BIOETHICS OUTLOOK

Plunkett Centre for Ethics in Health Care

Volume 12 Number 4

December 2001

The Principle of Justice: a bioethical perspective

Bernadette Tobin

In this Issue

This issue is devoted to a paper on justice given by Bernadette Tobin at the Eighth Forum on Bioethics held at the Department of Bioethics in the Faculty of Medicine and Surgery of the University of Santo Tomas, Manila, in February, 2000.

It originally appeared in the Forum Proceedings, published earlier this year, and in *Philippiniana Sacra*, Vol XXXVI, No. 106, pp 41-61.

Please note that enclosed with this issue is a Subscription Renewal Form for 2002. Please return it to the Administrative Officer at the Plunkett Centre.

Care of the newborn

Is there anything wrong in itself with infanticide, or does it depend on whether or not the child is wanted by his or her parents? Of course, most parents can be presumed to love and cherish their newborn children, so the question does not often arise in paediatric care. But it lurks in the background frequently enough to make it worth reconsidering. Parents who do not want their child to start out in life with prospects clouded by disability sometimes wish to cut themselves free of the ties that bind them to that infant and to make 'a fresh start' with another child who has better prospects. Some will not baulk at the taking of 'active means' to bring about the death of a disabled child. Others will, but they may tolerate 'allowing such a child to die'.

Care of the elderly

Is it legitimate to withhold health care from the elderly *just* on account of their age? There is evidence that this already happens in some parts of medicine.¹ Indeed, since no society can afford to provide all the health care that its citizens need, let alone want, many people think justice *requires* us to give priority to the health care needs of the young over those of the old. Some say that the elderly benefit less from health care than do the young², others that the elderly have already had their fair share of health care³, and others that the elderly have already enjoyed a life long enough to make the most of the opportunities that life typically affords to us.⁴

Responsibilities of researchers to participants in developing countries

Are the responsibilities of researchers to research participants governed by universal ethical standards? Or is it sometimes legitimate to conduct clinical trials which would be considered unethical in affluent countries on poor people in developing countries?⁵ A few years ago, some clinicians withheld efficacious drugs from HIV-infected women during perinatal transmission trials in developing countries. They wished to find out whether a shorter, cheaper course of zidovudine (AZT) would be as effective in preventing mother to child transmission of HIV as a longer, more expensive course. To do so, they proposed to run a clinical trial in which some women would be given no treatment at all.

These three sets of questions - about care of the newborn, care of the elderly and the treatment of research subjects - raise difficult issues of justice. What we think about each of these questions will depend - in part - on our understanding of what the principle of justice requires of us. However, we are often attracted, at least initially, to inadequate or partial accounts of that great principle, accounts which contain only some part of what genuine justice entails.

There are, I think, four different approaches to thinking about justice in the allocation of health care resources: one derives from 'utilitarianism', another from 'egalitarianism', a third from 'libertarianism' and a fourth from the 'natural law' tradition. In this article I shall outline the idea of justice embedded in each of these philosophical schools of thought and

then indicate what each might say about the three sets of questions raised above. I shall argue that, of the four, a natural law approach to justice provides the most reliable account of the obligations in justice of health care professionals.

Four paradigms of justice

What, then, is justice? Though the writer of the Hippocratic Oath insists that it is part of a doctor's duty to keep his patients free from injustices they can do to themselves, justice is generally thought to be giving others their due.6 This idea can be understood in different ways: (a) most narrowly, as fulfilling responsibilities defined by prior undertakings, (b) more widely, as being fair to others, (c) quite generally, as acting uprightly in any actions bearing on others. (Scripture uses justice in the widest sense, to mean goodness and holiness in general.) philosophers mostly use it in a more specific sense to refer to rightness in people's interactions and interrelationships.

Let us take this idea, rightness in people's interactions and interrelationships, as a general account of the principle of justice. Justice consists in the giving to others what is owed to them. Certain objective situations, certain morally good acts, the character of certain persons, and certain societies and social structures, may all be called just.

Three questions arise. First, what in general do we owe to others? Second, what in the way of health care do we owe to others? Third, precisely who are these others to whom we have obligations in justice?

I shall outline four different kinds of answer to those three questions: justice as whatever brings about the greatest good for the greatest number, justice as the fair distribution of (at least) some goods and services, justice as the lack of restraints on individual liberty, and justice as doing unto others what you would have them do unto you.⁷ I shall show what each implies about health care. I shall then

indicate the answer found in each approach to the question 'to whom is justice owed?' And I shall note some of the strengths and weaknesses of each approach.

