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The Abnormal Child

Moral Dilemmas of Doctors and Parents

R. M. Hare

I was asked to make a philosophical contribution to our discussions; and any philosopher who tries to do this sort of thing is up against a serious difficulty. If he is content to act merely as a kind of logical policeman and pick up bad arguments that are put forward by other people, he will be unpopular, but may (if he is competent at his trade) establish for himself a fairly strong negative position. But if he wants to do something more constructive than that, and is going to rely on something more solid than his own intuitions and more stable than the received opinions on the subject, he will have to start from some general theory about how one argues on questions like this; and then at once he is on much shakier ground, because there is no general theory about moral argument that is universally accepted. All I can do in this situation is to tell you in outline the theory that I accept myself and then argue from that.

However, I have perhaps made my position sound shakier than it actually is; for the theory that I shall be using is one which ought to be acceptable to most of the main schools of ethics, because it relies only on certain formal characteristics of the moral words or concepts which we use in these arguments. I *think* (though obviously I shall have no time to argue) that this theory is consonant with the Christian principles that we should do to others as we wish that they should do to us, and that we should love our neighbour as ourselves; with the Kantian principle that we should act in such a way that we can will the maxim of our action to be a universal law; and with the utilitarian principle that everybody is to count as one and nobody as more than one (that is to say, that their interests are to be equally regarded). Other approaches to the theory of moral argument which lead to the same kind of principle are the so-called Ideal Observer theory, according to which what we ought to do is what a person would prescribe who was fully acquainted with the facts and impartially benevolent to all those affected; and the so-called Rational Contractor theory which says that the principles we ought to follow are those which a rational self-interested person would agree to if he did not know which end of the stick *he* was going to receive in any of the situations to be adjudicated by the principles.

All these methods come really to the same thing, that when faced with a decision which affects the interests of different people, we should treat the interests of all these people (including ourselves if we are affected) as of equal weight, and do the best we can for them. This is the fundamental principle. There are a great many other principles, some of them of great importance, which occupy a different level from this fundamental principle, and may appear to conflict with it, as they certainly do conflict on occasion with one another. I mean principles like those which forbid

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lying or promise-breaking or murder; or that (very important to doctors) which demands loyalty to those to whom one is under some special obligation owing to a particular relation one stands in to them (for example one's wife or one's child or one's patient).

However, I think it is right to subordinate all these principles to the fundamental one, because in cases of conflict between these different principles, it is only the fundamental principle that can give us any secure answer as to what we should do. The fundamental principle is the law and the prophets; although particular laws (and particular prophecies for that matter) are no doubt very important, they take their origin from the need to preserve and to do justice between the interests of people (that is, to secure to them their rights); and when there is a conflict between the principles – or even some doubt about the application of a particular principle – it is this fundamental principle which has to be brought in to resolve it.

An example that may occur to you after having heard what has been said is this: granted that the obstetrician has a special duty to his patient, the mother, and that the pediatrician has a special duty to *his* patient, the child, surely what they ought all in all to do when the interests of mother and child conflict should be governed by equal consideration for these interests and not by what branch of the profession each of them happens to have specialized in.

I am going therefore, in the hope of shedding some light on the dilemmas of doctors and parents, to ask, first of all, what are the different interests involved in the sort of case we are considering. There is first the interest of the child; but what *is* this? We can perhaps illuminate this question by asking "What if it were ourselves in that child's position – what do we prescribe for *that* case?" On the one hand it may be presumed to be in the child's interest to live, if this is possible; but if the life is going to be a severely handicapped one, it is possible that this interest in living may be at least greatly diminished. Then there is the interest of the mother, in whose interest also it is to live, and whose life may be in danger; and it is also in her interest not to have an abnormal child, which might prevent or severely impair the normal development of the rest of the family. The other members of the family have a similar interest. Against this, it is said that good sometimes comes to a family through having to bring up an abnormal child; and I can believe that this is so in some cases.

Then there are the interests (not so great individually but globally very great) which belong to those outside the family: first of all those of doctors and nurses who are concerned; then those of the rest of the staffs of hospitals, homes and other services which will be involved in looking after the child and the family. There are also the interests of all those people who *would* be looked after, or looked after better, by all these services if they did not already have too much on their hands; and there are the interests of the taxpayers who pay for it all. And lastly, there is another interest which is commonly ignored in these discussions, and which is so important that it often, I think, ought to tip the balance; but what this other interest is I shall not reveal until I have talked about those I have mentioned so far.

