

With medical advances promising ever more detailed pre-natal genetic screening, do we have a duty to prevent the birth of physically and/or mentally impaired individuals?

ABSTRACT:

Medical advances, notably PGD, offer the chance to ensure that children can be born with much lower chances of developing disabilities. It is argued in this essay that disability itself is always a hindrance, and it is not only society's right, but its duty to prevent disability where possible to ensure social justice. Arguments against the proposition are addressed, notably the view that working to eradicate disability indicates a lack of respect for existing individuals who are disabled. This is refuted, and it is concluded that just as established medicine works to promote health to the cost of disease, these emerging technologies are morally justified and their implementation required where resources allow.

ESSAY:

Disability has traditionally had a significant social stigma attached to it. It is usually defined in terms of some sort of impairment to the individual, whether physical or mental, which prevents them from performing one or more day-to-day activities as well as a normal human being in similar circumstances.ⁱ It is uncontroversial to suggest that society has a duty to accommodate these individuals, and for medicine to seek to improve or cure their conditions. Much more contentious however are new technologies offered by medical science, which give the chance to actively prevent the birth of babies which will be disabled.

The desired outcomes from these two approaches are the same, yet the methods are considered by many to be in entirely different moral ballparks. Who decides which disabilities are bad enough to prevent life? Are the problems faced by disabled people really just prejudice from the rest of us? Are we playing god by making value judgments on who lives and dies? In this essay we will consider these questions more deeply, and look at potential avenues of reasoning that can steer us to a conclusion beneficial to all. We do not have space to touch on screening for late onset disability (Alzheimers etc) but this is also a consideration that the reader is encouraged to pursue.

We should begin by explaining what the technology makes possible. Being born with a

disability is because of a faulty gene(s) in the individual's genome. This may be as small as a single base pair mutation (as in cystic fibrosis, or CF), but can have consequences that range from a minor annoyance (myopia) to pain and distress so awful that death is considered by many as preferable to such a life (dystrophic epidermolysis bulosa, or EB being an example). In many cases the sites on the genome which contain the mutations for disabilities have been identified. A lab can screen a fertilized embryo's genome for the faulty genes and give probabilities on the occurrence of disability and disease in the person to be born from it. This technique is called preimplantation genetic diagnosis, or PGD.ⁱⁱ Some genetic tests need the embryo to develop first. For example the test result for EB is not available until up to 24 weeks into pregnancy^{iii iv} as it involves sampling skin cells in the amniotic fluid. To prevent disability in such cases, we are aborting a foetus rather than simply not implanting an embryo. In both cases however we are avoiding creating a live, self aware individual with a disability.

We now have an idea of what the technology is capable of. The next question is the rightness or wrongness of doing what is technically possible. The first point to consider is that of justice: the ideal correct state of things and persons. It is uncontroversial to say that ideally every person has an equal opportunity to live the life that they consider to be good so long as it does not hinder others. This liberal principle forms the basis of our national institutions such as the education system and the NHS. These bodies exist to provide universal education and healthcare – giving people an equal chance by letting everyone have the same foundations. We therefore already see it as society's duty to promote equal opportunities where this is possible. Being born with a disability is a disadvantage by definition. Even ardent campaigners against PGD such as Dr Tom Shakespeare admit that their disability affects their lives negatively.^v

If society, and indeed a child's parents, have a duty to provide that child with adequate opportunities for achievement,^{vi} then they are surely guilty by negative responsibility^{vii} if they fail to prevent a disability which will certainly impact on that child's opportunities. It is analogous to failing to send your child to school and thus rendering them illiterate through your inaction.

Critics would argue that it is not the disability which is the barrier to justice, rather society's attitude to disabled people; you do not blame black people for their colour when they suffer discrimination. However I would counter that it is simply prejudiced bigotry, as there is no

logical argument which can sustain the notion that someone's skin pigment should act as a barrier to their claims to equal opportunity. The same cannot be said for people with a disability, as this can and does affect their opportunities; a blind person will never be able to drive or enjoy a painting. We must not think this is reason not to try and accommodate them as far as possible, but we must accept that they are at a disadvantage.

