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Disability, Genetics and Global Justice

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Genetic developments are viewed with distrust by the disability rights community. But the argument that genetic screening promotes social injustice is not straightforward. Disabled people are affected by both the problems of impairment and the problems of disability. Preventing impairment should be a priority as well as preventing disability. Questions of social justice arise if biomedical approaches are prioritized at the cost of structural changes in society. They also arise when disabled people do not have access to genetic medicine. On a global scale, the priorities for impairment prevention are basic healthcare, not high technology medicine.

Disability rights versus genetic science

Civil rights and social justice have been central demands of the disability movement in recent decades. Whereas the traditional view of disability saw people with impairments as victims of the genetic lottery or casualties of disease and trauma, the disability movement has promoted a new view of people with impairments as disabled by society (Swain *et al*., 2004). Moving the causal emphasis to social arrangements creates a moral claim for redress, based on the injustices done to people with impairments who face discrimination and social exclusion. Inclusion and equality for disabled people, then, is not a superrogatory goal arising from charitable desires to benefit a group of unfortunates, but a demand of justice arising from the way society has created extra burdens for people with impairments.

Within this new view, genetics is seen by many activists as further evidence of injustices committed against people with impairments. Injustice, because impaired foetuses are denied the right to life. Injustice, because disability is once more defined in individual and medical terms. Injustice, because people with genetic conditions are subjected to discrimination, controls on their reproduction, and potentially to unwanted medical therapies (Shakespeare, 1998; Shakespeare, 1999; Parens and Asch, 2000).

Genetics and disability are regarded very differently by the two groups who celebrated 2003, which was both the European Year of Disabled People and the fiftieth anniversary of the discovery of the structure of DNA (cf. Shakespeare, 1999). For disability activists and scholars, disability is defined as the oppressive relationship between people with impairment and disabling societies. The priority is to use law and policy to remove the barriers that exclude people (Swain *et al*., 2004). For genetic scientists and medical professionals, disability is the unfortunate result of disease and deficit. The priority is to prevent disability through therapies, cures, and antenatal diagnosis and selective termination. For example, James Watson himself has written that 'seeing the bright side of being handicapped is like praising the virtues of extreme poverty' (2000). He views disability as something to be prevented or cured at all costs.

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Genetics is threatening to a disability rights perspective, not just because it suggests that disabled people should be prevented from being born, but also because genetic reductionism challenges social model understandings of the social creation of disability, re-defining disability in terms of biology and abnormality. The majority of disability scholars and activists have rejected genetic approaches to disability, claiming that genetics is discriminatory, or that it expresses negative valuation of disabled lives, or that it will lead to increased discrimination against disabled people in the population (cf. Parens and Asch, 2000).

The rejection of genetics is an extreme version of a generalised suspicion about medical and rehabilitation approaches to disability. Cures and therapies have often been challenged as inappropriate and individualist (e.g., Oliver, 1989). Such criticisms may draw on four claims:

1. Cures are wrong, because they may not deliver the promised solution or because they have side-effects. Cures raise unfair expectations and sometimes actually do harm.
2. Cures are wrong because they are a distraction from the important goal of removing social barriers. Structural change is more important than individual therapy.
3. Cures are wrong, because focusing on impairment reduction challenges the right of disabled people to be themselves, to do things their own ways, to be diverse and culturally distinct. Cure and prevention expresses negative valuation of the lives of disabled people.
4. Cures are wrong because there is nothing about being a person with impairment that requires curing.

In this paper, I want to challenge the rejection of biomedical cure, and show the complexity of arguments about genetics and disability. The first section of the paper explores the nature of disability, and criticises the neglect of impairment within disability studies approaches. The second section highlights the importance of preventing impairment, as well as preventing disabling barriers. This leads into a discussion of arguments about genetics and social justice. The paper concludes with observations about several key debates in bioethics, which may look different when viewed through a social justice lens.

