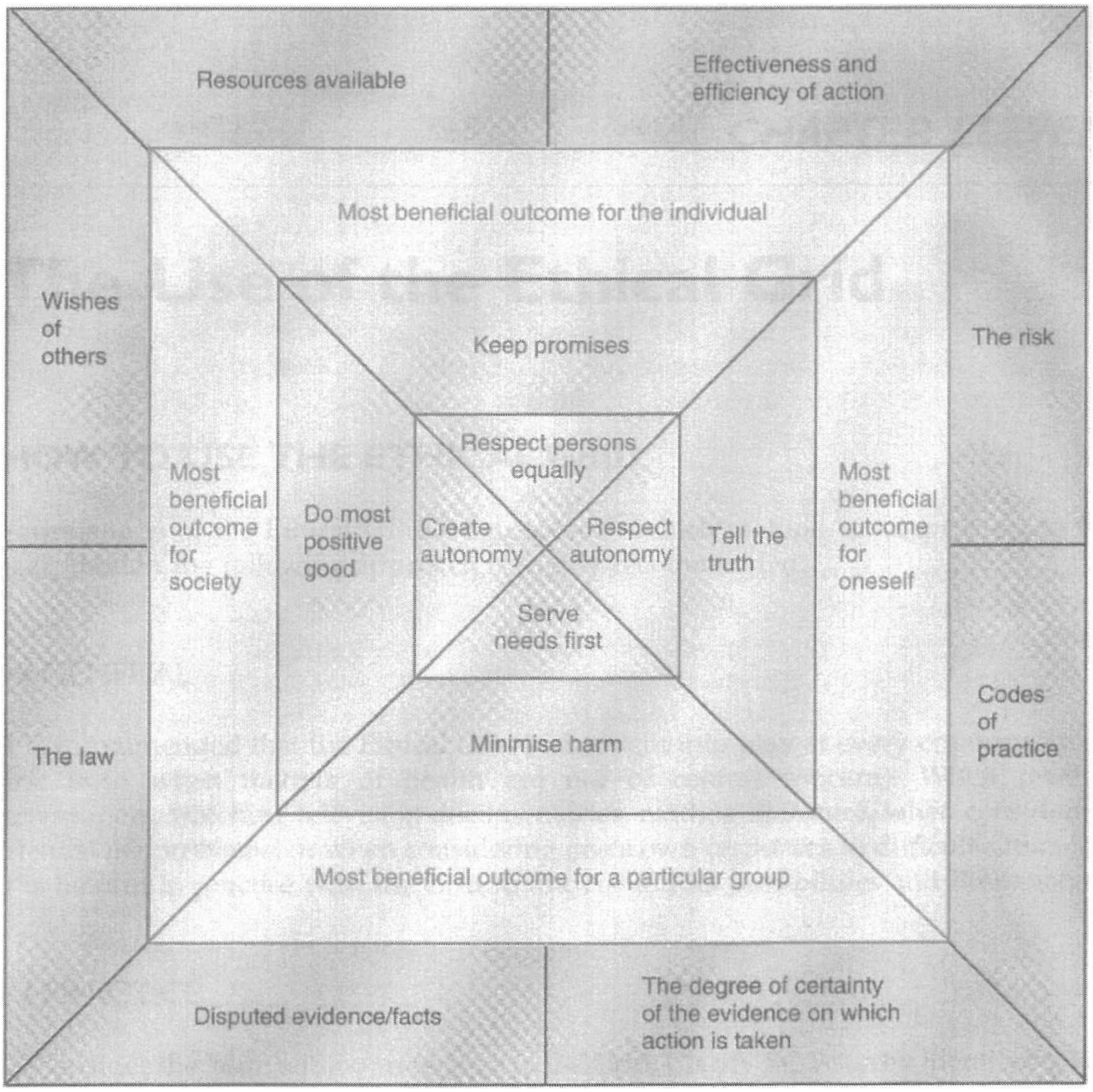

Figure 30 The Ethical Grid

thought – but it is not a substitute for personal judgement. True moral reasoning is an essentially human activity which touches sensitive nerves and exposes emotional frailty. Responsibility lies with the user, not the Grid.