BIOETHICS OUTLOOK

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Ethical Issues in Post-Natal Testing

In this issue

In several issues last year, we published papers which had been given at a Plunkett Centre seminar entitled "Our Genetic Future: Ethical Issues" which was held at the end of 1996. The first article in this issue is the last of the papers from that seminar which we mean to publish. In it, John Quilter identifies some of the questions which we need to ask as a community about the growing practice of post-natal genetic screening and testing.

Andrew Murray revisits that important question of social policy, whether a decent society should legalise euthanasia. He argues that any such legislation would, paradoxically, limit the range of choices open to patients whose lives are drawing to an end.

Fr Jean Kitahara-Frisch reads two recent reports on cloning human beings and notes that some significant ethical issues, arguable *the* most significant ones, are omitted from the recent Report of the U.S. President's Commission but given due recognition in a recent French Report.

Finally Keith Joseph comments on a common theme in our first three articles: each, he thinks, raises questions to do with the proper relationship between morality and the law.

John Quilter

Broadly speaking, we can distinguish four stages where ethical issues can arise in connection with genetic testing and screening. The first stage is that of gaining access to a subject's genetic materials. The second concerns the health-related purpose or purposes to which results of testing will be put. The third stage concerns further uses of results. Finally some questions need to be raised about the inherent social risks of an overly reductionist conception of the significance of molecular genetics for medicine and the general understanding of human nature.

Testing

First, consider gaining access to a person's genetic material for a health-related purpose. What ethical issues arise here? The most obvious issue is the autonomy of the test-subject. Whether it is screening or testing we are considering, the subject's autonomy must be respected. Essentially, this does not involve any new problems beyond those involved in other parts of medicine, though it is always worthwhile to emphasise certain points. Information must be relevant, honestly explained to the subject in adequately comprehensible language, without intellectually bullying, and the subject is owed the space in which to make her own mind up. Where the testing requires the cooperation of other family members (for instance to assess by link-marker methods whether the subject may carry a defective gene), this certainly should be explained to the prospective subject,

for it may bear on sensitive relationships that she has with family members.

An important question in this connection concerns the obligations of family members in whose genome a given person may have an interest. For instance, what obligations does a woman have to her husband regarding their possible future sons, where she has a brother who had Duchenne Muscular Dystrophy? Does she have a moral obligation to be tested to see if she carries the troubling gene? Does her mother have an obligation to be tested, on the grounds that she might be the original carrier?

It is plausible to argue that such relatives have some obligation to be tested for their relative's sake. But it would be altogether unreasonable to force the unwilling to cooperate. On the other hand, there may be certain risks for such a relative if he or she is tested. Finding that one is a carrier of a gene which one has transmitted to a child who is ill as a result can induce a cause of a species of guilt. Conversely, discovery that one luckily avoided a bad gene which, say, one's siblings have, can occasion survivor guilt. Also one's siblings could become resentful. Risks of this sort may counterweigh against other considerations which support the idea that someone has some obligation to be tested for a relative's sake.

Might there be grounds on which a community could be justified in coercing its members (or some of its members) to be genetically tested? I take it that it is possible in the abstract, for instance, where genetic screening is necessary and effective for controlling some serious public health risk. However, this would require very strong evidence that the public health risk is real, that it is genuinely genetically derived, that diagnosis does permit therapy and is not a smokescreen for oppression, and so on. So, while the envisioned scenario is possible in the abstract, ethical caution should lead us to be extremely circumspect about finding the abstract possibility realised.

The Medical Argument

If we have methods for determining that some individual has some chance of having (or certainly has) some condition which is dysfunctional, it can seem obvious that having the knowledge is better than ignorance. A best case is one where we can respond to diagnosis with cure. But, of course, there are other constructive responses which this knowledge might make possible. We might know how to take steps to retard symptom development, even though we cannot cure. Or we might be able to ameliorate the patient's condition by sundry prophylactic or forethoughtful efforts, though we are unable either to cure or to retard symptom development. Various methods of genetic testing give us such options for some conditions. Surely, then, genetic testing can only be a good thing.

"Might there be grounds on which a community could be justified in coercing its members or some of its members to be genetically tested?"

