
Preimplantation genetic diagnosis and the 'new' eugenics

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Abstract

Preimplantation genetic diagnosis (PID) is often seen as an improvement upon prenatal testing. I argue that PID may exacerbate the eugenic features of prenatal testing and make possible an expanded form of free-market eugenics. The current practice of prenatal testing is eugenic in that its aim is to reduce the numbers of people with genetic disorders. Due to social pressures and eugenic attitudes held by clinical geneticists in most countries, it results in eugenic outcomes even though no state coercion is involved. I argue that technological advances may soon make PID widely accessible. Because abortion is not involved, and multiple embryos are available, PID is radically more effective as a tool of genetic selection. It will also make possible selection on the basis of non-pathological characteristics, leading, potentially, to a full-blown free-market eugenics. For these reasons, I argue that PID should be strictly regulated.

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Introduction

Preimplantation genetic diagnosis (PID) is a method of genetic testing and selection of embryos. It involves the removal of one or more cells from embryos generated by in vitro fertilisation (IVF) and analysis of the DNA from those cells. Up to ten embryos may be produced in each cycle of IVF, of which only two or three, which have the desired genetic profile, are implanted, using standard IVF procedures. It is estimated that around 100 children have been born following PID.¹ To date, the technique has been used almost entirely to detect incurable monogenic disorders such as Duchenne Muscular Dystrophy and cystic fibrosis. In early examples of the use of the technique, genetic testing was used to eliminate male embryos, to prevent transmission of X-linked genetic disorders.² The main group of clients for this service have been couples known to be at risk of having children affected by a genetic disorder, often because they already have an affected child.

It is generally thought that PID represents an improved form of prenatal diagnosis, primarily because it allows women to embark on a pregnancy with the certainty (subject to testing errors) that the child will not be affected by genetic disorder, rather than face the trauma of pregnancy termination. Given the analogy with prenatal testing, most bioethical arguments in favour of PID have assumed that since prenatal genetic testing is widely accepted, the genetic selection of embryos is not, of itself, a problem. It has also been argued that since embryos are inevitably discarded in IVF, selection on genetic grounds is unobjectionable.³

It is not the aim of this paper to mount a philosophical argument that genetic selection is ethically unacceptable under all circumstances, or that prenatal testing should be abolished. However, I will argue that the current regime of prenatal testing and genetic selection is eugenic in purpose and outcome. I believe this situation needs to be addressed, because I believe that eugenics, at least in all incarnations that have occurred to date and are foreseeable this side of utopia, is socially damaging and harms people with disabilities. Some degree of eugenics is probably unavoidable, but we should do our utmost to restrict it. I will argue that, on the contrary, PID opens up the possibility of a radical expansion of the current eugenic regime, creating a consumer-driven form of eugenics in which selection for trivial medical conditions and non-pathological characteristics will occur. Although it has often been suggested that this is no more than a remote possibility, this paper aims to show that it is indeed a serious concern, which requires action to regulate PID as well as to curb other social and economic tendencies which point in the same direction.

Laissez faire eugenics

The dominant tendency in debates about the impact of human genetics research is to view eugenics as a purely historical phenomenon, and to minimise its relevance to the current situation. In the conventional definition, the key aspect of eugenics is coercion of people's reproductive

choices, for social ends, which may include improving the quality of the population, preventing suffering of future generations or reducing financial costs to the state. However, while it is true that in some countries eugenics movements succeeded in persuading the state to support their aims, coercion was never an essential feature of eugenic theory or practice. From its very beginnings, many eugenicists, including the founder of the eugenics movement, Francis Galton, were opposed to coercion, believing that if people were properly informed they would naturally make the "right" reproductive decisions. Definitions of eugenics which exclude Galton can hardly be taken seriously.⁴

Patient autonomy

After the second world war, as overt eugenics programmes became politically unpopular, the practice of "non-directive" genetic counselling became institutionalised in most Western countries. Later, this was reinforced by the trend in medical ethics and practice towards patient autonomy. It is generally thought that medical geneticists have abandoned their former eugenic views and that non-directive counselling, with the emphasis on individuals' personal decisions, insulates human genetics from charges of being eugenic. I would argue that, on the contrary, the current system produces eugenic outcomes.

