Screening for disability: a eugenic pursuit?

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Abstract

This article is written in response to the idea that selective termination may be eugenic. It points out that a mixture of motives and goals may inform screening programmes and selective termination for fetal abnormality without the intention being "eugenic". The paper locates modern genetics within the tradition of humanist medicine by suggesting that parents who choose to terminate a pregnancy because of fetal abnormalities are not making moral judgments about those who are living with these abnormalities already. Rather they are making judgments about their own lives and the lives of their children in relation to this genetic disorder. It concludes by introducing several caveats about the counselling that parents receive after the results of the testing and suggests that counselling inevitably contains a directive element because of the nature of the information covered.

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Some people reject antenatal genetic testing because they object to abortion as such. This is a familiar debate and, in the spirit of exploring the new ethics of abortion, not one that I intend to rehearse here. Instead, I want to focus on concerns about the selective aspect of selective termination and about screening programmes that may precede such terminations—concerns that are often, if not typically, voiced by people who are in general prochoice.1 The critical literature on this is expanding rapidly and becoming slightly more differentiated in the process. In this paper I look at one aspect of the debate by addressing the question: screening for disability: a eugenic pursuit?

The decision to undergo genetic testing during pregnancy rests with the woman, usually after consultation with her partner. When there is a family history of a genetic condition, the initiative, the initial suggestion that testing could be used, will usually come from the woman. In the case of population screening it is health professionals who take the initiative. For example couples might be offered screening with the aim of determining whether they are carriers for a condition; if they are and a pregnancy is established, antenatal testing will be offered.

For Modell, Harris and colleagues,2 the purpose of such carrier screening is to "permit couples who are at risk an informed choice among available options, including prenatal diagnosis in every pregnancy". A reduced birth incidence of the condition in the population as a whole might be an outcome, but it is not the aim. Others present things rather differently. Writing about cystic fibrosis (CF), Murray, Cuckle and colleagues3 boldly state that: "the aim of genetic screening for CF is to reduce the birth prevalence of the disorder. This is primarily achieved by identifying carrier couples who can have prenatal diagnosis and selective termination of pregnancy".

The truth of the matter is probably that both aims inform screening and testing programmes. However the issue is posed, the primary choice, in screening and also in patient-initiated testing is to avoid the birth of a child with a genetic condition. Is this eugenic? There are a number of variations of the argument which suggest that it is. These different aspects of argument are put with varying degrees of vigour by different critics of antenatal screening and selective termination, and clearly, whether or not these procedures are thought to be "eugenic" will depend on what that emotive term is taken to mean.

In this brief presentation of the arguments I cannot hope to do justice to the full range of opinion and writings on the subject. I do hope, however, to establish that the values of modern medical genetics are fundamentally different from those of the main strands in historical eugenics, and that approval for genetic testing prior to birth is compatible with equal treatment for people living with disabilities.

Francis Galton defined eugenics as the scientific study of the biological and social factors which improve or impair the inborn qualities of human beings and of future generations. Such study suggests a practice of eugenics. A modern definition might be any policy that alters the composition of the human gene pool. The philosopher Philip Kitcher4 develops this interpretation in his thoughtful book The lives to come: the genetic revolution and human possibilities. He then subdivides the notion into different types. Interestingly, he also characterises doing nothing when we have the ability to do something as eugenic. At this point the critics of genetic testing part company with him. For them, eugenics is about humanity changing the gene pool, specifically reducing the incidence of genetic disorders, whether it is government policy or the aggregate of individual decisions that brings this about.

Both Kitcher’s and the critics’ notions have their merits. But posing the issue in such a general way also tends to obscure crucial differences between historical eugenics and modern genetics. At the turn of the century there was a widespread belief that genetics influenced morals and personality
traits. The preoccupation was with controlling the
spread of these traits, rather than medical condi-
tions. The dominant strand in eugenics of old was
a state-led drive to alter the gene pool, in some
cases by coercive measures. It was used to justify
the sterilisation, and even murder, of people classed
as mentally insane and genetically inferior.

At the time, not enough was known about genetic-
s and disease/behaviour to highlight the scientif-
cally irrational character of many of the eugenic
proposals. Enough was known, however, about
population genetics by 1920 to invalidate, on sci-
tific, never mind humane grounds, eugenic argu-
ments for sterilisation. That such programmes con-
tinued regardless highlights perhaps the most
important point to understand about the dominant
strand of old eugenics: it was driven neither by sci-
ence nor by humanitarian concern but by a strong
political belief and fear—of national, racial, and
social decline. As the historian Daniel Kevles' puts
it, using the example of Britain at the turn of the
century: “To many British, the general fibre of the
nation—its overall moral, character, intelligence,
energy, ambition, and capacity to compete in the
world—was declining”.