Justice as whatever brings about the greatest good for the greatest number

For a utilitarian, justice is not an independent moral principle. Rather it is a principle dependent on, governed by, the principle of utility, which is taken to be the sole principle of morality. It names that most paramount and stringent form of obligation created by the principle of utility. The principle of utility says: Work out all the predictable benefits and all the predictable losses of some proposed change or state of affairs, calculate the net sum (or utility) of these proposed changes and then choose that state of affairs which will bring about the greatest good for the greatest number, that is, will maximise utility. Justice consists in the distributed result of that calculation. A state of affairs is just if it represents the greatest good for the greatest number and unjust to the extent that it does not effect that result.

In health care, contemporary utilitarians use two principal criteria for working out utility: quality of life measures and social contribution measures. Though different utilitarians advocate different health care policies, in general they tend to favour the following broad principles: (a) prevention is to be preferred to cure, and cheaper therapies are to be preferred to more expensive ones, (b) expensive or scarce therapies are to be available only to the young and those who are likely to lead long productive lives, (c) preference should be given to those likely to receive the greatest benefit in terms of improved length and quality of life and to those likely to make the greatest future social contribution; (d) short-term services are to be preferred to longer-term care, and institutional care eliminated as far as possible, (e) healthcare for the terminally ill, dying, elderly, chronically sick or incapacitated, severely handicapped and permanently

unconscious, is to be given the lowest priority.8

Who counts as 'the other'? Utilitarianism has no one theoretical answer to this question, except to insist on impartiality in the calculation of benefits and burdens.9 In practice, however, the most influential utilitarians in the field of bioethics tend to combine their utilitarianism with a view which excludes certain categories of human beings from counting as persons and thus as our "others" to whom we have obligations in justice. The Australian utilitarian philosopher Peter Singer combines his utilitarianism with John Locke's view about who counts as 'a person'. John Locke defined a person as a thinking intelligent being that has reason and reflection and can consider itself as itself, the same thinking being, in different times and places'. Singer argues that (a) certain categories of human beings (newborn infants, the permanently comatose, the demented) are not persons and (b) certain groups of nonhumans (gorillas, chimpanzees, the higher apes) might turn out to be persons. 10 The American utilitarian philosopher Michael Tooley has a similar view. According to Tooley, the morality of infanticide rests on one question. Is the newborn infant a person? For only if it is a person has it a serious right to life.11 This view has clear implications in utilitarian thinking for the ethics of prenatal diagnosis, selective abortion, infanticide, care of the disabled newborn, the use of anencephalic infants as sources of organs for transplantation and about the health care for the old, the demented, the permanently comatose, etc.

Strengths and weaknesses

It is true that Peter Singer has used utilitarianism to remind us, very effectively, of our obligations to the poor, particularly to the poor who live in far away places. He has also used it to reveal what is wrong with cultural relativism in ethics (which is relevant to thinking about our obligations to research subjects) and to remind us about the importance of efficiency and effectiveness in health care. However, utilitarianism is deeply flawed. It captures only a part of what is true

in morality: consequences matter, but they are not all that matter. It pays little attention to individual rights and duties and thus to the moral significance of particular relationships. In its insistence that we must always maximise the good, it asks too much of us. And it invites us to consider doing evil for the sake of some "greater" good. When it is combined with a Lockean account of personhood, utilitarianism threatens to undermine the authentic goal of health care.

Justice as the equal distribution of (at least some) goods and services

Taking their lead from the idea of impartiality, egalitarians argue that justice is essentially equality or, following the most influential of contemporary egalitarians, fairness. Unlike utilitarians, egalitarians treat justice as an independent moral principle, one among a plurality of moral principles of which (say) benevolence is another.

According to John Rawls' theory of egalitarianism, principles of justice can be derived from what people would choose if they were forced to be impartial, if they had to choose principles on which to base a social structure which would satisfy them wherever they turn out to be located in it. He argues that people would choose two principles: first, each person should have the most extensive system of basic liberties compatible with similar liberties for all; second, social and economic inequalities should be arranged so that they are to the greatest benefit of the least advantaged and are open to all under conditions of fair equality of opportunity. In brief, justice consists in fair equality of opportunity.

Though its application to health care is a matter of some debate, Rawls-inspired approaches to healthcare distribution (such as that of Norman Daniels) insist that each person, irrespective of wealth or position, should be provided with equal access to an adequate (though not maximal) level of health care (contingent on social resources), enough

to ensure 'equality of opportunity'. Distribution should be on the basis of need (which is understood as what is necessary for equality of opportunity). Better services, such as luxury hospital rooms and expensive but optional dental work, should be available for purchase at personal expense by those who are able to and wish to do so. But everyone's basic health needs should be met at an adequate level. On this approach, there is a right to a decent minimum of health care, enough to ensure equality of opportunity, and an obligation for society to provide that decent minimum to all its citizens.

