



Human Genetics

Duration: 0:10:48

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Interviewer: Welcome to the Arts & Humanities Research Council podcast.

Genetic testing is likely to be used more and more in the future as genetic technologies develop and as medicine becomes increasingly preventative.

There are growing concerns that people could be discriminated against by insurance providers, employers, healthcare professionals and others on the basis of their genetic information or markers. To date progress in the debate has been slow and an assessment of the need for appropriate policy and legislative responses has been hampered by a lack of evidence.

To address this issue the AHRC, the Human Genetics Commission and the Wellcome Trust invited a cross-disciplinary panel of experts from the fields of philosophy, law and the voluntary sector to discuss the issues around genetic discrimination and to look for ways forward in this increasingly complex field.

But first, precisely what is genetic discrimination? Ron Zimmern is the head of the PHG Foundation, an organisation that looks at the impact of genetics on health and health services. He's a public health physician by training and one of the expert speakers at the recent event.

Ron Zimmern: I find the term genetic discrimination totally meaningless, in the sense that the whole biological function of genetics is to enable one individual to be different from another. That is the basis of the biology of genetics, and the way it works is that there is random assortment of the genes as people get produced from one generation to another and that makes people different.

So, the differences and discrimination used in that sense of differences is part of what genetics is about. The issue here is not differences in discriminating between one individual and another, it's when that discrimination becomes unfair.

So to me, the relevant issue is about fairness, it's about justice and it matters not whether the things that lead to unjust solutions is genetically internally determined or whether they're determined by external factors.

Interviewer: For Paul Steven Miller, the Henry Jackson Professor of Law at the University of Washington in Seattle, the emphasis is also on fairness and justice.

Paul Steven Miller: To me genetic discrimination means, in the employment context, when an employer bases an employment decision, whether to hire or fire or promote an individual, based upon something that has no bearing on their ability to perform in the job successfully.

So, in the context of genetic discrimination it would be basing a job decision on somebody's genetic predisposition regardless of whether that predisposition manifests itself in any impairment. To

me, genetic discrimination fits four squarely within the context and a set of principals of all sorts of other employment discrimination; rubrics that are prohibited by law with respect to race and gender and age and disability.

It is basically using something that an individual has no control over, that's not relevant to one's success in the job and using that in a way to exclude them from the job.

Interviewer: But if this is what genetic discrimination is in general, what of its impact on us as people who could be discriminated against? Ruth Sands is a regional care advisor for the Huntington's Disease Association, an organisation that naturally has a particular interest in discrimination on the grounds of genetic information.

Ruth Sands: In order to, sort of, prepare for today I asked the question to some of our service users and the things they came back with, most people reported in insurance they felt that they were discriminated against but actually a lot of that came down to misconceptions.

Other people cited fear of discrimination in the workplace and also in relation to healthcare, perhaps specifically into reproductive choices.

Interviewer: Central to the discussions at the recent event was the question of how risks of genetic discrimination can best be addressed. For philosopher John Dupré there are some basic questions of definition, of developing shared concepts and developing a shared understanding that needed to be explored first. He explains.

John Dupré: I do think there's a great deal to be done in really clarifying the issues because I think, you know, as much of my work is concerned with the very concept of what is genetic, is very obscure and actually just came up in some of the discussion.

So, I think that prelimin- I think it would be – it's really important that we try and get as clear as possible about what we're talking about and what the problems and risks are before we start trying to address them. I think that it's maybe - it's a little premature at this point to say how to address them because I think we're really not sufficiently clear what they are.

I think we have good reason, given the explosive growth of genetic technologies, genetic testing and so on to anticipate and then of course, also given the history of the way people have thought about genetics and sometimes used genetics, I think there's every reason to be concerned.

I think while – that we should be careful not to rush into remedies before we're as clear as we possibly can be about what the actual problems are that we need to remedy.

Interviewer: For Ruth Sands, with her focus on service users and the more immediate and practical challenges the issue presents, the emphasis is on information.

Ruth Sands: I think, sort of, from my point of view and with our service users it's trying to get over the misconceptions. So, actually getting appropriate information to them about things like insurance and

enabling them to access that information in whichever way is best for them.

Interviewer: For Paul Steven Miller, the law has the crucial role not only in ensuring justice and fairness but also in reflecting what society deems to be good and bad behaviour, in what all acknowledge is a difficult and complex field.

Paul Steven Miller: I think that our knowledge of genetics is new, and that we as a society are just uncovering the science and implications of one's genome. Thus I think that employers may feel, or some employers, may want to use this information in order to, in the employment context, in order to either try to preference themselves.

In other words I think that regardless of whether ones genetic marker has a bearing or not a bearing on ones ability to do the job, whether it's bad science or whether it's actually predictive, I think that employers are going to seek refuge, or some employers are going to seek refuge, in trying to use this information as a way, as a proxy of making employment decisions.

To the extent that these proxies of genetic information have nothing to do with ones success in the job and to the extent that it is utterly unfair to penalise somebody for their genes. I want to be sure that employers are not permitted to do so.

In addition, since it is such a new science and we're all trying to figure it out, I think that the law can provide a really beneficial standard setting vehicle by which you establish what is good

behaviour and bad behaviour, so that employers know how to present themselves and how to act in this new world.

Interviewer: So, with all these complex problems requiring the input of a range of disciplines, did the experts think the seminar had made a useful start to the process of gaining knowledge and understanding? Here is Caroline Harrison, a barrister and member of the Human Genetics Commission and Chair of the working party on genetic discrimination.

Caroline Harrison: It's very timely because it comes at the start of the working groups project on genetic discrimination, so it has proved an extremely useful launch pad for our thinking and trying to set a framework for some of the principal issues that we're going to be discussing.

Valuable because it has given a lot of content to the thinking that I've already done and that we've done as a group and so, I think its been extremely useful, very informative and given me lots more places of knowing where to look for other things.

Interviewer: Ruth Sands agrees on the need to have a range of views represented but singles out those service users have been crucial to fully understanding the issues.

Ruth Sands: I think it was quite interesting in the seminar today to, sort of, mix with people from different backgrounds and at different levels who are all dealing with the same issue. It was nice to be able to put

forward some of the views of our service users and I think that's important to the people we work with, that they feel that they're being heard.

Interviewer: Finally, for Paul Steven Miller.

Paul Steven Miller: I think it's been valuable because of the way that the conference organisers have put together an interdisciplinary group of presenters who have really addressed the question of genetic discrimination from a variety of standpoints. Not only from the medical and legal standpoint but also from the historical, social and ethical standpoints.

I think the mix of all of those points of view and lively discussion and how they interrelate with each other has been really useful in helping people think about the question.

Interviewer: Thank you for listening to the Arts & Humanities Research Council podcast. To find out more please go to www.ahrc.ac.uk.

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