

Fear of eugenics shouldn't halt gene editing

Ethical concerns about a brave new world of designer babies are legitimate but we can't slam the door on the future

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If you walk southwest from the Brandenburg Gate in Berlin, on your way perhaps to the Philharmonic or the big art galleries, you will pass a long wall made of blue glass. It was put there two years ago and marks the spot at No 4 Tiergartenstrasse (the house no longer exists) that acted as the headquarters of Aktion T4, the operation to murder people deemed genetically undesirable. Under the aegis of the bureaucrats and doctors who worked there, as many as 275,000 people — mentally ill, physically disabled or “criminal” — were killed, usually by gassing.

To many people the Nazi programmes to “cleanse” the Aryan race of undesirable qualities represent the logical conclusion of the science of eugenics. This creed, which originated in Britain in the late 19th century, held that the future of humankind would be immensely improved by controlled breeding. Criminality, “imbecility” and stupidity would be expunged. In the name of eugenics forced sterilisation programmes were enacted in several western countries, with more than 60,000 being carried out in the US alone.

The appalling history of eugenics is always there in the background whenever the genetic manipulation of human beings is discussed, and this week was no exception. On Tuesday the Nuffield Council on Bioethics, an expert body set up in

1991 to help chart the choppy ethical waters of the new biosciences, issued a report entitled *Genome Editing and Human Reproduction: social and ethical issues*. In essence the report recommended that developments in gene-editing technology required a debate on the ethics of genetic manipulation. “We find ourselves in a new situation,” the committee’s chairwoman, Professor Karen Yeung, said. “The ground is shifting and this generates new responsibilities.” Under what circumstances, the report asked, might it be permissible to create genetically altered children?

Immediately a number of people said: “None.” Dr David King, who runs the pressure group Human Genetics Alert, called the report “an absolute disgrace. We have had international bans on eugenic genetic engineering for 30 years.” Marcy Darnovsky, of the US-based Centre for Genetics and Society, complained that “the report’s conclusion flies in the face of a

Dystopias may involve the consequences of unfettered choice

widespread global agreement that heritable genetic modification should remain off-limits”. In other words, let’s not go there.

So what are we talking about? Essentially, the ability to modify sperm, eggs or early-stage embryos so as to remove or to insert certain genetic material. This could mean snipping out a gene mutation that causes a life-shortening and often horrible heritable disease such as Huntington’s or cystic fibrosis, and in the process of modification possibly removing the disease gradually from the gene pool.

Or a whole lot of other things; it was reported recently that Chinese researchers had modified beagle embryos to give their dogs bigger leg muscles (Chinese researchers are always doing stuff like that). None of this is imminently applicable to humans, Nuffield says, but the capability is on its way.

So while Nuffield wasn’t recommending any change in the law now, it was suggesting that we consider the circumstances under which we would permit genome editing. This suggestion alone was enough to alarm many ethicists. But where once the fear was about what governments might do in the hunt for the perfect citizen (or, at least, in the quest to eradicate the most imperfect ones) now it’s all about how we as individuals and consumers might demand or be seduced into demanding perfect children. These days dystopias are as likely to involve the consequences of unfettered human choice as an almighty state.

Thus, says Darnovsky, what is happening is the opening of a door “to a world of genetic haves and have-nots” in which “parents pursued projects to improve their children at the one-cell stage”. Inevitably those with money would do as the private-school parents do: seek to purchase comparative advantage for their offspring, but at the zygotic stage.

Well, says Nuffield, in pre-emptive response, some of that is only what we do already. The report cites the fact that the average height of Dutch males has increased by 20cm over two centuries, taking Netherlanders from being some of the smallest to some of the most extended folk in Europe. Why? Because of the “relative reproductive success of taller Dutch men”. A parental desire



Ethicists believe we may be seduced into demanding perfect children

to help shape the futures of their children is hardly an unnatural or terrible thing per se.

A BBC programme this week featured a Huntington’s sufferer whose father died of the disease and who, for the sake of his children, envisaged a future in which the condition could be taken out of circulation through editing. Then there’s what the committee calls the “expressivist” objection. Even if, say, we limited any intervention to seeking to eradicate undesirable gene-based conditions, heritable or not, what story does that express about our attitude towards people with those conditions? Do we appear to be saying that the life of someone with cystic fibrosis is so bad that it can’t really be worth living?

Nuffield’s view is that future permission for such editing should be

based on two overarching principles. First, it should only happen when “it is intended to secure the welfare of and is consistent with the welfare of a person who may be born as a consequence of using these cells”. As the report points out, what this means can change. For example, given the high quality of life enjoyed by people with Down’s syndrome it would be very hard to justify genome editing for the condition.

Second, and into the minefield, editing “should be permitted only in circumstances in which it cannot reasonably be expected to produce or exacerbate social division or the unmitigated marginalisation or disadvantage of groups within society”. So no designer babies for rich folk, no “consumer eugenics”, no blanket ability to snip out material and get rid of heritable, survivable and tolerable conditions.

At this point Nuffield demands one of only two responses. The first is to slam the door shut on a future ability to edit the genome, saying we don’t want it and never will. The other is to allow an early peek through the window. In the end I go with Nuffield. Not out of a sense of scientific inevitability but because allowing people to do what I would want to do for my children, and to avoid what I would want to avoid, seems the best principle. Let’s not allow the fear of the worst to drive out any reasonable hope of the good.

But the point is, this is a debate. We’re only just beginning it. We could all change our minds.

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