Rawls argues that the state must be neutral about what constitutes a good life for an individual. It must allow maximum scope for self-determination in keeping with people's personal values and life-plans. His 'thin theory of the good' recognises only those 'primary goods' which people need in order to pursue their particular plans and projects and a few principles of justice-as-fairness. On this account, healthcare need ought to be understood as care which provides or restores opportunities in life to those whose opportunities are limited by illness. Healthcare needs are whatever is necessary to achieve, restore and maintain equality of opportunity at (species-specific) levels of functioning.

Who counts as the other in this approach? Rawls' theory assumes that individuals are to be understood in a Kantian sense as conscious and free moral agents who devise, revise and seek to achieve their own conceptions of the good. This has implications for those human beings who are not at a particular time, or may never be, competent moral agents. Anthony Fisher is right to claim that Rawls' theory at least invites the introduction of a 'consciousness criterion' in the allocation of health care. For Rawls' view of the person has been used in support of the idea that health care should be distributed with a preference for those who are or will be capable of exercising moral agency. 12 This clearly has implications for the provision of health care for all newborn infants and for some of the elderly.

Strengths and weaknesses

To my mind Rawls' theory marks an advance on utilitarianism in that it recognises both a plurality of moral values and the independent value of justice. His theory tries to provide an approach to justice which respects individuals and the diversity of conditions in which they flourish whilst at the same time providing a reasoned basis for a harmonious life between them. Its claim that 'need' is the criterion for the proper distribution of health care rings true, as does its steadfast insistence on what we owe the poor and disadvantaged. However, by insisting on a 'thin theory of the good', that is to say, by recognising only those goods which people need in pursuing their own lifeplans (whatever they are) and insisting on neutrality about what constitutes a good life for a human being, it may be internally incoherent.¹³ It seems both to preclude state involvement in the provision of health care (since individual people differ significantly about what health care they want) and at the same time to require it (since good health is clearly a precondition and determinant of the freedom and independence in the pursuit of one's life plans that Rawls' theory is intended to secure).

Justice as the lack of restraints on individual liberty

Contemporary libertarians often use Rawls' view of justice as the backdrop against which to present their own theory. They believe that it is not the role of the state to impose any pattern of distribution of benefits and burdens on its members, since that will violate the rights of individuals. Robert Nozick's claim that 'individuals have rights, and there are things no person or group may do to them (without violating their rights)' is the most famous modern expression of a libertarian approach to justice.14 Persons have a range of rights (to life, liberty, property) which they are entitled to enjoy and exercise free from external interference as along as they do not thereby interfere with the similar rights of others. The sole function of the state is to

protect citizens against unjust interference (by violence, theft, fraud or the non-fulfilment of contracts): it is not the business of the state to distribute benefits and burdens such as health care since that will violate the rights of individuals.

According to libertarianism, the only just system of allocation of health care is the operation of the free market. It is up to people individually to choose what healthcover or services (and from whom) for which they wish to spend their own resources. It is up to health professionals to decide how, when, for whom, with whom and for how much they wish to work. Libertarians thus treat autonomy, both of the patient and of the professional, as the central ethical notion in health care. Individuals must be encouraged to take responsibility for their own health.¹⁵ They should not look to others to bail them out, and nor should others be too ready to do this. 16 It is simply unfortunate, not unfair, if someone cannot afford to pay for health care or healthcare insurance. And the doctorpatient relationship should be understood as a relationship between two autonomous contracting individuals. Healthcare workers are obliged to provide only that health care which is in keeping with their own prior undertakings or present choices. And they may legitimately decide for themselves what distribution standards to apply to their own practices: profit maximisation through an 'ability to pay' criterion, personal satisfaction through a 'preferred group criterion' ('I don't treat people who cannot pay!') or some more altruistic criterion. Any attempt to distribute health care in any other way constitutes an infringement of the rights of individual health care workers.

Applying Nozick's libertarianism to health care, Engelhardt says that it follows that 'a basic human right to the delivery of health care, even to the delivery of a decent minimum of health care, does not exist'. Nor does anyone have a responsibility to provide it for others. Social intervention to secure health care for all perverts justice by placing unwarranted constraints on individual liberty. Organs, babies, the use of women's wombs, may be transferred for money by individuals in a free market. A libertarian is not opposed to any mode of health care distribution which

has been freely chosen by a group. However, in a complex modern state in which agreement amongst individuals is virtually impossible, a libertarian will generally prefer a system in which healthcare insurance is privately and voluntarily purchased by individual initiative.