After the second world war, eugenic practices
continued for some time, up until the 1970s in the
case of Sweden. Eugenists sought to pursue their
goals through the new field of reproductive and
genetic counselling, and some still believe that the
moral worth and future of nations depend upon
genetics. But in my view the predominant ethos of
the new genetics is concerned more with identi-
fiable medical diseases than with personality traits
and behaviours. It represents a biological appro-
ach to problems, not a reductionist approach
to the whole human being. This is not to say that
modern behaviour genetics and the genetics of
mental health are marginal fields of inquiry; they
are not. But leading researchers in the field under-
stand the limited contribution of many different
genes. Their study is primarily individual variation,
not purported race or social-group differences, and
very few working in the field link genetics to ideas of
racial or national success and failure. Finally, these
areas of genetics do not impinge on services offered
prior to implantation or birth, and are unlikely to
do so for the foreseeable future.

Some within the disability rights movement
might accept the distinction I have drawn, but con-
Tinue to object to antenatal testing and screening
because they believe it necessarily devalues those
living with the condition. Focusing on the motiva-
tions of parents in the first instance, I believe that
this is wrong, and that the critics are guilty of con-
flating impairment and the moral status of people—something they often accuse supporters of
testing and screening programmes of doing.

I have located modern eugenics within the tradi-
tions of humanistic medicine. Clearly, selective ter-
mination, a possible outcome of one aspect of
genetic science, is not a “cure” or treatment. I
would argue, however, that parental attitudes
towards fetal abnormality are framed by attitudes
towards illness and not unreasonable expectations
about the impact of such genetic disorders on their
own and their children’s lives. If they choose to ter-
minate an affected pregnancy they are making a
judgment about impairment, which is the level at
which antenatal selection operates, and a guess
about the life they, and a child with the particular
condition, would have, given existing levels of
medical knowledge and social support. That
judgment is a relative one if that life without the
condition is better than life with it. Parents are not,
as the caricature sometimes has it, saying that life
with a genetic disorder is not worth living or is too
terrible to contemplate. And certainly, they do not
see themselves as making a moral judgment about
the worth or rights of people living with that genetic
condition.

In conclusion I want to suggest that not only does
the service not have the faults attributed to it, but
the arguments of the critics could add to the faults
in the service as it exists, and may hinder its future
development. In short, the danger is one of poor
guidance and restrictive regulations.

It is the Genetic Interest Group’s experience that
some parents are left to make their decisions in a
vacuum because health professionals fear being
seen as directive if they fully discuss the available
options. Genetic counselling is concerned with
facilitating informed reproductive decisions. Fol-
lowing the eugenic experience prior to the first
world war, the emphasis has always been placed
firmly on the “non-directive” part of “non-directive
genetic counselling”. This is as it should be. But I
would introduce the following caveats:

(1) There is a danger of making anything appear
directive. Some say presenting testing as part of
antenatal care is directive, or that clarifying
likely implications of a condition is directive, or
that ensuring that risks are properly under-
stood is directive. All these procedures should
rather be seen as perfectly reasonable features
of patient care, and quite consistent with the
goal of informed choice. I note that in one
study, patients expressed satisfaction even
when they thought aspects of their care were
“directive”.

(2) We cannot avoid the fact that the primary
choice offered by these services is the choice to
avoid having a child with a genetic condition—
and that this is the choice made by most
people. If this is directive then non-directive
genetic counselling is impossible (a majority of
delegates to the Third European Meeting on
the Psychological Aspects of Genetics, held in
1992, took this point of view).

(3) A rigidly applied policy of non-directiveness
may not meet patients’ needs in all circum-
stances. Certainly, in a screening context, if a
family is unaware of the nature and implica-
tions of the condition that may affect a future
child and if the goal is indeed informed choice,
then it is the duty of the health professionals to present the family with the facts, and to inform them about the reality of the condition. As Modell and colleagues point out in their study of screening services for thalassaemia during pregnancy, the fact that this is not happening in many cases means that families are being denied the chance to make a choice.

Turning to the issue of the law and regulations, I think it would be fair to say that there is a deliberate element of ambiguity in relation to selective termination. Both the law and regulations are framed in such a way as to allow individuals and clinicians to come to an arrangement that meets individual needs in most cases. But they are also framed so as to deny absolute individual freedom of choice as a matter of principle. Thinking on antenatal screening appears to be in a more genuine state of confusion. Partly because of this, and partly because of issues relating to finance, it is proving difficult to formulate a national antenatal screening strategy. For the critics, the ambiguity in the law on selective termination is a source for concern. They would prefer it to be tightened up. Many would also like to limit the development of screening programmes, and perhaps restrict the range of conditions for which genetic testing in early pregnancy is allowed.

We might want to debate whether regulations should rather be liberalised further. But certainly, if the law was to be interpreted in a less “permissive” way than currently, and the option of testing denied, it would be hard to avoid the conclusion that real-life choices were being denied.

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**References**

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