

## Student Devised Assessment

### Aims:

This Student Devised Assessment is aimed at university students and anyone interested in the topics. It will consist of 5 blog-style reflection reports and it will explore points raised in seminars. I would like to invite critical reflection upon these topics that are not often represented in popular media and explore the interdisciplinary nature of genetic research.

### Contents:

1: Aims and Contents

2-3: The Effects and Implications of Genetic Testing

4-5: An Exploration into 'Saviour Siblings'

6-8: The Ethics of Procreative Engineering and Manipulation

9-10: Genetics (and the Myth of?) Ethnicity

11: Reflection

12-13: Works Cited

The Effects and Implications of Genetic Testing

The function of pre-natal genetic testing is to establish whether the foetus may have a faulty gene. If there is a faulty gene present, such as an indication for Trisomy 21, there is the option to terminate the pregnancy. I aim to explore the controversies surrounding the termination of pregnancies with faulty genes, and examine what a further notion of the elimination of disability might mean for humanity.

In 2008, a study was taken by the NHS concluding that 92% of women who receive the diagnosis of genetic disorder Trisomy 21 (also more commonly known as Down's Syndrome), terminate their pregnancies.<sup>1</sup> But what are the implications on humanity for the elimination of conditions such as Down Syndrome? I will explore some discussion points in contention for this trend. This is less for the reason of suggesting a 'correct' answer, and more for the encouragement of active discussion on the topic:

- Foetal abnormalities allow termination up to 40 weeks, whereas in a healthy pregnancy it is 24.<sup>2</sup> Does this contrast suggest that one life is worth more than another?
- People in need of care increase humanity and compassion. This will make characteristics evolve in humans if disability is eradicated.
- Is there a problematic subtext in the immediate offering of a termination in an abnormal foetus by suggesting that disabled lives are not worth as much as non-disabled lives?
- If there is an anomaly in the future, humanity may be unequipped to sufficiently deal with it unless precautions are taken to train for the possibility of this which will likely be inefficient due to little demand for it.
- Promotes negative views of disability.
- Disability does not necessarily equate to an unfulfilled life.
- People with disability often feel like their disability is part of their identity. Attempting to eradicate the disability therefore undermines a key part of their identity.

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<sup>1</sup>"Down's Syndrome Q & A". *NHS Choices*. Retrieved 01/05/17. Web.

< <http://www.nhs.uk/news/2008/11November/Pages/DownssyndromeQA.aspx>>

<sup>2</sup> Goleniowska, Hayley. "The Disability Abortion Lie." *Huffington Post*. 2014. Web. (Retrieved 01/05/17).

< [http://www.huffingtonpost.co.uk/hayley-goleniowska/abortion-and-disability\\_b\\_5881256.html](http://www.huffingtonpost.co.uk/hayley-goleniowska/abortion-and-disability_b_5881256.html)>

- The money spent on eliminating the condition might more wisely be spent on resources for society to create more accessible care and a better experience for those who are born with the condition.
- Genetic Counselling aims to provide support, and information about potential risks in the case of detecting a genetic abnormality in a pregnancy. It is therefore important to acknowledge that any decision regarding terminations will not be an uninformed one, and that every effort is being made to ensure an informed and conscious decision with these issues. If a woman or couple feel they cannot raise a child with a disability to the best it can be, then it would take away freedom and autonomy by refusing their right to terminate the pregnancy. This is particularly indicative of feminist discourse, proving an undeniable link with genetic testing, and critical theory and praxis.

The ethical implications are further explored at length in BBC's television documentary, *A World Without Down's Syndrome*.<sup>3</sup>

Julian Savulescu explores a couple who wanted a baby with a hearing impairment because they judged the of communication of sign-language as superior. This not only raises contentions with what is preferable in offspring, but also questions what constitutes as a 'disability'.<sup>4</sup>

This is a particularly rich topic to explore, and it is important to encourage an active discussion regarding the ethical issues that may arise with such genetic testing, as there cannot be the implementation of scientific progression without consideration of how it will be received in society.

#### An Exploration into 'Saviour Siblings'

The contentions over termination of pregnancy lead to the notion of retaining autonomy over one's own body, but this time, for the offspring. A prime resource communicating this, is the novel Jodi

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<sup>3</sup> *A World Without Down's Syndrome*. BBC. 2016. Television.