To whom does a libertarian think the obligations of justice are owed? Once again, there is no one answer. Engelhardt combines a version of libertarianism with a commitment not only to a Lockean notion of personhood but also to the idea that it is only 'persons' who really matter: 'Persons, not humans, are special ... obligations of respect or beneficence vary according to the moral status of the entities involved.'18 Generally, the centrality of autonomy in Nozick's theory would seem to support a 'consciousness criterion' in the allocation of healthcare resources. Those who can exercise moral agency ought to be preferred to those who cannot. In addition those who bring their ill health on themselves do not deserve to be rescued by the state.

Strengths and weaknesses

Libertarians are right to insist that health care is not (or is not entirely) a common resource (like land, air, rivers, the sea) which may be distributed according to some patterned formula. Those who work in health care are not merely 'resources' to be distributed according to someone else's interests or grand plan (though they employ a great deal of what is 'common stock'). And there is something right in the libertarian's emphasis on the entitlement of the individual to look after his or her own life and health: certainly, one of the starting points of the Catholic (natural law) tradition of healthcare ethics is the recognition that each individual person has the primary responsibility to preserve and maintain his or her own health (and that of any dependents). But libertarianism takes both of these ideas too far. Health care workers do not 'own' their labours. Their knowledge, skill and judgment are not entirely of their own creation (however crucial free will and personal motivation are

in their cultivation). Health care workers are educated largely at the public expense, usually in public institutions, and the knowledge they receive is a social product not of their own making. In addition, without a high level of collaboration, there would be no sophisticated hospitals, medical schools, etc. As for the responsibility of each individual to preserve and maintain his or her own health: many things which influence health lie beyond the scope of individual responsibility (poverty, social class, ignorance, genetic predisposition, to name a few).

Justice as doing unto others what one would have them do to oneself

Aristotle's remark that when human beings are friends they have no need of justice, and indeed that the truest form of justice is a friendly quality, sets the tone of what I shall call a 'natural law' approach to justice.19 On this account justice consists in favouring and fostering the common good of one's communities.20 The common good is the good of individuals, an aspect of whose good is friendship, understood as a readiness to promote the well being of other members of a community. 'Few will flourish and no one will flourish securely unless there is effective collaboration between members of a community and co-ordination of their resources and enterprises.'21 These common enterprises are not ends in themselves but rather means of assistance to individuals. So, one part of justice requires distributing things which are essentially common but which must be appropriated to individuals if they are to serve the common good: resources, opportunities, profits and advantages, roles and offices, responsibilities, taxes and burdens.

Given that the objective of justice is to secure the common good, the flourishing of all members of the community, a distribution will be just if it is a reasonable resolution of a problem of allocating the things that are essentially common but that need (for the sake of the common good) to be appropriated to individuals. Proportionality (rather than equality) is a key to recognising the demands

of distributive justice. Inequalities of wealth are not unjust per se. What is unjust is the failure of the rich to redistribute that portion of their wealth which could be better used by others for the realisation of basic goods in their lives.

Fisher has worked out the details of a natural law approach to the distribution of health care. Starting from the idea that health care truly is (at least in some regards) a distributable resource²², he argues that it ought to be distributed according to what he calls the 'Golden Rule of health care' as revealed by the application of the following two-part test. 'Would I think that a healthcare budget and principles of allocation were fair if I (or someone I loved) were in healthcare need, especially if I were one of those excluded from provision or were among the weakest in the community (ie sick with a chronic, disabling and expensive ailment, poor, illiterate, etc)? Would I think them fair were I (or someone I loved) a healthworker, healthplanner, taxpayer and/or insurer?'23 Applying this two part test, he argues, we can conclude that the primary basis for healthcare distribution is simply healthcare need, where satisfaction of that need is compatible with the fulfilment of similar and more important needs of other members of that community.

The concept of need as found in Fisher's work is not 'capacity to benefit', nor 'what is required for self-determination', but more generally (along with food, water, clothing, shelter, exercise, freedom, safety, rest, family) whatever is required for participation in the goods of human life and health. There is thus a certain necessary indeterminacy in the concept of healthcare need. Customs, expectations, standards of living, current technology all influence people's perceptions of their needs. However interventions which are not instrumental to participation in human life and health but which serve some other goal are not genuine healthcare needs: cosmetic surgery, breast enlargement, sex selection of children, euthanasia. For (as Hippocrates insisted) the specific goal of health care is 'the benefit of the sick'.