It has also been argued by Dr. Tom Shakespeare that there are a lot more pressing problems in society that lead to inequality of opportunity such as lack of social class mobility. He suggests that resources should be diverted to such problems to achieve a far more widespread widening of opportunities than PGD for disability. It is certainly true that there are other issues of inequality in the world which affect more people than disability. However that does not change the core moral principle that it is right to give people the best chances in life, it is merely an argument about the allocation of resources. Therefore, for reasons of social justice I feel that it is right to do as much as we can to prevent people having disabilities.

The second major point in this debate is that of the obligations of the medical profession in such cases. Glannon^{viii} states that medical practice is grounded in the principles of nonmaleficence (not harming), Beneficence (bringing benefit), Autonomy (individual self determination), and Justice (the right to fair and equal treatment). Let us consider these in turn.

For a doctor to adhere to the principles of nonmaleficence, they are obligated to act in such a way as to actively avoid harming their patients. Again this is an uncontroversial statement: nobody expects a doctor to be justified in harming someone. However an embryo is not 'someone' as it has no concept of itself; it cannot value its own existence. This theory, proposed by Harris and termed 'personhood'^{ix} stipulates that an embryo is merely a potential person, in the same way that a sperm cell is half a potential person. If a doctor chooses not to implant an embryo which has a risk of disability, then they do not harm any person, and so do not fall foul of nonmaleficence. If their actions lead to the birth of a disabled child, then they can be considered guilty of impersonal harm. This is the concept that even if no identifiable people are worse off than they could have been, harm can still be done^x, which is a contravention of medical ethics. To illustrate this, imagine a nuclear reactor exploding through negligent maintenance, and as a result of the radioactive fallout, mothers gave birth to deformed children (conceived after accident). Those children did not

exist when the reactor exploded, but the people who caused the explosion are still responsible for the children's deformities.

The next key point is that of beneficence. A doctor is obligated to offer to do good where possible within their sphere of medical influence. By preventing the birth of a child who will most likely have a disability, the doctor has done a good thing by that child for reasons of social justice and the benefits to the child's quality of life. Critics of PGD support the treatment or cure of an individual with a disability, but draw a distinction between this and the active prevention of a disabled human being born. They argue that preventing the life of a human can hardly be deemed beneficial to that human, and that by picking one embryo over another, one able bodied life has been valued as more worthwhile than a life with a disability.

This question strikes at the core of medicine. Nearly everybody deems a state of health to be preferable to one of illness. Doctors treat patients with the view to making them healthier than they are, but it does not follow that the patient has less value placed on their life because of this desire to improve their position. An embryo is not a life that can be valued – it is a holding vessel for genetic code which lays the foundations for the life that is created from it. It is this life which you do or do not benefit, not the embryo. Therefore for reasons of beneficence to the life of the person concerned PGD is justified.

Autonomy and the deontological principles surrounding it are complex when dealing with PGD. The embryo has no decision making power, meaning someone must decide what is in the best interests of the resulting child. This is less of a question of whether PGD is right or wrong and more of who has the right to decide. The HFEA 1990 states that the doctor may pick a suitable embryo, and leaves it to the Human Fertilisation And Embryology Authority to decide what suitable means. Can suitable ever be disabled when an active choice is exercised? However if parents would like to have a disabled child, or decline to allow a preference to be expressed, does this override the doctor? A doctor would be contravening the principles outlined above if they allowed a disabled child to be born when they could have prevented it. What then, of autonomy?

A parent is already permitted to raise their child in a way which they see fit, and the law has established respect for the autonomy and privacy of family life. However the law also protects families from doing harm (it is not permissible to sexually abuse your children).

Therefore, the argument that a parent has control of their child's autonomy is true up to the point where their actions will cause harm. Therefore, it is the duty of the doctor to provide PGD despite the wishes of the parents as the parent cannot do harm through action or conscious inaction. The 1989 Children's act says that parents have the power and duty to consent to beneficial treatment only. Examples of how this principle is already in effect can be seen in the provision of lifesaving blood transfusions to children of Jehovah's Witnesses despite their opposition.^{xi}

The third key issue surrounding this topic is our right to judge the quality of someone else's life, and how serious a disability needs to be before it is considered right to try and avoid its manifestation. It has been argued that it is an extremely arrogant attitude to consider ourselves worthy of deciding who may live and who may die. The Catholic Church is a particular proponent of this argument, and sees any child as a gift from god with which we must not meddle.^{xii} Aside from the fact that this argument would require us to be entirely subservient to nature (and hence close down all hospitals), it is not necessarily arrogant to feel that one life is preferable to another. Glover outlines a case from the Guardian newspaper in 1987 where parents had requested pre-natal screening for EB in order to prevent another of their children dying after 12 weeks of agonizing pain. It was not, he argues, arrogance that motivated this, rather the opinion that some lives are so painful and without reward, it is preferable to have none at all.