I do not want to challenge the general thrust of such a line of thought. In the abstract, it is unexceptionable. Forewarned is forearmed. But it is not good for an argument to be allowed complacently to rest on its laurels. We should poke it a bit, make it do a few laps and generally insist that it really pull its weight, before we give it a place in the team. We need to see how it comes up after we have leaned on it a bit with some critical attention. For I am a bit suspicious of this argument, indeed, of any argument that seems so straightforward.

The strongest applications of such an argument would be where curative treatment exists for the condition for which we are testing. Here we can actually do something for the patient with our knowledge that she has the condition. While this applies to many diseases and illnesses, it is not true of any genetic ones. Presumably, in time, it will be. Then the consideration of the medical benefit possible for the patient, given accurate

diagnosis, will be subject only to those other relevant considerations of clinical ethics familiar from other parts of medicine: patient autonomy, respect for bodily integrity, the fair and reasonable allocation of resources, and the like. However, genetic therapy is still somewhat bioethical science fiction.

For the fact is that the best we can do for genetic and chromosomal problems is either symptom inhibition (such as with phenylketonuria) or other kinds of amelioration. At this point we it can be urged that carers or patients can be prepared for what is in store for them and avail themselves of expert advice, counselling and so on. However much testing is only predictive or merely diagnostic. Moreover, depending on whether the testing method under consideration is link-marker testing or direct molecular analysis, other potential ethical complexities arise from the different features of the methods of testing and their results. Further, we understand more clearly now that familial indications of the desirability of testing a given individual are not a necessary condition for the desirability of testing. Some conditions have or seem to have a genetic basis, even though there is not an obvious family history (evidence mutations in the gene for B amyloid protein in Alzheimer's Disease; prion mutations in Creutzfeld Jakob Disease (CJD) dementia; and p53 mutations in multiple cancer syndromes). If genetic testing for conditions taken to be genetic because of patterns of family history is reasonable in the absence of cure, it is also presumably reasonable for persons at risk for conditions which turn out to be genetic, though they were previously thought not to be because of a lack of obvious family history. But where might this end?

We might say that we shall end it with conditions where phenotypical family history is evident. But already this is a step away from our original argument. Moreover, why should we limit it here? Perhaps because we cannot predict what we will discover to have a genetic basis. Perhaps because if we did not so limit the argument, we could be led into routinely analysing each individual's genome at birth, so wide is comprehension of disease predisposing genes. And since that could be too much trouble or too much expense for too little medical good done, it would not be defensible. Again, we might plausibly suppose that it would involve altogether too great an invasion of privacy, and therefore we could not condone it. We have to limit the scope of our argument's application.

But, of course, this only goes to show that the potential medical benefits to the patient of genetic testing do not, *on their own*, justify the testing. Other things matter too: the privacy of the test subject - the fact that potential benefits notwithstanding, she has the right not to have her genomic information revealed. There is the issue, too, of the fair and reasonable allocation of resources, in particular, if patients cannot be made better, nor the management of the symptoms they will suffer or have a chance of suffering be greatly ameliorated. Does the expense of testing receive justification from the other benefits patients (or parents or other carers) may derive from the results?

Finally, it is not true for all patients that the potential medical benefits of all available genetic tests represent for them benefit sufficient to balance other considerations they take to weigh against being tested. On the one hand, for instance, it seems that the vast majority of mothers want their newborn boys tested for Duchenne Muscular Dystrophy (DMD) if they are given the opportunity for testing elevated creatine kinase levels. But, interestingly, of the twelve confirmed positive cases of DMD up to November 1993 (in a study of a Welsh voluntary DMD screening programme), three families did not want confirmation of the diagnosis by a DNA analysis looking for deletion in the gene, and a further two families did not want a muscle biopsy done when no gene deletion could be found. These families preferred to live with the uncertainty. Moreover, there is research evidence on the presymptomatic predictive diagnosis of Huntington's disease which indicate that a large number of people, when they have the opportunity to confirm their own genetic status, decline to do so. Finally, in the case of neonatal molecular analysis,

some suggest that predictive knowledge can interfere with successful maternal bonding and threaten family stability.

I conclude from these thoughts that, though the abstract appeal of the main medical argument for genetic testing is undeniable, there are several considerations which, when taken seriously, qualify the argument's persuasive force.

