

Arguing about genetics and disability

(This paper appeared in the Journal *'Interaction'*, Volume 13, Number 3, pp. 11-14 (2000)).

Tom Shakespeare, University of Newcastle, February 2000.

This article presents a dialogue between two hypothetical characters, in order to rehearse some of the main arguments against prenatal screening, and highlight some of the problems with these arguments. The author's own views are a composite of both characters' positions.

Opponent of prenatal screening: Genetics is just the same as eugenics. It's about eliminating "lives unworthy of life", which is what the Nazis did.

Advocate of prenatal screening: I assume you're not implying that geneticists are Nazis, because that's untrue and offensive. But when it comes to eugenics, it depends what you mean by the word: it is notoriously difficult to agree a definition. The main differences between early twentieth century eugenics and the present practice of prenatal screening is that pre-1945 it was a matter of state policy, and it often involved coercion. In present-day Western countries, pregnancy termination is the free choice of individual women and men, within the parameters of the law.

Opponent: Well, I'm not opposing a woman's right to choose. If a woman decides not to continue with her pregnancy, then that's up to her. But choosing whether or not to be pregnant is a different choice from deciding which foetus to be pregnant with. I support that first right to choose, but not the second. I think it is discriminatory to make that choice on the basis of the characteristics of the foetus.

Advocate: I'm not sure you can separate the issues of 'being pregnant' and 'being pregnant with a particular foetus'. Consider the hypothetical case of an unmarried sixteen year old girl who becomes pregnant. Her decision as to

whether to continue and become a single parent might be different in the case of a potentially non-disabled baby than it would be in the case of a potentially affected baby. She might decide she could cope with the former situation - knowing that day care and all sorts of other support might be available - but that she could not cope being the single parent of a baby who had high support and care needs. And surely, it is counter-intuitive to allow women to exercise their right to choose termination for social reasons - such as failed contraception, or a change of heart, or being too old or young, or having too many children, but to deny it in the cases of diagnosed serious foetal impairment?

Opponent: Okay, I allow your point that choice is an important principle. But I don't believe that women and men are exercising free and non-constrained choices in practice, for several reasons. First, they are not given full information. Sometimes they are not given proper clinical information about the particular impairment that has been diagnosed. Usually they are not given full social information on what it's like to have that impairment, and the quality of life implications. They are rarely told about the psychological impacts of termination of pregnancy. And they are never provided with the perspectives of disabled people themselves, who are the real experts on being disabled. Second, doctors and other professionals are biased against disabled people. They are ignorant about disability. They think disability is a tragedy to be avoided at all costs. They do not counsel non-directively. They believe screening is a good thing, and this influences their patients. Third, the clinical context influences the choices made: for example, making a test available implies the desirability of that test. Antenatal testing is like a conveyor belt, and many women are not given the time and information to make an informed decision. Finally, society is increasingly blaming women for not having tests or not having terminations. For all these reasons, there is no real choice at the moment, and women are not supported to continue with pregnancy, if they want to do so.

Advocate: I accept your argument. Choice at the moment is rather limited. Society needs to ensure that resources are invested to enable women

and men to make fully informed choices. But, if we managed to achieve that, then you would have no reason to prevent women having the choice of terminating pregnancy affected by impairment, if they wanted to, would you?

Opponent: I'm not sure. I don't like the idea of people trying to avoid the birth of disabled people. It's like saying disabled people aren't worthy of life...

Advocate: That's not necessarily the case. I can think of four reasons a woman might choose to avoid the birth of a disabled child. One is because they don't think disabled people should exist, or because they think that disabled people aren't worthy of life. Another is the argument that society should not have to pay the costs of supporting disabled people. These both seem to me to be morally dangerous. I would join you in opposing them, and I would call them 'eugenic' reasons. But the second two reasons seem to me to be important. One is that impairment involves suffering and physical difficulties, and it is unfair to bring people into the world to suffer. The second is that it is often difficult for the parents and siblings of disabled children. There is sometimes a very negative impact on the whole family. Relationships break up, and brothers and sisters may become neglected or resentful.

Opponent: I am glad you agree that your first two reasons are oppressive and should be opposed. But I think you've missed the point about disability. Both your second two reasons are not really about what it's like to have an impairment. They are about the way society treats someone with impairment. Disabled people say their real problems are discrimination and prejudice in society. That's what makes life difficult for disabled people and their families. We should remove the social factors that cause suffering and isolation, rather than remove disabled people from the world. We need social engineering, not genetic engineering!

Advocate: Okay, fair enough, I agree we should try and change the world, although I reckon that it might be much harder than you think to change some of these social problems. But surely, not all impairments are the same. There are

some impairments which are invariably very difficult. Babies die in their first year of life, or people die before their twentieth birthday, or people live very difficult lives with limited consciousness and self-awareness, or else with extreme pain and physical difficulties. However much you change society, surely these problems will remain and should be avoided if possible?

Opponent: Well that's just it. I don't think it's up to us to try and remove impairments from the world. Impairment is a fact of life - after all, we're all going to die. Being alive involves suffering. We shouldn't be playing at God.