Although non-directiveness remains the professional norm in Western countries, research on geneticists' attitudes and practices reveals that eugenics is far from dead. Wertz and Fletcher^{5,6} conducted a survey of the attitudes and practices of nearly 3,000 geneticists and genetic counsellors in 37 countries. Their results show clearly that only geneticists in English-speaking countries and Northern Europe (ENE) can make any claim to non-directiveness and abandonment of eugenic thinking. In Eastern and Southern Europe, the Middle East, Asia and Latin America (Rest Of the World, ROW), geneticists not only hold eugenic ideas, but see no problem in directing their clients in accordance with those ideas. For example, in response to the clearly eugenic suggestion that: "An important goal of genetic counselling is to reduce the number of deleterious genes in the population", 13% of UK geneticists agreed. In Eastern and Southern Europe this rises to an average of 50%, and in China and India to nearly 100%. An average of 20% of ENE geneticists feel that, given the availability of prenatal testing, it is not fair to society knowingly to have a child with a serious genetic disorder. In the rest of the world, majorities of geneticists supported this view, rising to nearly 100% in some countries.

Approximately 15% of ENE and majorities of ROW geneticists admit that they would provide biased prenatal counselling (emphasising negative aspects of a condition without actually suggesting termination) for a variety of child- and adult-onset genetic disorders. For conditions judged more serious, nearly 30% of US genetics professionals would provide negatively slanted counselling. Conversely, where the condition is viewed as less serious, more positive counselling would be given.

Wertz and Fletcher's research details what geneticists say they think and do, in response to a questionnaire. Figures derived from such answers almost certainly underestimate the degree to which counsellors contravene their professional norms in practice. Their conclusions are supported by studies in which genetic counselling sessions were videotaped.⁷ These revealed a high level of directiveness by genetic counsellors. Most disturbingly, the level was highest when clients were from lower socio-economic groups. Most counselling for non-monogenic prenatal tests is performed by obstetricians, who admit to being more directive than geneticists.⁸

Even were much greater efforts made towards non-directiveness, structural features of the prenatal testing situation militate against a genuinely free choice for patients. Firstly, as Green and Statham⁹ and Clarke¹⁰ note, the very fact that a test is offered by doctors tends to suggest to women that its use is warranted and desirable: such is the situation in all other areas of medicine. Once it becomes routine, and is presented as such, this effect is exacerbated. Research also shows that many women are simply unaware that prenatal tests have been performed, which indicates that the level of informed consent is low.¹¹

Presumption of termination

Secondly, the dynamic of undergoing testing leads to a presumption of termination, should abnormality be found. Many women feel that once they have agreed to testing they should opt for termination, since otherwise there was little point in undergoing testing.⁹ The still common practice amongst obstetricians of refusing to offer amniocentesis, unless the woman agrees in advance to termination,¹² enforces this logic.

The offer of testing also tends to lead to acceptance in that women anticipate their own feelings of guilt, should they decline and subsequently discover that the fetus is affected by a genetic disorder.¹³ They also anticipate being blamed by others for failing to take a test.¹⁴ In one British study, 13% of obstetricians agreed with the statement that: "The state should not be expected to pay for the specialised care of a child with a severe

handicap where the parents had declined the offer of prenatal testing^{11,12} (This figure is similar to Wertz and Fletcher's results concerning eugenic attitudes amongst geneticists.)

It is even more important to realise that the conventional accounts about how reproductive decisions are made tend to ignore social context. It is assumed that prospective parents take decisions based primarily on personal feelings and values. It is, of course, true that parents' decisions over termination are affected by many factors, including attitudes towards abortion, the degree of disability involved in particular disorders, the level of risk and their own personal histories. However, underlying social pressures, some of which have already been referred to, strongly affect people's attitudes.

A key social pressure is the oppression of people with disabilities.¹⁵⁻¹⁷ This affects parental reproductive decisions in several ways. Firstly, able-bodied people receive negative images of people with disabilities and general misinformation about what their lives are like. Parents receiving prenatal genetic counselling are rarely put in touch with people who actually live with the genetic disorder in question. Secondly, parents are aware of the material aspects of disability oppression: insufficient welfare provision, lack of access and discrimination. Women, who still bear the vast majority of responsibility for child care, are sharply aware that the extra burden of caring for a disabled child will fall on them. Lack of adequate welfare provision, in particular, will affect not only the child but may create financial problems for the family, as well as increased stress.

These social pressures, combined with the attitudes of geneticists and obstetricians and the structural bias introduced by routinisation of testing, guarantee that allowing parents a "free choice" results in a systematic bias against the birth of genetically disabled children, a bias that can only be called eugenic. In noting this reality, I am not attempting to deny parents' personal experience, free will, or the existence of countervailing social forces and resources (which are often religious).