When I said that equal consideration ought to be given to all the interests affected, I did not mean that we should treat as equal the interest of the mother in continuing to live and that of the doctor in not being got out of bed in the middle of the night. As individuals, these people are entitled to equal consideration; but because life matters more to one than sleep to the other, that makes it right for the doctor to get out of bed and go and look after the mother. If the doctor had a car smash outside the mother's front door and she could save *his* life by getting out of bed in the middle of the night, then by the same principle she should do so. As individuals, they are equipollent; the difference is introduced by the differing importance to each of them of the various outcomes.

The number of those affected can also be important; if a GP can save a patient from a sleepless and distressful night by going along in the evening and providing a pain-killer, he will often do it, even in these days; but if a pill were not enough, and it were necessary for a whole team of nurses and an ambulance to turn out, he might decide to wait till the morning unless there were a real danger of a grave deterioration in the patient's condition. A very large number of people each of whom is affected to a small degree may outweigh one person who is affected to a greater degree. So even the fact that 60 million taxpayers will have to pay an average of 20 pence extra each a year to improve or extend the Health

Service is of some moral, as well as political, importance. But I agree on the whole with those who ask us not to attach too much importance to these economic arguments; although I totally failed recently to get from an economist a straight answer to the question of the order of size of the sums involved in looking after handicapped children, I am prepared to accept for the sake of argument that they are relatively small. So let us leave the taxpayer out of it, and the rival claimants for care, and just consider the interests of the immediate family.

Here, however, we must notice the other important interest that I mentioned just now – that of the next child in the queue. For some reason that I cannot understand this is seldom considered. But try looking at the problem with hindsight. The example I am going to use is over-simplified, and I am deliberately not specifying any particular medical condition, because if I do I shall get my facts wrong. Suppose the child with the abnormality was not operated on. It had a substantial chance of survival, and, if it survived, it had a large chance of being severely handicapped. So they didn't operate, and what we now have is not that child, but young Andrew who was born two years later, perfectly normal, and leaves school next summer. Though not brilliant, he is going probably to have a reasonably happy life and make a reasonably useful contribution to the happiness of others. The choice facing the doctors and the family was really a choice between (if they didn't operate) a very high probability of having Andrew (who would not have been contemplated if they had a paralysed child in the family) and on the other hand (if they did operate) a combination of probabilities depending on the precise prognosis (shall we say a 10 per cent chance of a living normal child, a 40 per cent chance of a living but more or less seriously handicapped child, and a 50 per cent chance of a dead child plus the possibility of Andrew in the future).

If we agree with most people that family planning is right, and that therefore this family is justified in limiting its children to a predetermined number (however large), then that is the kind of choice it will be faced with, and in the situation I have imagined *was* faced with. We should try discussing with Andrew himself whether they made the right choice.

If I have characterized the choice correctly, then nearly everything is going to depend on what the prognosis was, and on our estimates of the value *to the persons concerned* of being alive and normal, and, by contrast, of being alive and defective or handicapped in some specified way. In making these value-judgements I do not see that we can do better than put ourselves imaginatively in the places of those affected, and judge as if it were our own future that was at stake. Since a sensitive doctor is bound constantly, in the course of his practice, to make this sort of imaginative judgement about what is for the best for other people, looking at it from their point of view, I do not think that it can be said that it raises any difficulties of principle; but it obviously raises very great difficulties in practice, which the sensitive and experienced doctor is as likely as anybody to be able to overcome in consultation with parents and others affected.

But the problems mostly arise from the difficulty of prognosis. That is why the work reported by Professor Smithells is so crucial. In principle it might be possible to put a numerical value upon the probabilities of the various outcomes, and having estimated how the various outcomes for the people involved affect their interests, to make a utilitarian calculation and choose the course that gives the best prospect of good and the least prospect of harm for those concerned, all in all. In practice we are bound to rely a lot on guesswork; but when guessing, it is an advantage to have a clear idea of what you are guessing *at*, and I have suggested that what we should be guessing at is what is for the best for all the parties taken together.