Advocate: Well, impairment may be inevitable, but that doesn't mean we don't have a duty to try and minimise it, especially when it is very severe and debilitating. After all, we agree on some tactics for removing impairment, such as the vaccination of children, or mine clearance, or looking both ways when we cross the road. Nobody would have a problem with impairment prevention, would they?

Opponent: I think there's a difference between impairment prevention and removing people with impairment from the world. And where do you draw the line? If you are giving women the right to choose, does that mean the right to terminate pregnancy on the basis of the sex of the potential child, or perhaps sexuality or intelligence? If you are going to be consistent about choice, then why stop at impairment?

Advocate: There is no requirement to be either totally pro-choice, or totally anti-choice. Ronald Dworkin argues against the notion of 'foetal interests' and believes that termination of pregnancy is not immoral. However, he argues that this does not mean that termination of pregnancy is a morally insignificant act. It involves halting life once it has started, and should not be entered into lightly. Because termination of pregnancy is morally significant and important, it should be chosen only when the alternative would be much worse for the parents or potential child. For this reason, termination of pregnancy on grounds of personality characteristics - for example gender and sexuality - should be avoided.

Opponent: It's all very well resorting to philosophical arguments. But the fact is, that I might not have been born, if these selective termination techniques had been available to my parents' generation...

Advocate: Your statement has immense emotional weight, but it does not make sense. Saying 'I would not have been born' is not logical. The point is that you were born. Prior to your birth, there was no 'I'. Only after your birth, was there an 'I'. Souls do not wait in limbo before birth, being prevented from coming into the world by particular acts of contraception or termination of pregnancy.

Opponent: Okay, I accept that, if you want to be pedantic. What I meant was, these techniques stop disabled people in general from being born.

Advocate: But that's not strictly true either. You have accepted that termination of pregnancy is morally acceptable, presumably on the basis that up to a certain stage of pregnancy - say 24 weeks - there is no 'person' involved, just a 'potential person'. Termination of pregnancy stops a collection of cells developing further. It does not stop a disabled person being born. However, the effect of selective termination may be to reduce the number of disabled people in the world.

Opponent: That's exactly what I mean. Selective termination reduces diversity. And what's more, terminating foetuses affected by the same condition as me is a form of discrimination against disabled people. It's a judgement on me and on my life. It will lead to more prejudice against disabled people.

Advocate: I am not sure that there is any evidence that selective termination of pregnancy increases prejudice against disabled people. In China, for example, there is a strong eugenic policy, but there is also increasingly good provision for disabled people. And the fact that we take a sugar lump inoculation against polio does not cause discrimination against people with polio. Prevention and support are not incompatible.

Again, I can see the emotional relevance of your feeling discriminated against because of a screening programme designed to eliminate your

impairment, but I don't think it is just or rational. After all, let's say you got your way, and out of respect to you, society decided to prohibit selective termination on the basis of your impairment. What would you say, in twenty years time, to the person who was born with the impairment, when they complain that you stopped the technology being used to prevent the birth of people with that impairment? Why should they suffer because the idea of impairment prevention makes you unhappy or feel discriminated against?

Opponent: Okay, maybe I shouldn't have talked about discrimination. But I notice that you haven't dealt with my argument about diversity. I still think that selective screening could go too far. I accept that people should have reproductive choice, but I don't want to see a world in which all impairment has been eliminated. We should value every individual, and we should support difference. I want to see these technologies carefully regulated, I want to see informed and supported choices, and I think we should recognise the contribution which disabled people make to the world, and their right to be a part of it. If we challenge the prejudice and fear which surrounds disability, prospective parents would be less likely to feel that termination was the only answer.

Advocate: I don't have any problem agreeing with that. I can see why you feel insulted and denigrated by the rhetoric which supporters of genetic intervention sometimes adopt. I think we should be careful not to say disability is invariably a tragedy, and I think we should try and reduce the discrimination which often makes the lives of disabled people so much more difficult. But I do believe that we should offer women and men access to screening information, and give them a free choice about whether to continue with pregnancy.

Perhaps there's also a difference between testing, which involves families who already have a history of genetic conditions, and who know what they involve, and screening, which extends genetic intervention to the whole population. Screening is often introduced on the basis of cost-benefit calculations about avoiding the birth of disabled people. It seems to be where

genetics comes uncomfortably close to eugenics. Perhaps we should be in less of a hurry to introduce the latest tests, or extend them as widely as possible. Biotech corporations might be keen for us to take advantage of these technologies, but if we cannot guarantee that people will be informed and supported to make the best choices, then perhaps it is too risky to push onwards with this type of screening.

Further reading

Dworkin, R. (1993) *Life's Dominion*, Oxford.

Shakespeare, T. (1998) Choices and rights: eugenics, genetics and disability equality, *Disability and Society*, 13, 5, pp 665-682

Shakespeare, T. (1999) Losing the plot? Medical and activist discourses of contemporary genetics and disability, *Sociology of Health & Illness*, 21, 5, pp 669-688

Stone, D. (1996) A law to protect, a law to prevent: contextualising disability legislation in China, *Disability and Society*, 11, 4, pp 469-484