Further Uses of Results

Let us now move to the third stage. Assuming that access to genetic material for testing or screening is ethically obtained and that the results of tests are put to ethically good purposes, is there anything else to think about?

There are issues about the records of results: How are they to be stored? Should they be entered into medical records? Should there be a system of notification? What should be done with a deceased's results given that relatives may benefit from knowledge of the results? Other questions will arise depending on details of the condition, methods of testing and so forth. In general, the considerations which are relevant will be familiar ones: confidentiality, harm/benefit to third parties, and so on. In general confidentiality is not an absolute duty, but it is a very serious one. Any justification for breaching it must rest on serious reasons.

Other issues arise concerning the retention of samples used for testing. Again, the problems in connection with genetic testing are not essentially different from those related to other methods of testing. For example, informed consent for testing a sample for a specific condition is most important. Should, say, new knowledge develop which identifies a polygenetic condition, a new request for informed consent to test stored samples for a subject may be in order. Or again, where a condition is discovered to have a genetic basis previously unsuspected, a new request so that informed consent to test stored samples for a subject will be in order. The possibility of eventualities like this should be explained to subjects, as far as possible, at the initial stage so that informed consent for testing and obtaining samples can then be sought.

A particularly thorny situation to be in, for example would be to have test results from a relative, A, who has hitherto been thought not to have genetic risk nor to carry a troublesome gene, and who has been tested only for another's benefit (for example, link marker tests for person B). Imagine that A's results presymptomatically predict disease or show that A carries a "bad gene". Where B had been one's patient, does A now become one's patient? It is best to be prepared: A should be informed of such possibilities at the initial stage of being sought to cooperate for B. Our predicament with A is avoidable.

Testing and Screening and Social Matters

When we consider genetic testing for medical purposes, where the genetically-based conditions uncontroversially represent illnesses, diseases or other kinds of dysfunction which are (as it were) part of medicine's "core business", it is no different from any other part of medicine. Provided that such testing respects the ethical considerations which any medical testing should respect, and those which arise because of the involvement of family relationships, unsuspected genetic susceptibility and the like, such genetic testing is ethically at least as good as the character of those who perform it.

However, it would be naïve to think that this is all there is to consider. For not all "genetically based" conditions are uncontroversially diseases, illnesses or the business of medicine. The methods of testing and the emerging knowledge of the Human Genome Project will be just as easy to use in circumstances which are more controversial. And the uses to which they can technically be put are, correspondingly, not necessarily health-related ones. Of course, this fact is precisely the idea that initiates hysterical doom-saying speculations that a totalitarian society or majoritarian mainstream of society will screen all newborns and coercively sterilise carriers of genes thought to underlie

undesired traits (such as certain skin colours, fatness, and independence of mind).

But, as fantastic as such scenarios are, there is a point in considering them. For the boundary between genetically-based conditions which are the business of medicine and those which are not, is not a hard-edged one. If you like, the precise membership of the set of diseases is not a matter of hard natural fact like the membership of the set of electrons. The definition of disease is, even if only at the boundaries, sensitive to non-scientific criteria (which is not to say that these criteria are unscientific). These criteria may be environmental, cultural, ethical, political, or religious, depending on the details.

"... we can all be tempted by the heady success of profound discovery and powerful technology..."

But if this is so, there are certain pitfalls of which the scientific community and the community at large must be mindful in the application of any technology, and in genetic technology in particular, outside the "core business" of medicine which is focussed on the sick.

One of these pitfalls is that we love Science, (with a capital "S"!) and in particular, we love enquiries into our origins and into ways of "making life and society better". We are therefore somewhat receptive to bold claims that, in particular, the sources of our ailments and problems are in our genes. When such tendencies are combined with the desire to maximise profits, entrench existing interests, racial and other prejudices, and undemocratic victimisation of those who are different or minorities, the availability of predictive genetic tests is a formula with real potentiality for evil. And one would be naïve not to credit human beings with the inventiveness to apply these tests to such ends.

This is not, of course, a criticism of science in general nor of genetic technology in particular. But notice, it is not, as we say, criticism of Science and Genetics *as such*. The "as such" is important. Its force is to immunise us from conclusions such as that we should cease the effort to refine our methods, we should massively cut funding for basic genetic research or we should otherwise send genetic technological work to Coventry.