Who counts as the other in a natural law approach to justice? As in the case of the other three approaches, there is no one answer to this question. Certainly Aristotle was at least tempted to think that what is owed in justice is owed only to male members of one's political community. However the most vibrant expression of a natural law ethic is today found in Catholic Christianity whose answer to that question is conditioned by its concept of the sacredness of human life itself. Every human being is to be treated as one's neighbour, and there is also a special requirement of solidarity with the poor and the vulnerable. The very young, the very old, the disabled, the sick, the frail, the demented, the permanently unconscious, those who may be thought to have contributed to their own illness: all these deserve 'preferential' care. This version of the natural law tradition thus rejects - as unjust - the idea that only those who possess 'personhood' are the proper recipients of health care.24

Strengths and weaknesses

Some health care administrators are impatient with a natural law approach to justice in the allocation of health care resources because it does not generate absolutely-general rules of resource allocation. Some philosophers think that at least the most sophisticated contemporary version of the theory, that advanced by German Grisez and John Finnis, requires support from a Catholic moral theology and thus does not provide a rationally-compelling basis for decisionmaking for any human being of good will.25 So this approach deserves the same careful critical attention as does any philosophical approach. Nonetheless, to my mind at least, it is the most coherent of the four approaches to justice that I have sketched. Like utilitarianism, it insists on the equality of all persons and on impartiality between persons. Like egalitarianism, it insists on what is owed (as a matter of fairness) by the rest of us to the poorest and most vulnerable members of our communities. Like libertarianism, it recognizes the centrality of individual autonomy. But, unlike all of them, it treats solidarity with every other human being, in particular with the poor and disadvantaged, the sick, the disabled, the vulnerable, the very old as well as the very young, not only as elements of communal life but as irreducible aspects of the flourishing of affluent, healthy, articulate, powerful people. What the rich owe to the poor, the healthy to the sick, the independent to the dependent, is not merely a matter of fairness to them but, more deeply, of solidarity with them.

Bringing the paradigms to bear on particular questions

What do these four traditions have to say about the original three sets of questions? Let me make some suggestions.

Care of newborns

A critical question about care of the newborns is: are newborn infants the kind of being to whom we have obligations of justice? Utilitarianism, egalitarianism libertarianism, at least as they are represented by the thinking of the philosophers I have mentioned, may all agree that newborn infants are not the kind of being to whom justice is owed. If this is so, all other points of disagreement between them with respect to what they have to say about the allocation of resources to newborn infants fade into insignificance. For what this implies is that newborn infants do not matter in themselves, that they matter only in so far as they matter to their parents, and that therefore the kinds of health care they should be offered may legitimately be unrelated to the child's health care need.26 Though we should not cause a newborn child unnecessary pain, a newborn child is not entitled to the kind of protection owed to a "person". Having made this move in common, utilitarianism, egalitarianism and libertarianism then offer their own distinctive approaches to how parents should go about making up their minds about the treatment of newborn infants.

The version of natural law I have sketched starts from the very different idea that justice is owed to every human being and that

therefore (no matter how much parents may wish for a perfectly healthy, if not a perfect, child,) they have at least the obligations of justice to their newborn children that they have to all other human beings. (Of course, they have other substantial obligations to their own children.) It is contrary to justice deliberately to bring about the death of a newborn child, whether by deliberately killing or by deliberately letting the child die. True, it is often the case that difficult decisions have to be made about what constitutes appropriate treatment for severely disabled newborn children, but these decisions need to be made in the light of a set of very different ideas: the goals of health care itself (the restoration and maintenance of health and the relief of the symptoms of ill health), the responsibility of parents for the health and well-being of all their children, the legitimacy of forgoing futile or overly-burdensome treatment, etc.

Care of the elderly

The same question - are they the kind of being to whom we have obligations of justice - is also central to our thinking about justice to the elderly. A 'consciousness criterion' for the allocation of resources which is endorsed by writers in all of the first three approaches to justice has the effect of encouraging us to think that we are not obliged to provide health care for some categories of the elderly, in particular the permanently comatose and the demented: for they may not be 'persons'. In this respect all three traditions stand in stark contrast to the version of natural law outlined earlier.27 Even when we set aside what we owe the elderly as a matter of gratitude and piety, this version of natural law reminds us that justice requires us to devote healthcare resources to the elderly as a matter of priority: for as a group they are often amongst the most powerless and the most socially vulnerable in our communities.

What about the legitimacy of an age criterion in the allocation of healthcare resources? Certainly, utilitarianism, in its emphasis on the maximisation of returns on

healthcare investments, is not opposed to the use of such a criterion. Since we should give preference in our allocations to those most likely to receive the greatest benefit in terms of improved length and quality of life, and since the elderly cannot benefit 'as much' from health care as can the young, utilitarianism will tell us that we should devote scarce resources away from the elderly.