Coming to terms with biomedicine

Within disability studies, there is a general rejection of work in medical sociology, chronic illness, rehabilitation and other fields which explore issues of the body and biomedicine. This refusal to recognise the importance of the body has been criticised by many scholars, particularly from a feminist perspective (Morris, 1991; Crow, 1996). Neglect of impairment is neglect of something important to many disabled people's lives. Many disabled people experience disease and impairment effects (Thomas, 1999), which often bring them regularly into contact with biomedicine. If 'the personal is political', then experience of bodies and impairment and medical intervention should be part of the disability studies analysis. If disability studies neglects bodies and impairment then the field is left to researchers who may not share the commitment to disability equality and social justice, and who may not ask appropriate questions or use appropriate methodologies. Social model researchers, therefore, should not neglect biomedicine (Hughes, 2002).

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Those researchers who reject, or wish to go beyond, the social model, argue that the social model fails to account for the multi-dimensional nature of disability (Shakespeare and Watson, 2001). By contrast, the WHO's International Classification of Function (ICF) aims to be a 'medical–psychological–social' model, enabling inclusion of different levels of disabled people's experience. Because the ICF stresses social and environmental barriers to participation, it has the potential to promote a civil rights approach to disability, and perhaps for this reason has been endorsed by Disabled People's International. Conceptually, the new approaches suggest that a non-exclusive approach to disability is needed, one in which perhaps the different meanings of the year 2003 may each be able to find a place.

Looking at disability, this highlights the need for different approaches to the complex and multi-dimensional problem of disability. For example, political change can lever resources and lead to anti-discrimination legislation. Social policy, architecture and design can remove barriers to the social and physical environment. Social work and psychology can assist disabled individuals and their families. Rehabilitation, medicine and genetics can help restore function or combat disease. Improving the quality of life of disabled people – and non-disabled people – requires different forms of knowing and intervening in the world. Social justice cannot be limited to social change, but should also embrace access to advanced medical technologies and basic healthcare, on a global scale.

Problems arise when interventions to solve disability problems address an inappropriate level. For example, providing a medical solution to a problem of discrimination – such as cosmetic surgery for people with Down's syndrome – can be both inefficient and oppressive, because it reinforces rather than challenges discriminatory social relations. Yet accepting this does not negate the need for individual and medical approaches, alongside the plurality of disability-reduction measures. The year 2003 was a celebration both of medical and scientific progress, and also of social change. Both have potential to reduce the burdens of disability in the world and to improve the quality of life of disabled people.

Disability prevention

If disability is a product of the interaction between impaired bodies and excluding social environments, and if disability is often experienced as a problematic social and physical status, then disability prevention also should be multi-dimensional. This necessitates attention to a controversial issue in disability studies. A social modellist might define disability prevention in terms of barrier removal, civil rights and other structural interventions. A public health analyst would define disability intervention in terms of health promotion, medical cures, and care and rehabilitation. Disability studies and disability rights perspectives approve of the former, but tend to ignore the latter. Where preventing impairment means preventing impaired people, many disabled commentators suggest that the two approaches are contradictory: it is often claimed that prenatal diagnosis and selective termination (PND) is discriminatory or unjust (see for example many contributors to Parens and Asch, 2000).

By contrast, I argue that preventing people becoming impaired is as important, on a global scale, as preventing people from becoming disabled. For those who already have impairments, or whose impairments cannot easily be cured, the priority may be removal of social barriers and promotion of inclusion and equal respect. But for the vast

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population of individuals vulnerable to impairment, measures to forestall impairment are vital. Whereas some disabled activists see impairment as part of diversity, sometimes even to be welcomed, I would support the position that ill health and impairment should be prevented wherever possible, but not at all costs.

