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Carriers of Genetic Disorder and the Right to Have Children*

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INTRODUCTION

The are two common replies to the question of whether carriers of genetic disorder should have children. The first simply ends any argument by claiming that everyone has an inalienable right to have children. In many ways this view is quite attractive. The right is said to be universal as well as inalienable. It avoids odious comparisons and applies to everyone, including those whom society has deemed unfit for the flimsiest reasons.

In the United Kingdom, for example, a High Court judge recently upheld the decision by Sheffield Health Authority to refuse IVF treatment to Julie Seale, who was then 36, on the grounds of her advanced age. This latest salvo in what one writer has called "the fertility war" follows on from the Grand Peninsular Campaign against IVF treatment for post-menopausal women and the recurrent guerilla battle over enforced sterilisation. As this author remarks, "What has happened without our really noticing it is that, with every new skirmish in the fertility war, we are becoming more and more comfortable with the idea that some people deserve to be parents more than others"[1]. And in an age of what is essentially payment by results, there is a great temptation for health-care providers to think that those who deserve to be parents are those with the best clinical chances.

But is the right to become a parent a positive or a negative one? Julie Seale was claiming the former: she had a positive right to assisted conception, she claimed. A weaker version of this argument would make much of the distinction between assisted and natural conception in such a case. Individuals have a negative right when it comes to having children: a right against state interference, but not a right to state provision. Those who assert that the right to have children is a negative one would say that society has no right to meddle with individuals' decision about child-rearing. Both forms of the rights argument make great use of slippery slope considerations. If a 36-year-old woman is denied assisted conception, why not a 35-year-old woman? A 30-year-old? A 25-year-

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old? Yet women are increasingly postponing trying to become pregnant, under the pressures of advancing their career by male-orientated timetables, or simply having to pay the mortgage. By the time many realise they are infertile, they, like Seale, may find themselves deemed too old.

Where do we draw the line? If women with learning difficulties are forcibly sterilised, what prevents us from rolling all the way down the slippery slope to Nazi eugenics? Once we begin looking at slippery slopes and their degrees of incline, we are not far from the second approach to the question of who should have children. This view avoids the term rights, which it views as being contentious and misleading. Instead it concentrates on degrees of risk.

What is wrong with saying there is a right to have children? The nineteenth-century philosopher Jeremy Bentham thought that rights meant nothing more than wants. If I assert that I have a right to a minimum income provided by the state, that means nothing more than that I want a minimum income. As Bentham put it, the demand for a right is not a right, any more than the hungry person's request for bread is the bread itself. In this utilitarian view, asserting my right to have children simply translates into my wanting to have children. But there is nothing particularly special about my wanting children, except to me. What basis is there for that right? Where does it come from, and where does it end?

If we have our doubts about rights claims from carriers of genetic disorders who want to have children, we might concentrate instead on the degree of risk involved. Rights claims do not readily admit of quantification and compromise. But the risk management approach does. Genetic disorders with a high probabiliy of transmission, in this view, are more 'wrong' to disregard than those which pose only a small risk. Of course, this approach has its flaws too. The Nuffield Report on Genetic Screening cautioned that risk assessment is not as far advanced as may appear from media coverage. Although it is possible to isolate some genes and even screen for them, polygenic and multifactorial conditions such as heart disease and some cancers are not yet "tamed" in terms of risk assessment. In any case, risk is a statistical concept. It tells me what the probability of transmission is for all carriers of a particular genetic disorder, but not whether *this* conception by *this* genetically disordered parent will produce an affected child.

According to the strong interpretation of the right to have children as a positive entitlement – for example, to IVF treatment – it appears that health authorities are obliged to provide as many courses of treatment as the couple want. Julie Seale had already been under other forms of fertility treatments for seven years. Was enough enough? Even according to the weaker interpretation of rights as negative claims not to be interfered with, there might be some individuals or groups whose claims leave us feeling uneasy. One such, to my mind, is a man I shall call Peter, whose story is a particulary poignant and telling example of the dilemma concerning who should have children and who should be born. I want to apply both the rights and the risk approaches to Peter's case study involving Huntington's Disease: an autosomal dominant, incurable condition whose likelihood of transmission is roughly 50 percent if one parent is a carrier. The single gene for the condition can now be identified and isolated in a test involving numbers of repeats: this is not a multifactorial condition. Yet Huntington's Disease survives because the average age of onset is in the late thirties, after many sufferers have already had children.

Case Study

A man with two young children, 'Peter', refused to undergo genetic screening for Huntington's Disease after his father 'Henry' died of the condition. The first, rights-orientated approach would defend Peter's right to refuse screening, ignoring the impact on the rest of his family, particularly his wife. The second, risk-orientated approach would come to the opposite conclusion: that Peter is wrong to refuse screening because Huntington's Disease is a condition with a very high probability of transmission.