But dwelling on the "as such" for these reasons, that is, dwelling on the correct distinction between Medical and Scientific knowledge, research and technology *as such*, on the one hand, and the abuses to which society may put them, on the other, is actually disingenuous. For instance, unscrupulous employers might abuse Science by screening workers for genes for work-place related vulnerabilities as a pretext for discriminating against blacks. Or heartless insurance companies might set their face against people seeking medical or life insurance who test positive for genes which may make these people vulnerable to diseases which could be costly to the companies. While such socially, ethically and politically questionable use of genetic testing do not show that the Science and the technology is not valuable, they do make a point about the people who are the scientists. Scientists are human beings. They have ethical and political biases like the rest of us. They are as susceptible to the flattering word as the rest of us. In fact, some members of noble professions, particularly Medicine, have been party to most unconscionable exploitation, wickedness and deception, in the name of Science. This is simply a fact.

And the point is not just a story of a few bad apples. The real point is that we can all be tempted by the heady success of profound discovery and powerful technology. We can be tempted by an unquestioning acceptance - *as a community* - of standards of practice that are wrong. We can use people viciously in the name of truth. We can trample rights - especially of those already vulnerable - when driven by the compelling desire to push the technology just that bit further.

There are only two sources of check upon the natural human tendencies: oneself and others. The genetics community has to adopt an attitude of ethical self-scrutiny and not sag into the complacent acceptance of unquestioned assumptions - for example, that there certainly are no ethical questions here, or that there is an ethical consensus in the genetics community. Consensus in values troubles me wherever I see it: it is the stuff of ethical complacency and prejudice. But this is a general lesson which can be applied to all communities.

Genetic Reductionism

In this connection, more directly related to the issue of screening and testing, it is desirable to challenge genetic reductionism in particular. Before we get too enthusiastic about widespread genetic testing and screening, let us be sure that there are not other, non-genetic factors which we do better to attend to before we differentiate between people on the basis of their genome. For instance, let us strive to make workplaces safer before we use genetic testing to exclude certain categories of people from certain work, because they carry a gene which might contribute to a higher than average level of vulnerability to toxic and dangerous workplaces. Let us strive to bring the kind of balance in our societal life which reduces the environmental stress factors which can trigger conditions to which genetic abnormalities may contribute, rather than limit the access of people so genetically endowed to those environments and their benefits.

The point here is that, between the conception and death of an organism, there are so many potentially causally relevant factors that are partially explanatory of eventual outcomes that all but the most rigorously confirmed and tested application of the genetic determinist idea should be treated with suspicion. If this is right, pioneers at the edge of genetic medical research and general genetic technology have a responsibility to be cautious about fanning lay enthusiasm for genetic explanations of human differences and about fostering the application of these technologies (especially predictive testing where only limited medical benefit is possible) by extending them beyond the kinds of condition that are clearly the core business of Medicine. An unself-critical or philosophically naïve acceptance of Genetic Determinism will not provide such checks.

The other source of an ethical check is *others*. Other people, the broader community. Of course, this is actually a somewhat unreliable check because so many of the broader community often want predictive testing. But what I am here talking about are those applications of testing which raise political and social questions such as its application for eugenic purposes in families, or in employment and insurance screening. While they depend on it, such questions are not purely questions of finding scientific truth.

In the pursuit of truth and in the provision to individuals or corporate entities of services they want, there are social consequences and issues of social and political values. We must discuss them honestly and openly and with patience. To do anything else regarding the potential of genetic testing is to leave to the market values which touch us all too deeply. And the market is only as ethical as its least ethical player. As a community, we should do better than that.

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Protecting choice - against the legalisation of euthanasia

Fr Andrew Murray SM

Persons suffering a terminal disease do not come to what might be called the final moment instantaneously. Rather they go through stages of diagnosis and treatment, which are accompanied by moments of challenging readjustment to the situation and by complex renegotiation of familial and other relationships. This process is not normally completed even at the beginning of the final medical phase, when treatment becomes palliative rather than curative.

"Although legalised euthanasia may seem at first sight to increase personal freedom, when examined more carefully it is seen, in fact, to diminish freedom."