Although slogans and statements such as 'disabled by society, not by our bodies' and 'we do not want cures' are common in the world of disability rights, it is my contention that in practice many disabled people agree with the general assumption that impairment and illness should be prevented or cured if possible. In particular, many disabled people with degenerative conditions are very supportive of biomedical research: for example gene therapy or stem cell research. Evidence of these claims comes from Agnes Fletcher's survey of the disability community for RADAR (Fletcher 1999): 73 per cent of respondents believed it would be great if new genetic treatments could be developed for conditions like cystic fibrosis or muscular dystrophy. If your condition is steadily worsening, and if you are likely to die as a result of it, you may be far more positive about the role of biomedicine than if you have a static impairment which does not impact on your health or longevity (see for example patient views expressed in the journal *Euroataxia* www.euro-ataxia.org).

Further, no disabled person rejects *all* cures or medical interventions. Most people who become paralysed, for example, want to maximise their movement and strength, and cooperate with surgeons and therapists to restore and build function as far as possible. A disabled person may have accommodated to their condition, or may be used to it since birth, yet if their condition starts degenerating – perhaps through age – they may be keen to prevent further deterioration, and seek the help of medical professionals and professionals allied to medicine to assist this.

Disability rights commentators may draw a distinction, however, between biomedical interventions which remove or mitigate impairment or illness, and forms of prenatal diagnosis (PND), which prevent the birth of people with impairment. The former is impairment prevention, but the latter is prevention of disabled people. If you support disability rights, it is claimed, you cannot support access to PND.

There is official agreement in the UK and most other western societies that the aim of PND should be to help pregnant women and their partners to exercise an informed choice about their pregnancy. Patient autonomy is the dominant principle in medical ethics. However, there is evidence that screening programmes do not always achieve this goal: professionals may be prejudiced about disabled people; information may be inaccurate, incomplete, or biased; clients may face pressure to accept tests or to opt for termination (Shakespeare, 1998). Where these situations obtain, they are not only antithetical to disability rights, they are also antithetical to the ethos of medicine and of screening services. The disability rights critique of actually existing PND has merit.

But many disability rights commentators object to PND in principle, as well as in practice. I will not consider here those who base their objections on foetal rights, because this is a general argument against all abortion, not an argument specific to abortion on the grounds of disability. However, many commentators support abortion rights, but object to PND and selective termination. In other words, they support the right of women to terminate pregnancies for social reasons, but not because the foetus is diagnosed as having an impairment. This position appears inconsistent, and over-reliant on the 'expressivist objection' that such PND is discriminatory, sends negative messages about disability, or will lead to the devaluing of disabled people.

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I believe the expressivist objection to be weak. There is no empirical evidence that promotion of PND leads to deterioration in services or civil rights. As earlier suggested, there is consensus that avoiding impairment and illness post-natally is desirable, and few complain that this expresses discriminatory views about people with impairments and illnesses. There is no evidence that the majority of those who chose PND are motivated by prejudice against disabled people or eugenic ideas. Nor will PND have a major impact on social diversity. Most forms of impairment are not detectable antenatally, and even a very efficient screening programme will not make a significant difference to the numbers of disabled people in society. The autonomy of potential parents is an important consideration, and the expressivist objection does not seem strong enough to suggest it should be restricted, or that parents should voluntarily forgo PND as a gesture of solidarity with already existing disabled people.

While many claim simultaneously to support a woman's right to choose, while decrying termination of pregnancies affected by disability, I believe that anxieties about selective termination of foetuses with impairment are evidence of implicit anxieties about termination per se. I interpret opposition to termination of 20 week old impaired foetuses as evidence of the implicit belief that a foetus at 20 weeks is a disabled person, and that terminating such a pregnancy is equivalent to killing a disabled person. If this is the basis of opposition, then logically the disability rights critic should oppose termination on any grounds. After all, each year there are around 180,000 terminations on social grounds in the UK, and only 1,800 terminations on disability grounds.

It is the claim of this paper that providing screening programmes which help reduce the incidence of congenital impairment, on the basis of informed consent, is compatible with upholding rights and services for disabled people, both in theory and in practice. There is no intrinsic ethical problem with PND, appropriately offered and delivered, nor with gene therapies and other genetic interventions.