Egalitarianism will be ambivalent on the matter. It ought to oppose the use of an age criterion on the grounds that this would be unfair to the elderly. However Norman Daniels has argued that most people would prefer to use their healthcare entitlements when they are young, when they can get the most benefit from them, and that the healthcare system should reflect this fact. And egalitarianism itself might positively support the use of an age criterion on the grounds that it spreads opportunities more widely. After all, it might say, the elderly have already had their fair share of healthcare resources! It may not be unfair to limit the elderly's access to healthcare resources since, in the normal case, everybody will be subject to ageing and thus will be entitled to the same range of health care over a life time.

The libertarian tradition has little to say about the withholding of healthcare resources from the elderly since libertarians do not believe it is the role of the state to impose any pattern of healthcare resource distribution on the society. But, by claiming that the only duties we have are those deriving from contracts we have voluntarily entered into, libertarianism does encourage us to ignore the debt of gratitude we owe the elderly and the duties of care which follow from our particular relationships with them. However, the current debates about libertarian-inspired managed care arrangements in the United States have barely engaged with ethical issues associated with care of the elderly.28

Contemporary natural law sends a very different message. It is critically sensitive to prejudice against the elderly. The way we look after our elderly reveals what kind of people, as individuals and as community, that we really are. Though it is true that health care does not aim at the endless extension of life but rather at the maintenance and restoration of health, this does not justify the abandonment of the elderly, even those who may have lived a reasonable length of life. Certain kinds of hi-tech medical intervention may be recognised as inappropriate for the elderly and even, in circumstances of substantial scarcity, may have to be routinely withheld from the elderly. But even if such hard choices have to be made, the elderly are still entitled to a broad range of communityprovided care such as good pain relief, home and institutional nursing care, hospices for the dying, etc.

In addition, the natural law tradition reminds us that we need to approach the challenges of providing health care to the elderly with a certain kind of character, one marked by the virtues of compassion, moderation, courage, prudence. To take just one example: medical moderation involves a willingness to stop treating, and to stop asking for treatments, in the face of the limits of medical endeavour. Life-sustaining treatments which are reasonably judged to be therapeutically-futile or overly-burdensome ought to be forgone. However we have no right to leap (as some commentators seem to do) from considerations which might motivate some elderly people to volunteer to decline some health care to the conclusion that society or healthcare workers might decide this for all elderly people.²⁹

Responsibilities to the subjects of research in poor countries

In spite of the commitment of some individual utilitarians to the relief of poverty and suffering amongst the poor, utilitarianism itself seems to require the very kinds of revisions to the Declaration of Helsinki suggested by the American Medical Association (cf. footnote 5). In spite of its insistence on impartiality in the calculation of benefits and burdens of proposed actions or policies, in spite of its emphasis on what

people in affluent circumstances owe to people who live in poverty, utilitarianism may well endorse the shift of much of the research by for-profit organisations to Third World countries which would predictably follow such revision to the Declaration. Utilitarianism requires the bringing about of the greatest good for the greatest number. If diluting the standard of equivalency from 'best current practice' to 'local practice' and diluting the requirements of informed consent are likely to bring that about, then those changes ought to be made. The generally low standard of health care in developing countries would give researchers the opportunity to undertake more efficient trials there than in developed countries, and these differences in the availability of treatment between developed and developing countries could be exploited by Western researchers to reduce the costs of clinical trials.

Egalitarian theories of justice, in particular a Rawlsian theory which emphasises our obligations to the poor and disadvantaged, would resist changes which would dilute the ethical standards according to which research on human participants is conducted in underdeveloped countries. Libertarianism would be ambivalent on the matter. On the one hand, a libertarian approach would insist on genuine respect for the rights and liberties of potential research participants and would remind us to be particularly attentive to their capacity to give genuinely free and informed That capacity may be so consent. compromised, by social and political circumstances and by extreme poverty, that research should not be conducted at all. On the other hand, a libertarian approach informs much of the recent growth in research conducted by for-profit organisations and the concomitant emphasis on market principles. Pharmaceutical companies face very high costs in developing new products. Libertarianism would support their right to apply their own standards to their own research projects.30

The natural law approach sketched above would, I think, oppose the changes to the Declaration which were proposed. There are cultural and national differences in the

availability of health care resources, and we should not insist on the achievement of impossible goals in the provision of health care in developing countries. However exploitation of the poor is unjust. Recruiting subjects to a clinical trial, and giving some of them a placebo when a known cure for their condition is available, is a form of exploitation, whether it maximises utility or not: a moment's reflection on the fact that it would not be possible to conduct such a trial in most developed countries reveals that. It is not enough to argue that the research population will not be harmed (even if they are in a 'no treatment' arm) because the local standard of care is 'no treatment'. Nor is it enough that successful results bring overall benefit to human health. Clinical trials are just only if there is a reasonable likelihood that the population in which they are carried out itself stands to benefit from successful results.31 In addition, though a natural law approach does not treat the principle of informed consent as an ethical trump card, it would nonetheless resist any relaxation of that principle. The common good requires the active participation of individuals in decisions which affect their own lives.³² Researchers should treat potential research subjects as partners in a project they understand and in which they volunteer to participate. The local community should be involved in the working out of its own priorities in health care. 33