I would also argue that the purpose of the existing system is eugenic, in that its aim is to reduce the number of births of children with congenital and genetic disorders. In most countries, as Wertz and Fletcher's surveys have shown, this point is not contested. In some English-speaking and Northern European countries, some official statements, such as those of the Nuffield Council on Bioethics,¹⁸ assert that the aim of the system is purely to allow parents more informed reproductive choice. On the other hand, equally authorita-

tive statements, such as that by the British Royal Society of Physicians,¹⁹ clearly indicate that the purpose of offering screening is to reduce the number of births of congenitally disabled children. Although many genetic counsellors express discomfort with the practice, arguments for the introduction of genetic screening programmes are often couched in terms of financial benefits to the state.²⁰⁻²² As Green and Statham note,⁹ it seems unlikely that prenatal screening would have been resourced to the degree that it has been if the purpose were purely to enable more informed choice, or if it were expected that most parents of a fetus with an abnormality would choose to continue the pregnancy. Obstetricians' practice of refusing amniocentesis unless the woman agrees to a termination in advance, is evidence of a lack of willingness to support parental choice.

In arguing that the purpose of the existing regime is eugenic, I am not suggesting the existence of some conspiracy, on the part of doctors, scientists, or the state. Kitcher²³ has dubbed the current situation "laissez faire eugenics", in order to capture the way that social "market forces" result in predictable outcomes, even though everyone still has a nominally free choice. I do not claim that the present system is anywhere near as harmful as the earlier state-sponsored eugenics. Clearly, for many people who wish to avoid the birth of disabled children, it is experienced as highly beneficial. It is, none the less, eugenic, and would no doubt have pleased Galton and his fellow eugenicists. I agree with Kitcher that in a utopian future, it might be possible really to achieve an uncoerced free choice for everyone in reproductive decisions. However, that is not the current reality. If we want to achieve the utopia that Kitcher proposes, then, as he points out, we will be obliged to combat the social forces that produce laissez faire eugenics.

The purpose of this discussion is to point out that the "consumer eugenics", often invoked by bioethicists as a problem which might, (but, it is usually concluded, probably will not) occur in the future is, in fact, different only in scale from the current regime. It is important correctly to assess the existing situation in order to understand what an expansion of prenatal testing and PID might lead to.

Can PID become widespread?

In my view, both social forces and developments in genetics point towards an expansion of the current system of laissez faire eugenics in the near future. However, if this does happen, it will depend on the practice of PID becoming widespread, for one simple reason: few women

will be prepared to undergo abortion for the sake of avoiding minor or late-onset medical conditions, or non-pathological but undesired physical or mental characteristics.

At present, PID is limited by technical problems, such as uncertain reliability, due to potential contamination by extraneous DNA. It is often suggested by scientists that an expansion of genetic selection is unlikely, because genetic tests will be never be sufficiently predictive. It is also commonly thought that there is a sharp line between single-gene disorders and the more common multifactorial conditions, and that we will never be able to develop predictions of a person's predisposition to heart disease, for example. It is also argued that whether a person develops heart disease also depends on environmental factors such as diet.

There are two issues here. The first is the adequacy of the testing technology, which will have to assess variations in many different genes. In fact, there are already gene chips that can look at major mutations in a hundred different genes at once.^{24 25} Genetic testing technology is continually improving and becoming cheaper, and it would be a mistake to expect this not to continue.

The second point is that it may indeed be difficult accurately to predict not only health status but also behavioural and personality characteristics from genetic tests. I believe that the jury is still out on this issue. It seems quite likely, however, that some genes with relatively major effects on predisposition to important diseases will be found. It is almost certain that prediction with an accuracy of two decimal places will never be possible. But for people trying to select embryos, two decimal places are unnecessary. Neither will they be concerned about the uncertainties due to environmental factors. Since in PID they are obliged to select two or three embryos from the pool of ten, they will accept a certain amount of inaccuracy, and simply try to select the "best" embryos that they can find, according to the information presented to them on the embryo's genetic predispositions.

The other key technical development which will be needed to make PID widely available will be the ability to obtain multiple eggs in a more user-friendly fashion than in current IVF protocols. Robertson³ argues, correctly, that most women will be unwilling to undergo IVF, which is at least uncomfortable and may be dangerous, for the sake of access to PID. A major problem in IVF is the variable number and quality of eggs which are produced by hormonal stimulation of women's ovaries, and the effect that this has on women. It is possible that this problem may be solved. I believe

that the most likely way in which this limitation will be overcome is through the in vitro maturation of eggs. There is considerable research in this area, particularly in the agricultural field, which is likely soon to bear fruit. It seems likely that in five to ten years it will be possible to remove a small slice of ovary, containing hundreds of eggs, which can be frozen and matured at will. It has been suggested that it may become common practice for women to undergo such a minor operation in their late teens, and for the eggs to be stored until the woman wishes to have children.²⁶

At that point, the only barrier to widespread use of PID will be the low pregnancy rate of IVF. This may not be a major problem for a number of reasons, since the IVF pregnancy rate is not much lower than the pregnancy rate achieved in natural fertilisation; the difference is that it is much easier to make repeated attempts by natural methods. Once the egg supply problem is dealt with, repeated implantations of embryos will not be particularly taxing to women.