Henry was a 73-year-old man who had been diagnosed with depression and then subsequently with atypical Alzheimer's Disease. Various other diagnoses had been tried and found wanting, hydrocephalus and vascular disease among them. But Henry's symptoms were still not fully explained by the diagnosis of atypical Alzheimer's Disease. The family history, however, included a number of other members who had manifested jerky movements or dementia late in life. In October 1993, Henry's clinicians decided to request permission from his family to use a newly available genetic screening test for Huntington's Disease, which has no known cure at present. (Although next of kin have no right in English law to consent or withhold consent, the clinicians felt obliged to consult the family because Henry's own competence and comprehension fluctuated.) Henry screened positive for Huntington's Disease ten days before his death.

The screening procedure, so far tested on approximately 4000 patients, is based on the number of repeats of the gene for Huntington's Disease, which was only isolated in March 1993. The number of repeats determines with great predictive accuracy and very few false positives whether the individual will manifest Huntington's Disease, but it does not enable the clinician to predict the age of onset or the severity of the condition. Huntington's is a progressive disease of the central nervous system which most commonly appears in middle age, with death occuring between 15 to 20 years later. Because the abnormal gene is dominant, the chances of inheriting the condition are roughly 50 per cent in every pregnancy, assuming that the affected person's partner carriers the normal gene. The overall incidence of the disease is about 1 in 10,000 in the UK population.

The clinical team had obtained both oral and written consent from three key members of Henry's family: his wife 'Mary', his son 'Peter' and his daughter 'Ann'. But once the diagnosis of Huntington's Disease was confirmed, it was clear that none of the three had fully understood the implications for themselves or the rest of the family. All three reacted very differently, causing considerable conflict on top of the family's bereavement. Henry's wife Mary wanted to test everyone in the family immediately – the four grandchildren, in addition to the son and daughter. Peter, himself a health care worker, was determined that he did not want to know, refusing even to tell his wife that he had an appointment to discuss his family, to the clinicians' dismay, since Peter had two young children and was of an age to father more. Henry's daughter Ann wanted to be tested herself, immediately, without any counselling. She was glad the issue had been brought out in the open; Peter wished he had never been told.

I do not think that the psychiatrists were wrong to discuss Henry's diagnosis of Huntingtons's Disease with Mary, Peter and Ann. But I do think that the case raises unusual issues about ownership of information and informed consent: when the family gave their consent to having Henry tested, the son and daughter, at least, were also consenting to a certain level of torment about their own genetic status. This also raises novel

questions about rationality and the possession of full information. In the case of Henry's son Peter, is it *irrational* not to want to know you have inherited the gene for Huntington's Disease? Is it *unethical* not to want to know? I will argue that it is not irrational for Peter not to want to know, but that it is unethical.

Philosophers have tended to associate rationality with full possession of information. The most basic condition for rational decision-making, one author has argued, is that all relevant information should be in view [2]. This author believes that with foresight we *can* control the outcome of our choices at least minimally. So there is also an ethical imperative behind being fully informed: it enables you to make the right choices, in both prudential and moral terms. And indeed many other thinkers have tended to connect rational actions with ethically correct ones.

Medical ethicists have likewise tended to assume that full information is A Good Thing, in the words of *1066 and All That*. Arguments in favour of informed consent rest on the assumption that a rational, autonomous individual will want to know as much as possible about his or her condition before making treatment decisions. The usual dynamic in medical ethics has been the demand for more information from the patient, against paternalistic secrecy from the clinician. So again this case looks odd: here we have clinicians who want the (prospective) patient, Henry's son Peter to know whether or not he carries the dominant gene for Huntington's Disease, so that he can make an informed decision about whether or not to father another child. But Peter doesn't want to know. Why does the archetypically rational individual want full information? So as to minimise mistakes resulting from inadequate information, argues the previously cited author, who has written that "a rational action is by definition one which avoids all mistakes deriving from inadequate reflection" [2]. So the point of having full information, for the rational individual, is to act on that information in a prudent manner. Having information is instrumental, as indeed is being rational. The point is action: well-conceived, well-informed decisions resulting in happy outcomes.

But in the case of someone who knows they have the gene for Huntington's Disease, how can there be a happy outcome when no cure is possible, and when the person with the affected gene may have to live fifteen or twenty years with the prospect of a miserable end? Why should you want to know when nothing can be done? If no good outcome can be had, what is the point of acting in a rational manner? Perhaps it is too simplistic to say that no good outcome can be had. It might be rational for Peter to be tested, even if it reveals that he does carry the abnormal gene. When he does develop the full-blown disease, he will perhaps be treated with more sympathy than if he were merely to manifest vague depression. Henry's carers had difficulty keeping their patience with him before they knew for certain what condition he had; for the carers to possess full information actually benefits the patient. Or it might be rational of Peter to want to maintain good relations with the rest of his family, which will be injured if he refuses to be tested. If his young children want to be screened when they reach the age of consent, and they test positive, Peter will almost certainly know that he also carries the gene (almost, because it is possible though unlikely that his wife carries the defective gene.) Perhaps it might be rational to want to avoid that particulary nasty scenario. And perhaps it might be rational to realise that you cannot go on hiding from the information forever.