Conclusion

Justice is only one virtue. (Rawls, however, argues that it is the cardinal virtue of social institutions such as healthcare systems. If an institution is not just then, regardless of what other virtues it has, it ought to be changed or demolished.) I have tried to illustrate how four strands of thought about justice influence our ideas about care of the newborn, care of the elderly, and the responsibilities of researchers to human beings living in poverty who may be the subjects of research. I have attempted to identify the elements in each approach which truly capture some aspect of our responsibilities in justice to the very young, the very old and the very poor.

Footnotes

1 See for example Boyd, Kenneth (1983) 'The ethics of resource allocation', Journal of Medical Ethics, 9: 25-27

2 See, for example, Kluge, Eike-Henner W (1988): 'The calculus of discrimination', in JE Thornton (ed) Ethics and Aging: The Right to Live and the Right to Die, British Columbia UP, Vancouver, 1988, 84-97

3 Norman Daniels, Am I My Parents' Keeper? Oxford University Press, Oxford, 1988

4 Daniel Callahan, Setting Limits: Medical Goals in an Aging Society, Simon & Schuster, New York, 1987

5 The American Medical Association proposed a series of revisions to the Declaration of Helsinki which would have sanctioned such practices, the most far-reaching of which were as follows: (a) to do away with the distinction between 'medical research in which the aim is essentially diagnostic or therapeutic for a patient' and 'medical research, the essential object of which is purely scientific and without implying direct diagnostic or therapeutic value to the person subjected to the research'; (b) to water down the requirement that 'every patient - including those of a control group, if any - should be assured of the best proven diagnostic and therapeutic method' to the weaker requirement that a research subject should not 'be denied access to the best proven diagnostic, prophylactic or therapeutic method that would otherwise be available to him or her'; (c) to waive the requirement that a physician should obtain the subject's freelygiven, informed consent, preferably in writing if an ethics committee determined that the risks posed by the research were slight or if the procedures to be used in the research were customarily used in medical practice without informed consent; and (d) to water down the prohibition on publication of research not in accord with the articles of the Declaration and allow individual editors to consider the justifications that investigators offer and make their own decisions about the publication of 'unethical' research. (See Bulletin of Medical Ethics, in particular No 150, August 1999)

6 Paragraph 3 of the Hippocratic Oath: 'I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.' See Leon Kass' 'Is there a Medical Ethic? The Hippocratic Oath and the Sources of Ethical Medicine' for an examination of this idea. Leon Kass, Towards a More Natural Science, The Free Press, New York, 1985

7 For the fourth of these approaches see Anthony Fisher OP: The Principles of Distributive Justice considered with reference to the Allocation of Resources (DPhil thesis). In my judgment this thesis contains not only the best analysis of the elements and implications of contemporary moral philosophy on this subject but also the most sound and coherent account of what justice actually does require of us with respect to health care.

8 Fisher (op cit) identifies these four broad principles.

9'... in making ethical judgments we go beyond our own likes and dislikes. From an ethical point of view the fact that it is I who benefit from, say, a more equal distribution of income and you, say, who lose by it, is irrelevant. Ethics requires us to go beyond 'I' and 'you' to the universal law, the universalizable judgment, the standpoint of the impartial spectator or ideal observer.' Peter Singer, Practical Ethics, Cambridge University Press, Cambridge, 1979, 11

10 Peter Singer, Rethinking Life and Death, Text Publishing Company, Melbourne, 1994

11 An organism possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity.' Michael Tooley, 'Abortion and Infanticide' in Marshall Cohen, Thomas Nagel and Thomas Scanlon (eds) The Rights and Wrongs of Abortion, Princeton University Press, 1974, 59

12 Fisher, op cit

13 Fisher, op cit

14 Anarchy, State and Utopia, Blackwell, Oxford, 1968, ix

15 See, for example, Ronald Dworkin, 'What is equality?' *Philosophy and Public Affairs*, Vol 10, 1981

16 Well meaning charity may simply discourage people from taking responsibility for themselves.

17 H Tristram Engelhardt, The Foundations of Bioethics, Oxford University Press, 1986, 336. Fisher (op cit) queries whether this actually follows from the details of Nozick's theory.