Genetics, ethics and justice

Although PND may not be discriminatory or unjust, in principle, this does not mean that genetics has no implications for justice, in practice. There are wider questions about the role of genetics in medicine, and the role of technological medicine in global healthcare. Stronger disability-based concerns about genetics and biotechnology may arise from distributive justice concerns than from anxieties about prenatal selection or normalising therapeutic interventions.

Three different sorts of arguments that genetics may be antithetical to social justice can be identified:

1. Because there may be lack of equal access to, and funding for, genetic services;
2. Because it is inappropriate and inefficient to prioritise prevention of impairment, rather than prevention of disability;
3. Because the pre-occupation with genetics and technological medicine detracts from the priority of providing basic healthcare for all.

None of these arguments is based on a claim that genetics is intrinsically wrong. Each arises from the context in which genetic services are offered, and the inequities which may result as a consequence.

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Injustice due to lack of access to services

The first argument starts from the assumption that genetics is beneficial to families and societies. It may enable couples to prevent recurrence of serious genetic diseases which harm children and place a heavy burden on families and society. Research may eventually lead to gene therapies which will enable individuals affected by genetic disease to live longer, better lives, and ultimately to be cured entirely. The genetic endowment which an individual is born with is beyond their own control. Genes are a natural lottery, not a matter of individual responsibility. A just society might compensate individuals for any misfortunes they experience as a result of the genetic lottery (Buchanan *et al*., 2000). Access to genetic goods will therefore become another important dimension of social justice.

This argument can be played out in different ways. It could be suggested that rich people will have more opportunities to rectify the genetic lottery than poor people. Rich people might be more likely to avoid having children affected by genetic disease. And poor people with genetic conditions could suffer a double jeopardy, unlucky to have the genetic disease in the first place, and doubly unlucky not to be able to access costly treatments. An egalitarian National Health Service may avoid this problem. But alternatively, it could be suggested that people with rare diseases are more likely to lose out than people who experience common diseases. For example, if there is insufficient state funding or potential commercial profit to allow research into rare 'orphan' diseases then injustice will result to disabled people and to families of disabled people. Alternatively, if research is successful, leading to the production of pharmaceuticals, which are then rationed because of their expense and the rarity of their beneficiaries, then people with rare or complex conditions could lose out. These problems again represent forms of double jeopardy.

Injustice because reducing disability is more important than reducing impairment

The second argument raises objections to genetic prevention or therapy, not on the grounds that it is intrinsically wrong, but that it is an inappropriate or inefficient intervention to deal with the disability problem. A social model philosophy suggests that the major problems for disabled people are social barriers and social exclusion. This generates two problems. First, gene therapies may be less efficacious than social change in improving quality of life for people born with genetic impairments. Better social support, housing, and education may contribute more to quality of life than medical treatments.

Second, if prospective parents are deciding on PND, then they may be motivated by their beliefs about the quality of life which may be available to disabled people and families with disabled children. If it appears that disabled individuals and families are poor and socially excluded, then they will be more likely to opt to terminate a pregnancy affected by impairment. Effectively, these prospective parents would be making a decision based on the society they lived in, not the intrinsic effects of impairment. This situation does not seem far away from the decision of a poor couple not to have children because of lack of social opportunity, or a minority ethnic couple not to have children because of problems of racism. Each of these decisions seems to be unjust, and an example of 'blaming the victim'. The conclusion might be that society is morally obliged to do more to remove discrimination and social barriers and to support all its members, before offering PND to avoid the birth of individuals from socially excluded groups.