In all of this there are many choices to be made. Early on, decisions may be made largely in terms of medical benefits and side effects, but, as the situation worsens, other factors such as the person's age and commitments, relationships, wishes for his or her final days, hopes, fears and spiritual goals become far more significant. These are matters calling for personal choice.

Choices have to be made about who to tell about what is believed to be a likely outcome of a disease and when to tell them. Neither an early fatalism nor adamant denial to the last minute on the part of either the sick person or members of a family are helpful, yet the middle ground is found only by careful negotiation of feelings and understandings as the overall situation develops. Doing this well demands careful and enlightened judgement, so that the sick need to feel that they have freedom to choose carefully.

In a liberal society, a fundamental role of law is the protection of people's freedom. This is often expressed in terms of rights - the right to free speech, the right of assembly, the right to representation in government. These freedoms can also be expressed in terms of choices - choices about career, children's education, where to live and so on.

In the simplest case this protection is envisaged as protection from the activities of the state itself. However, it is generally extended to protection from other individuals as in the case of security of person and property, and to protection from society as such, as when we insist on allowing minorities to be different. In an egalitarian society the pressure to conform to common opinion can be enormous, so that the state has a role in protecting even those who want to be different as long as that difference is not disruptive of other people's rights or of harmonious living.

The problem with legalising euthanasia is that euthanasia is such an apparently easy solution to a very difficult situation that it obliterates not only all other choices but the very structure of choice itself. In the face of such an easy option, a patient will not be able to find his or her way into those many issues that call for resolution at the end of a life. Yet this will have denied the person the possibility of a much richer process of choice and adjustment. Families, too, will have had to adjust not to a gradual process of coming to terms with death and separation but to the stark reality of a *fait accompli*. Although legalised euthanasia may seem at first sight to

increase personal freedom, when examined more carefully it is seen, in fact, to diminish freedom.

The state does have a significant role in protecting people's freedom and choice in the event of terminal illness and death. Part of that role is to legislate against euthanasia so that the complex structure of choice at this most difficult time remains intact.

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The argument set out above is presented in a mild form. Expressed in this way, it is intended as an indicator to those opposed to the legalisation of euthanasia of a way in which they might argue in the public forum. It needs to be adapted to the circumstances in which it is to be used whether they be pastoral, academic, polemical or any other.

In a pastoral situation, namely, one dealing with a person who is faced with terminal illness and with the needs of that person's family, hardly any argument at all would be appropriate. A pastoral carer would rather listen and reflect and then help elucidate the various avenues of choice available and the value of each of these. This would be a rather slow process that would call for constant attention.

For argument in an academic or professional setting, far more needs to be worked out. Histories could be made of the course of illness, choice and outcome for numbers of individuals and their families. Were these presented as case studies, they would provide both good evidence and persuasive force for the positions stated above. Further work could be done on liberalism itself, so that the validity of application of this argument to the various forms of liberalism could be tested. It will be found that for some forms, such as the Hobbesian position, it will not be valid, though for most later forms found in the eighteenth and nineteenth centuries it will be valid. It is designed to speak to broader forms of liberalism than just utilitarianism. Research could be done on the common liberal presuppositions of Australians today, perhaps through analysis of commonplaces recurring in the popular press.

In public debate, all of the above research could be used. Arguments would need to be honed both to address those offered by opponents and to put the case on the basis of premises they have already accepted. Language would need to be stronger and more direct, and useful illustrations and catchy phrases would need to be developed. Public debate shifts, so that considerable flexibility in argument and approach would be required.

This discussion has been based on the claim that to be persuasive in the public forum we have to present arguments that share common premises with those whom we wish to persuade. Whatever we might think of it, liberalism is pervasive in the West and so offers rich ground for argument. This does not exclude reason and argument based on other principles nor the likelihood that some of our audience may be better swayed by these. Nor does it imply a lessened concern for truth, which we may, indeed, have first sought in other ways.[1]

"Whatever we might think of it, liberalism is pervasive in the West and so offers rich ground for argument."

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Footnote

1. I am grateful to Professor Robert Sokolowski at Catholic University of America and to Professor Quentin Skinner at Cambridge University for suggestions that lead to the writing of this article.