If oocyte maturation succeeds, therefore, IVF may become a much more accessible choice for normally-fertile couples. At that point, PID may become potentially accessible to any woman. It is quite possible that, given the possibilities that it holds for selection, PID may become the technology of choice for the conscientious couple who want to make sure they give their baby the best start in life. It will be relatively easy to market PID as a way to ensure children's genetic health, and as a guarantee of a problem-free pregnancy.

The eugenic implications of PID

If PID becomes more user friendly, and genetic prediction reasonably robust, what are the implications? I believe there are a number of features of PID which will encourage an expansion of *laissez faire* eugenics.

The fact that PID operates on embryos rather than on an established pregnancy differentiates it decisively from prenatal testing, in ethical, legal, social and psychological terms. As noted, PID has no inbuilt brake on its application for purposes of genetic selection, because it does not involve abortion, with all the physical and emotional trauma which that can entail. Embryos which are still outside the mother's body have a far lower emotional weight than a fetus which a couple already think of as their baby.

Because abortion is not involved, if PID were to become widely available it would deepen the social pressure on parents to avoid genetic disorder and undergo testing. While there is still widespread sympathy for a woman who refuses prenatal testing or abortion, because she cannot

kill her child-to-be, it is unlikely there would be such sympathy for parents who rejected the opportunity of PID, simply on the grounds of wishing to leave things to chance.

A further consequence will be a strengthening of the culture of prevention. The option of continuing with an affected pregnancy will be abolished, because most people will think it wicked to implant an embryo which will develop into a child with a genetic disorder. Le Bris²⁷ has already suggested that once a gene causing a disorder has been detected in an embryo, couples should not be given the option to implant it.

The very fact that the embryo is outside the woman's body, and before the onset of pregnancy, means that the argument for "a woman's right to choose" is weakened, and the decisions over the embryo's fate become much more open to intervention from male partners, doctors and society at large. In particular, the site of PID, the IVF clinic, means that doctors will have a much greater say than in prenatal testing.²⁸ In the IVF clinic, decisions over which embryos to implant are controlled by medical expertise, in contrast to the genetic counselling situation, where the couple decide. Since it will be so easy to prevent disability, doctors will tend to feel a greater responsibility to the child than with prenatal testing. Preimplantation diagnosis thus represents a new intensification of the medical surveillance of human reproduction, which would institute a far more preventive regime than currently operates for prenatal testing.

The second important aspect of PID is the multiplicity of embryos available for selection. Since most couples aim for a small number of children, a likely consequence will be the development of a culture of choosiness: since some embryos must be chosen above others it will appear common sense, and "in the best interests of the child" to pick embryos with the "best" genetic profile. This would, in effect, be a system of positive eugenics, in contrast to the negative eugenics we have now.

Another part of the culture of choosiness will be a tendency to eliminate those embryos which may result in children with relatively minor, curable or late onset conditions. Strong,²⁹ for example, citing reproductive freedom, argues that there is no problem with using PID for such conditions. There have also been discussions³⁰ of the possibility that parents will opt for elimination of embryos that are heterozygote carriers of disorder genes, on the grounds of sparing the individual difficult reproductive decisions in the future, or of eliminating such genes from the gene pool. Such carriers will generally be entirely healthy. Eventu-

ally, it seems likely that it will be possible to select for desired biological characteristics and aptitudes. Given existing trends in our society, such as the increasing prevalence of cosmetic surgery, it is naive to expect that either doctors or the state are likely to prevent the use of PID for such characteristics, unless a determined effort is made to regulate PID. Part of the problem in attempting to do this is that there is little agreement about the domain of medicine and a constant process of redefining biological and behavioural variation as pathological. It is, for example, common practice in the USA to prescribe human growth hormone to short children who have no deficiency of the hormone.

In summary, in PID, the combination of the lack of need for abortion and the availability of multiple embryos creates a radically different situation from that of prenatal testing. Allowing selection between a number of embryos, before pregnancy has commenced, creates an entirely different attitude towards reproduction from prenatal testing and abortion, which serves merely to deal with serious mishaps. In PID, parents adopt a far more pro-active, directing role, choosing their children in a way which is not so far removed from their experience as consumers, choosing amongst different products.