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Injustice because genetics will not reduce global burden of impairment

The third argument is based on utilitarian and egalitarian assumptions. According to these approaches, justice demands that investment in health and well-being should aim to provide the maximal increase in quality of life, and to ensure that the benefits are spread as widely as possible. If such assumptions are accepted, then the current preoccupation with genetics and high-tech medicine seems unjust. For example, it is commonly claimed that 90 per cent of the world's pharmaceutical research is conducted on diseases which affect 10 per cent of the world's population (Flory and Kitcher, 2004: 40). Genetics is prioritised in developed societies, because most of the common problems of communicable diseases, poverty and malnutrition have been solved over the last two centuries. Yet, on the global scale, there is vast health inequality (cf. Benatar, 1999). An estimated 30,000 children die every day from starvation and easily preventable diseases. HIV/AIDS ravages sub-Saharan Africa. As Philip Kitcher argues 'When millions of children die every year from malaria, how can we justify our expenditures on research into Lesch-Nyhan syndrome, cystic fibrosis, even the common forms of cancer?' (1997: 324)

Genetic research is predominantly conducted on rare single gene disorders, each of which only affect one in several thousand individuals or fewer, or on common late onset disorders, which only affect people who have reached their sixth decade of life or later. Much medical research is devoted to solving health problems which have arisen due to excessive rates of consumption in western countries, for example heart disease and diabetes resulting from diets high in cholesterol and carbohydrates. In another context, Jonathan Glover (1984) uses the image of two houses built at the top and bottom of a hill. In the top house, the inhabitants are deciding what colour wall paper to choose. In the bottom house, the inhabitants are being drowned by rising flood water.

These arguments suggest that the context and consequences of genetic research and applications may raise more moral questions than the interventions themselves. The relevant arguments and analysis may come from political philosophy and social policy, rather than bioethics or moral philosophy. Rather than looking at individuals and their actions, a social or global perspective shows the potential for wider injustice that results from unrestrained and unregulated genetic intervention and investment.

To summarise, it is claimed that problems with genetic research and intervention often arise from political contexts and consequences, rather than intrinsic moral questions or the messages about disability which such genetics may be sending.

Conclusion

This paper set out to explore how questions of social justice might be applied to the field of human genetics in relation to disabled people. It has challenged simplistic assumptions that genetic screening or therapy is intrinsically unjust or discriminatory, and has outlined wider justice questions relating to access to treatment and priorities for improving the lives of disabled people. These sorts of arguments raise difficult questions, which are beyond the scope of this paper to resolve.

It is not my intention to argue against genetic research. But taking impairment prevention and treatment seriously on a global scale would require a very different set of research priorities. Genetics undoubtedly has a role in healthcare – in developing countries as well as in the developed world. Yet investment in genetics may not be the most

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cost-effective way to improve overall quality of life. Given resource constraints, prevention of disease and removal of social barriers may be the greater global priority. However, structural change usually creates social costs, not commercial profits. Pharmaceutical companies are bound to concentrate on research which may generate markets and financial returns on their huge investments.

Given that genetic research will continue to be a major investment priority, these arguments also shine a different light on another hot debate in bioethics. This is the question of whether a line can be drawn between interventions which are therapeutic (curing disease or restoring functioning) and interventions which are enhancing (providing an improvement on normal or average ability). Logically, it has proved difficult to make a robust distinction and draw a firm line between the two approaches (Buchanan *et al*., 2000: 118). Commercially, there would undoubtedly be a market in developed countries for genetic or other biomedical interventions which could improve intelligence or creativity or athleticism. The principle of autonomy would demand individuals have the right to spend their own money on these techniques, even if they were never provided as part of healthcare systems.

However, arguments from social justice would surely apply. Inequality already results from the natural lottery, and is exacerbated by inequalities in access to healthcare and other resources, both within and between nations. The priority for medical research and healthcare investment should be to intervene to reduce inequalities, and reduce the overall burden of disease. If a minority of the population are able to access medical enhancements to take their already privileged health status to new heights, then the effect would be further to widen inequalities. This seems to generate a strong case for social regulation. The priority for genetic research should be to bring everyone up to a basic state of health, rather than to enable rich individuals to exceed it further.

Disability rights and disability studies commentators have largely opted out of discussions of health inequalities and impairment prevention. Arguably these debates are of crucial importance to disabled people. To prioritise medical responses to impairment and neglect removal of social barriers seems unjust and misguided. To neglect the imperative to reduce the global burden of impairment would be equally wrong. In genetics, questions from social justice are more pressing than intrinsic bioethical dilemmas.

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