The Children Born From Human Cloning

Fr Jean Kitahara-Frisch

An article by Daniel Callahan in the *Hastings Center Report* (September-October 1997) discusses "the work not done" by the U.S. National Bioethics Advisory Commission in its report *Cloning Human Beings*. He refers particularly to what he sees as "the ethical weaknesses" of the report. Those are according to him, (1) the weak moral reasons given for recommending a revision of the report's conclusions after five years, (2) the lack of an extended serious discussion about what the children born from cloning need for a good life, and (3) the absence of a consideration of the appropriate limits of scientific research.

Among these weaknesses, I am particularly impressed by the lack of deep attention paid to the interests of the children produced by cloning. They seem to have been largely forgotten. This is true, one will notice, not only of this U.S.Report but of much of the discussion that appeared in the mass media after the successful cloning of an adult sheep was made public last February. I was thereby reminded of the title of a book written by a well known French geneticist, Jean-Francois Mattei, on new methods of assisted reproduction: *L'Enfant Oublié*. In that book, the author makes use of his abundant clinical experience in assisting infertile couples to conceive a child. The main point of many true stories told in the book is to show how often children are not desired for themselves but for the kind of satisfaction they bring to their parents' expectations.

That a similar "forgetting of the children" should have attracted the attention both of the French geneticist and of Daniel Callahan in evaluating the American Commission Report is of great interest. It suggests that all methods of artificial reproduction, when viewed from a bioethical point of view, may raise questions similar to those raised by human cloning.

Callaghan's article raises the following questions. First, to what extent is a concern with the welfare and happiness of children indeed absent from the U.S. Commission Report? Second, is the same omission also characteristic of the report commissioned by the French President? And finally, ought not the questions raised by cloning be the occasion to reconsider the ethics of a wider range of reproductive technology?

According to Daniel Callahan, although the report repeatedly warns about potential physical hazards to children, it does not consider the needs of these children or the way biomedical research may respond to these needs. Whenever mention is made in the report of "reproductive rights", the accent is said to lie mostly on the rights of the parents, not on what children rightfully require for a good life. Is this indeed the case?

Reading the introduction to the U.S. Report's fourth chapter, entitled "Ethical Considerations", one sees how it mentions a concern about physical or psychological harms to children produced by cloning. Mention is also made of a degradation in the quality of family life if parents are tempted to seek excessive control of their children's characteristics, or to value children according to how well they meet parental expectations.

This general introduction is followed by more specific testimonies of Commission members on potential physical harms; cloning and individuality; and cloning and the family. All this, however, covers little more than a quarter of the chapter devoted to Ethical Considerations. Certainly, though a concern with children was not paramount in these physical harms, some valuable reflections are made on the sense in which every person has a right to a unique genetic identity, and

children a right to an open future. But it is pointed out that "all of these concerns are not only quite speculative, but are directly related to certain specific cultural values". One cannot help feeling that, to the authors of the report, such "specific cultural values", including probably religious ones, ought not to weigh much in comparison to the undoubted benefits cloning would bring to infertile couples.

A further two pages deal with "Cloning and the Family". Here, concerns about the use of cloning as a means of controlling the child's personality are rightly shown to be rooted in a misplaced belief in the ability of genes fully to determine behaviour and personality. Yet, such fears are also said to be rooted in the way cloning appears as a form of "making" children rather than "begetting" them. Thereby the children, in the words of Leon Kass, are seen as "simply another of the man made things", while the maker stands above its product "not as an equal but as a superior, transcending it by his will and creative process". Such also would seem to be the view of Meilaender, a protestant theologian, when he stresses how cloning causes a turn to be made from "the mystery of the child" to "the child as a product of human will". To these undoubtedly grave concerns it is replied that children born through assisted reproductive technologies may also be viewed in a similar way, and that there is no evidence that harm has thereby been caused to them by these technologies (although, it is granted, the subject has not been carefully studied). But, one may ask, how could harm caused to children be detected if one fails to identify what values essential to the welfare of children should be respected? Here is an issue certainly as important, if not more so, than potential physical harms.

Answering my first question, it seems thus correct to conclude that, while a consideration of the children's interests is not entirely absent from the Commission Report, little space given to a serious discussion of what children have a right to expect from those who bring them into the world.