The prognosis, however, is always going to be pretty uncertain, and the question therefore arises of *when* the decision should be made. I suppose that it would be agreed that if there is doubt in the very early stages of pregnancy, it might be advisable to wait until the fetus had developed sufficiently to make the prognosis more certain. A hard-headed utilitarian might try to extend this principle and say that in cases of suspected abnormality we should let the child be born, operate if appropriate, and then kill the child if the operation resulted in a very severe handicap, and have another child instead. In this way we should maximize the chances of bringing into the world a human being with a high prospect of happiness. If the medical profession finds this suggestion repugnant, as it almost

certainly does, and does not *want* the law changed; or if it is thought (perhaps rightly) to inflict too much mental suffering on the mother, then we shall have to be content with a far less certain procedure – that of either terminating or, if we don't terminate and then the child is born, estimating the chances *before* deciding whether to operate, and (if we do decide to operate) taking the risk, however small, of being left with a dreadfully handicapped child.

If we imagine our possible Andrew and his possible brother (the former existing only as a possible combination of sperm and ovum, the latter already existing as a fetus) – if, I say, we imagine them carrying out a prenatal dialogue in some noumenal world (and of course the supposition is just as fantastic in one case as it is in the other) and trying to arrive at a solution which will give them, taken together, the best chance of happy existence, the dialogue might go like this. Andrew points out that if the fetus is not born there is a high probability that he, Andrew, will be born and will have a normal and reasonably happy life. There is of course a possibility that the parents will change their minds about having any more children, or that one of them will die; but let us suppose that this is rather unlikely, and that there is no particular fear that the next child will be abnormal.

To this the fetus might reply, "At least I have got this far; why not give me a chance?" But a chance of what? They then do the prognosis as best they can and work out the chances of the various outcomes if the present pregnancy is not terminated. It turns out that there is a slim chance, but only a slim chance, that the fetus will, if born and operated on, turn into a normal and, let us hope, happy child; that there is a considerable chance on the other hand that it will perish in spite of the operation; and that there is a far from negligible chance of its surviving severely handicapped. In that case, I think Andrew, the later possible child, can claim that he is the best bet, because the chance of the parents dying or changing their minds before he is born is pretty small, and certainly far less than the chance that the present fetus, if born, will be very seriously handicapped.

In order for the fetus to prevent Andrew winning the argument in this way, there is one move it can make. It can say, "All right, we'll make a bargain. We will say that I am to be born and operated on, in the hope of restoring me to normality. If the operation is successful, well and good. If it isn't, then I agree that I should be scrapped and make way for Andrew." I think you will see if you look at the probabilities that this compromise gives the best possible chance of having a healthy baby, and at the same time gives the fetus all the chance that it ever had of itself being that baby. But it does this at the cost of abolishing the substantial chance that there was of having this particular child, albeit in a seriously handicapped condition. I call this a *cost*, because many will argue (though I am not sure that I want to follow them) that life with a severe handicap is preferable, for the person who has it, to no life at all. Of course it depends on the severity of the handicap. And of course this policy involves so much distress for the mother that we might rule it out on that score alone, and terminate instead.

Perhaps I should end by removing what might be an obstacle to understanding. In order to expound the argument, I asked you to imagine Andrew and the fetus having a discussion in some noumenal world (and, by the way, it needn't bother you if you don't know what "noumenal" means; I only used it in order to keep my philosophical end up in the face of all your no doubt necessary medical jargon). This way of dramatizing the argument is perhaps useful though not necessary; and it carries with it one danger. We have to imagine the two possible children conducting this very rational discussion, and therefore we think of them being in a sense already grown up enough to conduct it; and that may lead us to suppose that, for either of them, to be deprived of the possibility of adulthood *after* having had this taste of it would be a very great evil. People (most of them) cling tenaciously to life (though it is a matter for argument, at what age they start to do this); and therefore to deprive a person of life is thought of as *normally* an evil. This certainly does not apply to Andrew, since he is not alive yet and so cannot be *deprived* of life in the relevant sense, though it can be *withheld* from him. I do not think it applies to the fetus as such, since it has as yet no conscious life (which is what we are talking about) and therefore cannot feel the loss of it or even the fear of that loss. If anybody thinks that fetuses *do* have conscious feelings sufficient to be put in this balance, I ask him to agree at least that their intensity is

relatively small, and likewise of those of the newborn infant. So I do not think that the harm you are doing to the fetus or the unsuccessfully operated upon newborn infant by killing them is greater than that which you are doing to Andrew by stopping him from being conceived and born. In fact I think it is much less, because Andrew, unlike them, has a high prospect of a normal and happy life.

In my view as a philosopher, these are the sorts of considerations that doctors, surgeons and parents ought to be looking at when they are faced with these dilemmas.