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Science, technology and our future: the big questions

The Search for perfection

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Tom Shakespeare, Director of Outreach, Policy, Ethics and Life Sciences Research Institute, Newcastle



Tom Shakespeare: It's always entertaining to listen to John. That's less so on that occasion because I obviously realise that the world he suggested wouldn't have me in it, or my two kids or me dad or a lot of me friends so, you know, it is quite sort of difficult to, in a way for people, to listen to that.

So where do I start? I start in the real world, not he world that John envisages or indeed in which he constructs his arguments and I want to say two things about that real world and one thing about the values, which I think we should be thinking about. The first thing is medicine, and with trepidation in a science temple, I suggest that we are guilty of overestimating the power of medicine and there are assumptions about what medicine can do and will do, which many scientists in the audience will not recognise. To talk to doctors and scientists, they stop, not just at the headline but also some of the projections of philosophers and sociologists like John and myself.

Many of the most interesting problems we're confronted with, the problems of gene expression, the problems of gene interaction, the problems of how exactly brains work, are, to say the least, not trivial. They will not be solved any day soon. There are massive areas of ignorance as to how our complex bodies and brains work and,

indeed, how we should best intervene to change them or to even improve them. So, I think there are two particular problems.

First of all, the solutions that we do get now tend to be incomplete. They don't do what they're meant to do and secondly, they have side effects. They do what they're not meant to do and if you take almost any of the interventions that we might talk about tonight, that criticism or one of those criticisms could be levelled at it from genetics to surgery to Prozac or anything else. There are problems associated with it because we are complicated, physical beings and we are incomplete engineered. We don't live in that utopia. I say that philosophers and journalists and sometimes sociologists get carried away and I think we want to orient to where we are now.

Secondly, I want to say a few things about society. I'm a sociologist, which perhaps I should apologise for, but I would hope that it means that I'm oriented to a world which is messy and complicated and hopefully close the world that you and I live in, as opposed to a world in which people make arguments and write academic books and I think that there is a problem, a particular problem with the way we think about these things, which philosophy and medicine tends to get itself into, which is why I don't apologize for taking up your time tonight. And that is that we think of these problems and these dilemmas and these choices in almost purely individualist terms. We take them abstractly, as if we were merely a body and a brain or we were merely an individual free agent. We do not consider the complex patterns of other people that we're involved with - the families and the systems and the communities and societies in which we're implicated and which we influence and which influence us.

Sociologists obviously talk about the operations of power, i.e. politics, and they talk about complex meanings, in other words, culture and I think we have to situate any discussion of those technologies that we're examining tonight within those very, very complicated systems. I just want briefly to talk about four dimensions of the social consequences of the sorts of individual decisions, which John, as a libertarian philosopher, thinks that we ought to be free to like. One, and this emerges out of actually practiced genetic interventions at the moment, is a reduced tolerance of diversity. That's not why the interventions were introduced. It doesn't even mean that it's wrong to use those interventions but it is a social consequence of using those interventions, which we should think about.

For example, my colleague Theresa Martin has done some psychological work showing that, because we can now test pregnancies for Downs Syndrome and screen pregnancies for Downs Syndrome, there is a reduced tolerance of people with Downs in some of the experiments that we did. Let me elaborate on that. She probably wouldn't say it in those terms. I hope she's not in the audience getting very upset with me misrepresenting her!

Just anecdotally then, in the past, when we walked down the street and we saw a family with a Downs baby, what did we think? Depending on our perspective, we might have thought, that's sad, how unfortunate, or how blessed they are or we might have thought, that's different, but whatever we thought of, it was bad luck; it was not something that could have been stopped. Now we ask, and John thinks that we should ask this, we ask, why didn't you have a test? Did you want to have that child? Do you know that you needn't have had that Downs baby. Now, what I'm suggesting there is that individual choices that John espouses to that individual woman or man in the present situation, are contained, restrained. They can do whatever they like but we're going to blame them for it!

Bob Edwards, one of the pioneers of IVF, said, in the future it would be a sin to have a disabled baby. That throws direct blame to individuals for exercising their free choices. They're supposed to be free choices. Insurance companies in the United States will not cover your medical costs if you have, what they call, elective disabilities. So what sort of freedom is that for the individual to do what they want to do? Reduced tolerance and diversity works in lots of different ways.