But how could Peter *act* on the information that he has the Huntington gene, given that the disease is incurable? What mistakes would the knowledge that he has Hunting-

ton's Disease enable Peter to avoid? There are no treatment decisions to be made here, because there is no treatment possible. I would argue that it may be perfectly rational for Peter not to want to know. Rationality is instrumental, and if there is little to be gained by being rational, in the sense of wanting full information, then it may even be rational not to seek out full information. A rational decision, in other terms, is one that stands a good chance of promoting the individual's own values, whether or not these coincide with those of the doctor. If Peter does have the Huntington gene, remaining ignorant could give him a few years' peace of mind before he develops the symptoms; time enough to be tested when they do develop, he might say. Many people in high-risk categories for HIV have decided not to be tested, and who are we to say they were all irrational? Or for that matter, rational only insofar as they were concentrating on their jobs and health insurance? I know a gay man who made that choice ten years ago, and who is now dying of prostate cancer, not AIDS. With hindsight, of course that seems the rational decision to me, because it left him ten comparatively worry-free years. And with a genetic disorder such as Huntington's Disease, there are none of the ethical questions about unintentionally transmitting the disease if you do not know your status.

But there *are* other ethical questions. In addition to his pre-existing responsibilities towards his family *qua* family, Peter has incurred responsibilities by giving consent for Henry to be tested, even if that consent was not actually legally binding. He does not consent to be tested himself, but at the time he consented to have his father tested he knew that the results would affect the entire family. It now seems hypocritical of him to want to go back to an innocent state of total ignorance. The main question here, however, is whether Peter has a right to father another child who may have a 50% chance of developing Huntington's Disease. This case highlights the inadequacy of both the rights and the risk approaches to the question of who should have children and who should be born. The issue, I think, is not the particular level of risk; Peter would be behaving just as badly if the risk were lower, to my mind. In any case, who decides what level of risk is acceptable? Is it entirely up to Peter? Or does his wife also have a right to know the risks and make a choice? In this way, rights creep in through the back door of what had initially seemed the approach which viewed them as unproductive and controversial, that in terms of degree of risk.

Peter's wife needs to know, before she undergoes another pregnancy, whether she is bearing a child who may die of the disease. His young children may not need to know now whether he, and they, are carrying the Huntington gene, but he and his wife do in order to plan as best they can for their collective and individual futures. This is where another philosophical problem comes in, that of future generations. What responsabilities do we have toward the unborn? Are they greater or less than our duties towards those who already exist? Perhaps Peter has responsibilities not to behave in a way which will harm his descendants, *even those he will not have*. Perhaps if he were completely impartial, he would admit that he might well choose not to be born rather than to be born with the defective gene. Then he should accept a policy which minimises the risk of being born with the defective gene. This policy would require those who have a family history of Huntington's Disease to undergo voluntary screening, and to refrain from having children if their status is known. Would such a policy, made on behalf of future generations, legitimise *compulsory* genetic screening? If we could prevent suffering in the future by forbidding people with the Huntington gene from breeding, then should

we override their individual rights and do so? The Brave New World resonances of this view, its advocates might argue, will only trouble the narrow-minded.

This seems a very long way to me from actual clinical practice, in which individual doctors deal with individual patients and their families. Who would enforce such compulsory screening on behalf of future generations? Not the clinicians, presumably. In the United Kingdom, the Nuffield Council stated that "the primary responsibility for communicating genetic information to a family member or other third party lies with the individual and not with the doctor [4]. Obligations of confidentiality preclude doctors from communicating the status of even those people who have consented to be screened, let alone compelling them to be tested. Even though I think Peter is acting unethically, the clinicians have no right or duty to pressurise Peter to be tested, I would argue.

The Nuffield Council asked, "Does the person with a defective gene have a right to withhold this information from other family members? Does he or she have a duty to disclose it?" [3]. I have argued above that Peter does have such a duty. His responsibilities towards his family were not created by his father's illness, though they are highlighted by it. This third approach, grounded in the concept of duty, sems to me far more satisfactory than either the rights or the risk formulations. But I would draw the line at extending the duty to disclose a genetic disorder beyond the affected individual. Peter has that duty, I think; the clinical team do not have it on his behalf. Peter's duty does not in itself give the medical practitioner a corresponding duty or right to override the failure to disclose. Nor do I want to call this an absolute duty not to have children. I think it is much more a duty of entering into a relationship, rather than standing on the high horse of rights or taking refuge in the spurious accuracy of risk assessment. Peter's duty in this case, first and foremost, was to talk to his wife. I can report, one year on, that he has done so, and decided to be tested. Now it is his sister 'Ann' who doesn't want to know.

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