What's wrong with consumer eugenics?

There are a number of reasons why an unrestricted free-market eugenics would be highly undesirable. Firstly, selecting the "best" amongst multiple embryos sets up a new relationship between parents and offspring. As illustrated in a recent play, *The Gift*,³³ such children are likely to feel that the essence of themselves, in an important sense no longer belongs solely to them, since it has been overseen by their parents, using the all-seeing eye of genetic technology. They are no longer a gift from God, or the random forces of nature, but selected products, expressing, in part, their parents' aspirations, desires and whims. As Kahn has noted in reference to cloning³⁴:

"Part of the individuality and dignity of a person probably lies in the uniqueness and the unpredictability surrounding his or her development. As a result, the uncertainty of the great lottery of heredity constitutes the principal protection for human beings against biological predetermination imposed by third parties, including parents. One of the blessings of the relationship between parents and their children is their inevitable difference, which results in parents loving their children for what they are, rather than endeavouring to make them what they want."

At a social level there are further undesirable consequences. Opening the human gene pool to the winds of social market forces on a large scale might have a number of effects. Clearly, there is likely to be a tendency for parents to select offspring which conform best to social norms, with regard to health and physical ability, appearance and aptitudes. Disabled people have often expressed fears that an expanded free-market eugenics would correspondingly lessen society's tolerance for those with congenital and genetic disorders. While it may be true in theory that there is no moral inconsistency between respect and support for disabled people and attempting to prevent their birth, in the real world, and in the minds of prospective parents, the two things are intimately related, as discussed above. It is difficult to believe that in a society which had overcome its fears of disability and truly considered disabled people as equal members of the community, there would be such an interest in prenatal screening.

As the examples of treatment of short children with growth hormone, and the use in some countries of prenatal screening for selection against females illustrate, some of the social market forces which operate are inherently oppressive. It is also possible to imagine selection on grounds of IQ, skin colour, physical build and facial features, etc. It does not seem desirable to allow such forces to operate at the level of selection of who is permitted to be born. Rather, we should combat the social forces which lead us to devalue some individuals and idealise others.

As Silver has recently expounded,³⁵ a logical consequence of a system of free-market eugenics in societies where large disparities of wealth and social class continue to exist is a gradual polarisation of society into a genetically privileged ruling elite and an underclass. It may be argued that this is not a problem related to PID as such, but simply requires us to make PID universally available. While this may be true in theory, it seems unlikely to be realised in practice, particularly in countries such as the USA. Certainly, a guarantee of universal availability would seem to be a precondition of allowing widespread access to PID.

It is also important to realise that the line between state eugenics and free-market eugenics is not sharp. It would be perfectly possible for state bureaucracies to intervene in the free market, on grounds of public health or national competitiveness. Such interventions need not be obvious or require coercion.

Finally, in the long term, there are good biological reasons for not allowing market forces to shape the human gene pool. Many people, for

example, would prefer their children not to have tendencies towards being fat; being overweight is a risk factor for many diseases including heart disease and diabetes. Should we allow free access to genetic testing for obesity? We do not have sufficient understanding of human biology to allow us to judge the evolutionary value of genes, which in existing societies produce disease.

Conclusion

At present, the major barriers to the routine use of PID are technical. Although it is by no means certain that such barriers will be surmounted, current scientific trends suggest that we should not be complacent. If it becomes more user friendly, and the present climate of reproductive liberalism continues, PID might be widely promoted by private clinics. Widespread access to PID would not merely be a necessary condition for a radical expansion of laissez faire eugenics; different aspects of PID would actively encourage such an outcome.

Clearly, there is a need for specific regulation of PID. In addition to the usual requirements of competence and safety, Le Bris²⁷ argues that laboratories which conduct PID should be in the public sector, ideally in teaching hospitals, and that there should be adequate provision of genetic counselling. The key issue, however, and the most difficult question is: for which conditions should it be permissible to conduct PID. There is currently little discussion of this issue. As noted, there is a tendency to assume that, since it is so easy to discard embryos when others are available, there is no ethical problem in selecting against relatively trivial medical conditions. However, it is vital that we do not allow technical developments to decide fundamental ethical and social questions.

It is important that we attempt to find some consensus about where to draw the lines around the application of PID. Such lines are inevitably somewhat arbitrary, and there should always be some flexibility in individual cases. However, if no lines are drawn, it is difficult to see what will prevent a progression towards a full-blown consumer eugenics. It would be better to dig our heels in now than to suffer the consequences at a later date.

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