If you look at media, television debates, (I wouldn't advise it) from politicians in Britain and America in the 1960s, or you see the interviews on tape, you will notice one thing, which is very striking. Their teeth aren't level. They have gapped teeth. They do not have good teeth. You could not survive as a politician in Britain and America today if you didn't fix your teeth. So use your power for individual choice as to whether to fix your teeth because we have no tolerance for politicians with dodgy teeth! That's a trite silly thing but this pressure to conform, the way that the collective effect of individual free choices actually restricts many of us, can be seen in very toxic ways in the lives of teenagers and in approaches to, particularly, to the way women should look.

Twenty-five years ago top models weighed 8% less than the average woman so that the people that were aspired to weighed 8% less than the average of what women were like. Now, they weigh 23% less. The media ideal for what a woman should look like is achieved by less than 5% of women. I'm sorry these are only statistics

about women. I'm sure it's increasingly applying to men. Both John and I have no future in the media in this country. 81% of 10-year-old girls in America have been on a diet at least once. 25% of 7-year-old girls in Sweden have dieted at least once. I think those are statistics that are actually quite shocking, quite disturbing, especially to those of us who have daughters. So there's reduced tolerance, there's a pressure to conform arising out of individual choices and commercial imperatives, which are selling certain solutions to certain socially defined and created problems.

Thirdly, we are entering a world in which we are applying individual solutions to social problems. One of the reasons is you can make a lot more money out of individual solutions to social problems. Collective, structural solutions to social problems might be things like education. They might be in public health. They might be changing environments to make it more acceptable to disabled people. Individual solutions are cosmetic surgery. They are corrective surgery for people like myself to make them 6 inches taller. They are cosmetic surgery to Downs people so they don't have slanted eyes, and there's a whole lot of individual solutions which we are being... which are being foisted on us.

And my fourth point here is the lack of access to these technologies. These technologies cost. If they're available through public services then they're rationed. You queue. You wait and not everybody can get access to them and the bottom line is that, if you want these things, you have to pay for them. Clearly, not everybody can pay for them. So this increases inequality. We are entering a world in which we can intervene in the natural genetic lottery so people who are born like me, we're born with a bad hand genetically but society can intervene to change that. Well, no it can't, because of course we don't have enough money to do what we can already do, let alone to enter this utopia ideal of fixing, improving and perfecting, and we should remember on a global scale...

Chair: Could we have one more minute.

Tom Shakespeare: Sugar! Let me talk! Let me talk in conclusion. Let me make two points about the difference and these are obvious points. Disabled rights to viable, worthwhile lives. I think an eliminate at all costs mentality is a real problem. Most of the creative work and many of the worthwhile contributions to human history have been made by disabled people. Disability is the grit in the oyster, which fosters and promotes a lot of interesting ways of looking at the world and contributing to it. And moreover, a good society looks after it's weakest members regardless of

whether they produce pearls or not. That's how we should be judged, on how we support people with Downs. We should be looking at ourselves as part of a community which is inter-dependent rather than being a competitive, individualistic, I'm going to be the best I possibly can society, rather than see old and frail and disabled people as a burden, which we should avoid at all cost.

My final point, embodiment – this is my metaphysical point; I'm sorry to tread on John's area or indeed my friend's from the Church of Scotland – embodiment is about limitation, restriction, suffering and mortality. That's the sad truth. Of course we use medicine to reduce suffering, to reduce the burden of disease. Nobody wants to live in the Stone Age. I'm not a luddite. Medicine's been very beneficial to me and to my disabled mates but there is a limit to what we can do to stave off death or to limit our exposure to the limitations of our physicality. Robert Louis Stevenson, I quote, "We are all, old and young, on our last voyage". That's my quote message for you. We need to come to terms with this. We need to accept our glorious perversity, the fat and the thin, the tall and the short and the young and the old. All you lot, that is to say. You're human beings and you always will be like this, rather than to resort to evermore undignified toxic and expensive attempts to deny reality and achieve perfection. Thank you.