In comparison, a recent French Report *Réponse au Président de la République au sujet du clonage reproductif* calls our attention to three kinds of harms that may affect children produced by cloning. First, genetic identity, by causing the same body and face appearance, would deprive the child of an important physical support for her personal identity. While unique as persons, these children would be perceived by others, and perceive themselves, as 'copies' of other children. The more so as they would be known to be genetic copies. Second, the personal autonomy of these children would also be threatened since their biological characteristics would be due not to chance, as in sexual reproduction, but to the choice of the person responsible for the cloning. Most importantly, however, these children would not be born of two parents, but produced by a process similar to vegetable cloning. The parental couple would be replaced by an association between two anonymous providers, that of the cell nucleus and that of the oocyte. Thus, orphans of father and mother, the children produced by cloning would be simultaneously the offspring and the twin of an adult person. The words "son" or "daughter" would thereby be emptied of meaning.

The French Report, by showing very concretely how cloned children would be deprived of what all children in the world possess simply by being born, allows us therefore to better locate the weaknesses detected by Callahan in the American report. Moreover, it also calls our attention to how similar ethical problems may already arise from the spreading practice of prenatal and preimplantation genetic screening. For here too biological characteristics of the offspring are being chosen by the parents, disregarding thereby the autonomy of the children to be born as a result of this screening.

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Postscript

Keith Joseph

At first sight, the articles in this edition of *Bioethics Outlook* appear quite disparate. However, one theme is common: How does society frame a response to the ethical challenges posed to it by new technologies?

Typically, a new technique first excites popular imagination when a scandal occurs or when a novel scientific breakthrough makes the headlines. The cry is then heard: "We must do something!", and that something is often a legislative response.

But is the law an appropriate instrument for dealing with these matters? It would seem here that we are caught in a dilemma. If we fail to legislate, then the community loses influence over the development of these new technologies and the ethical problems that they pose. Furthermore, legislative inactivity gives rise, by default, to judicial activity. In the absence of reasonable guidelines from the legislature for medico-ethical disputes which reach the courts, the judiciary needs to adapt the common law to reach some sort of conclusion to the matter before them.

However, a "black letter law" legislative response - in which the legislature tries to cover all eventualities - will fail. Such prescriptive laws cannot keep up with new technologies. For example, concerns have been expressed that a law banning human cloning may be so drafted as also effectively to prevent cloning of human DNA for pharmaceutical processes. Attempts by the legislature to deal with ethical problems by comprehensive and exhaustive legislation often end up being unwieldy and impracticable, and create more confusion than they tried to end. A further problem is that the traditional legislative sanction is the use of punishments derived from criminal law, such as fines or imprisonment for breaking the law. Such punishments are based on concepts of retributive justice which do not sit well with the resolution of new ethical problems.

On the other hand, legislation which gives the imprimatur to self-regulation by commercial interests is even more unacceptable than "black-letter law": for it will usually result in the exploitation of the new technology in whatever areas are deemed profitable, with little regard for the ethical problems that may arise. In a sense, legislation which allows self-regulation is also a "do-nothing" approach, as it abdicates social responsibility to industrial and scientific interests.

Perhaps the problem here is with the legislative models that we tend to use. An alternative approach, but one which is rarely used, is for the legislature to set out the guidelines and entrust the enforcement and timely development of those guidelines to an independent body. This body would also be required to adjudicate individual cases and new issues, and to make relevant regulations. It could also have a research and educative role, and act to raise public awareness of these issues in a way that no current body does.

Such an independent body will, from time to time, make mistakes; and it will need to be subject to review by the legislature. However, it is likely to be far more effective in "doing something" about the ethical dilemmas posed by new technologies than other approaches such as the "self-regulation" approach, the "death by over-legislation" approach, or the "do-nothing" approach.

Therefore the challenge raised by these articles is, in part, the challenge to find a way for society to do something about these medico-ethical issues. Some preliminary suggestions have been suggested above; clearly, we need something besides either resort to traditional legislation or abandoning the attempt altogether.

Keith Joseph lectures in Philosophy and Applied Ethics at the Australian Catholic University. He is also a Research Associate of the Plunkett Centre for Ethics.

NOTEBOOK

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