18 F. Tristam Engelhardt, op cit, 104-5

19 Nicomachean Ethics, 1155a25

20 Stephen Buckle's short history of a 'natural law' ethics shows how disparate are many of the elements of the natural law tradition. See his 'Natural Law' in A Companion to Ethics, Peter Singer (ed), Blackwell, 1991

21 John Finnis, Natural Law and Natural Rights, Clarendon Press, Oxford, 1980, part vii.i

22 Though healthcare professionals should not be treated as though they were hospital beds or doses of drugs which can be moved about, reorganized, allocated, etc., health care itself is a largely social creation (an accumulated body of knowledge and skill which is passed on in public universities and exercised in public hospitals) which must be appropriated to particular individuals if it is to occur at all.

23 Fisher, op cit, 135

24 As Bernard Williams has pointed out, almost all the characteristics associated by philosophers with 'personhood' - such as the capacities for responsible action, for relations with others, for first-personal reflection, and so on - come in degrees. Indeed, they come in different degrees, and are not simply correlated with each other, nor with different ages, states of mental health or other such attributes. Bernard Williams: 'Which slopes are slippery?' in Moral Dilemmas in Medicine, edited by Michael Lockwood, Oxford University Press, 1985

25 According to Jean Porter, Grisez and Finnis have articulated a version of natural law theory which defends Catholic moral teaching (particularly about the beginnings and end of life) at the cost of being rationally necessary. See John Finnis: Natural Law and Natural Rights, op cit. Germain Grisez: The Way of the Lord Jesus, Vols 1-3, Franciscan Press, Vol 1:1983, Vol 2: 1993, Vol 3:1997. Jean Porter: Moral Action and Christian Ethics, Cambridge University Press, 1995

26 Singer, Rethinking Life and Death, op cit, 212

27 Recall the first part of Fisher's golden rule of healthcare resource allocation: Would I think that a healthcare budget and principles of allocation were fair if I (or someone I loved) were in healthcare need, especially if I were one of those excluded from provision or were among the weakest in the community (ie sick with a chronic, disabling and expensive ailment, poor, illiterate, etc)?

28 See, however, Helen McCabe, 'The ethical implications of Managed Care: a matter of context', *Bioethics Outlook*, Vol 11, No.3, 2000, 1-6

29 Boyle, JM: 'Should age make a difference in health care entitlements?' in Luke Gormally (ed) The Dependent Elderly: Autonomy, Justice and Quality of Care, Cambridge University Press, 1992, 147-157

30 Increasingly, as ethics committees of forprofit organizations become as prominent as university-sponsored research ethics committees, and the global economy seeks out the cheapest way of testing new products, market place principles threaten to undermine the Declaration of Helsinki's commitment to the protection of each individual research subject.

31 Perinatal HIV Intervention Research in Developing Countries Workshop Participants, *Lancet*, 1999, 353, 832-5

32 A substantially revised version of the Declaration of Helsinki was approved at a meeting of the members of the World Medical Association in October 2000. The revised version is available in the Bulletin of Medical Ethics 162 (October 2000) 8-10. The major changes include a greater emphasis on the priority of the well-being of research participants over the interests of science and society, more emphasis on an assessment of the risks and benefits of the research and greater ethical guidance for research that is sponsored by developed countries but undertaken in developing countries. In response to the changes proposed by the American Medical Association the suggestions to weaken the requirements for consent and for publication of research not in conformity with the existing version were not accepted. The distinction between therapeutic and non-therapeutic research was removed. The requirement that each participant be assured of the "best proven diagnostic and therapeutic method" was changed to the "best current diagnostic and therapeutic method". No qualifiers diluting this standard to allow for local medical practice were added. A further discussion of this and other changes to the Declaration will be the subject of an article in the next edition of Bioethics Outlook.

33 Researchers should determine actual rather than supposed local attitudes and not treat the approval of a government or national ethics committee as a substitute for community consultation.

Bioethics Outlook is a quarterly publication of the Plunkett Centre for Ethics in Health Care, a university research Centre of Australian Catholic University and St Vincents & Mater Health, Sydney Telephone (02) 8382 2869 Facsimile (02) 9361 0975 e-mail plunkett@plunkett.acu.edu.au Editor: Bernadette Tobin Layout: Linda Purves Subscription is \$65.00 (Institutions), \$40.00 (Individuals) and \$20.00 (Students or Pensioners). \$15.00 overseas airmail 10% GST

Plunkett Centre for Ethics in Health Care, St Vincent's Hospital, Darlinghurst NSW, 2010 ISSN 1037-6410