It is easier to make a moral case for serious cases such as EB as the quality of life is so very awful. However in order to be morally consistent with our principles of medical practice, should we not then always select for the best outcome? Where does this leave disabilities which are more moderate – they may be disabling, but not so much as to make life unbearable. The compromise policy^{xiii} seeks to prohibit PGD on all but the most severe disabilities. I believe this to be wrong. Medicine is a profession dedicated to maximising health. It is clearly obvious that a disability is a disadvantage no matter how slight. Having a squint still allows a good quality of life, but if it could be avoided it would be of benefit. This argument can further developed into one of the 'slippery slope'; that is we will shift from the blurry boundary of moderate disability into selecting for positive enhancements above normality (intelligence, wit, strength). However we need to question what is wrong with such a proposition. Do we not raise children to have these traits? This is not Nazi eugenics where we are discriminating against a race, it could be a good thing to select for universally

virtuous traits such as honesty. However the complex interplay between genes in these so called enhancements is far ahead of contemporary understanding – if we switch off a gene for violence, do we also remove tendencies toward strong business acumen?^{xiv} We should not dismiss positive eugenics outright, but currently we should only intervene in clear cases where we know the effects. CF is an example where we know there is 1 mutation on 1 gene, and if this is corrected, the only effect is that the symptoms of CF do not occur.

In conclusion, there needs to be a dissociation of disability from consideration of individual moral worth. Although a person's disability will affect their lives to varying degrees it does not define them. It is a part of their character which is a hindrance. To do away with disability is not to consider the individual as lowlier than others, but to alter their anatomy and physiology to give them the same opportunities as healthy people. We must respect disabled people, but we must also acknowledge their condition is a bad thing to happen to a person – hence why we offer them medical treatment and devices to help them function normally. It is my view that we have a clear duty to prevent disability wherever possible, and that this should be available to everybody from the NHS to prevent a social super-class of disease free affluent people coming into existence. At the moment there may be more pressing priorities in healthcare than universally available PGD, but this does not change the fact that it is ethically permissible and when resources allow, required.

ⁱ Disability Discrimination Act, 1995

ⁱⁱ Handyside AH, Delhanty JD., 1997, Preimplantation genetic diagnosis: strategies and surprises, Trends Genet. 13(7) pp.270-275

ⁱⁱⁱ U.S. Department of Health and Human Services, 2003, Questions And Answers About Epidermis Bullosa, National Institute For Health, No. 03-7038

^{iv} Glover J., Future People, Disability And Screening, 2001 in Harris J.(ed.), Bioethics (pp.431), UK: OUP

^v Gene Genies Video Transcript, Bioethics BL3152 Resource page, 31st January 2007, University Of Manchester Faculty Of Life Sciences Intranet – www.sbsinfo.man.ac.uk

^{vi} W. Glannon, Biomedical Ethics (Fundamentals Of Philosophy), 2005, pp.235-238, UK:OUP

^{vii} Harris J., The Value Of Life, 1985, pp.31-33 UK: TJ International Ltd

^{viii} W. Glannon, Biomedical Ethics (Fundamentals Of Philosophy), 2005, pp.1-32, UK:OUP

^{ix} Harris J., The Value Of Life, 1985, pp.31-33 UK: TJ International Ltd

^x J. Glover, Future People, Disability And Screening, 2001 in Harris (ed.), Bioethics (pp.437), UK: OUP

^{xi} Case: Re R(Minor) – Blood Transfusion [1993] 2FLR 757

^{xii} Catechism Of The Catholic Church, number 2378, www.vatican.va/archive/catechism/ccc_toc.htm

^{xiii} Glover J., Future People, Disability And Screening, 2001 in Harris J.(ed.), Bioethics (pp.433), UK: OUP

^{xiv} Gene Genies Video Transcript, Bioethics BL3152 Resource page, 31st January 2007, University Of Manchester Faculty Of Life Sciences Intranet – www.sbsinfo.man.ac.uk