<sup>4</sup> Savulescu, Julian. "Deaf Lesbians, Designer Disability, and the Future of Medicine." *BMJ: British Medical Journal* 325:7367. 2002. Print.

Picoult's *My Sister's Keeper*,<sup>5</sup> and Nick Cassavetes' film adaptation of the same title.<sup>6</sup> They both deal with complex ethical dilemmas in the exploration of 'saviour siblings'.

In the film's diegesis, much of the story concentrates on the ethics of Anna's wish to retain autonomy over her own body. However, in the end, it is revealed that the motivation leading to Anna's decision was Kate's wish for her right to die on her own terms, due to the advanced stage of her leukemia. An interesting notion to consider, is that upon the revelation that this was Kate's decision, it is mostly regarded as acceptable (albeit still difficult to process). The reaction towards Anna's wish for medical emancipation was, in contrast (and especially from her mother), regarded as selfish and met with contention. Does this contrasting reaction devalue Anna's autonomy? Is the argument for Anna's autonomy indicative of selfishness, or liberation? I will list some key discussion points regarding the controversy:

- Are 'saviour siblings' treated as a commodity, or a 'means to an end'?
- Will the 'saviour sibling' feel pressure to conform to parent's wishes, ignoring their own as a consequence?
- Will the 'saviour sibling' grow up to develop identity issues?
- Will the 'saviour sibling's' autonomy throughout the process be treated with respect if they wish to seek medical emancipation?
- Do 'saviour siblings' cause a sliding scale towards 'designer babies'?

This particular seminar and discussion prompted me to explore scholarly articles and examples in favour of the notion of 'saviour siblings'. Sheldon et al have contentions with the logic against 'saviour siblings' and render the arguments as specious and limited claims. Here are two of their counter-arguments:

- "The fact that the parents are willing to conceive another child to protect the first suggests that they are highly committed to the well-being of their children, and that they will value the second child for its own sake as well."<sup>7</sup>

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<sup>5</sup> Picoult, Jodi. *My Sister's Keeper*. Atria. New York. 2004. Print.

<sup>6</sup> *My Sister's Keeper*. Nick Cassavetes. United States. 2009. Film.

<sup>7</sup> Robertson JA, Kahn JP, Wagner JE. "Conception to Obtain Hematopoietic Stem Cells." *Hastings Cent Rep.* 32:34. 2002. Print.

- “A [...] practical objection to this argument [of creating a child as a means to an end] is that it does not adequately distinguish between creating a child as a saviour sibling and creating a child for some other "instrumental" purpose? For example, "completing a family", being a playmate for an existing child, saving a marriage, delighting prospective grandparents, or providing an heir. Perhaps these things are different from creating a saviour sibling but, if they are, the difference isn't that they are any less "instrumental" for in all these cases, the child is used as a mean”<sup>8</sup>

These examples invite critical examination into conflicting values present. It is important to explore what these conditions are dependent on, as these answers can determine a significant part of life for both the ill child, and their ‘saviour sibling’. It is clear that there are many contrasting mentalities and thoughts surrounding this complex topic. From the evaluation on the points, it can be concluded that each argument is highly subjective and dependent on the parental judgement and circumstances, and the willingness of the parents to respect all human lives with their own autonomy, as embodied in the characterisation of Kate, Anna, and their mother. It is important to acknowledge that each case is subjective, and while some parents may be more averse to letting a child make their own decisions about being an organ donor, this is not the case in every example.

### The Ethics of Procreative Engineering and Manipulation

One topic of great interest to me discussed multiple times in the seminars is the notion of gene editing and manipulation, sometimes referred to in popular culture and mass media as creating “designer babies”.

I noticed there was a clear distinction between the disciplines – that scientific research, at its core, is focused with what *can* be done, and ethics (and how it is largely regarded in society) is focused on

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<sup>8</sup> Harris J. *The Value of Life*. Routledge. London. 1985. Print.

what *should* be done. However, the two must interlink in the implementation of scientific research into society. For instance, CRISPR/Cas 9: Ewen Callaway notes that CRISPR/Cas 9 remains illegal in the UK to alter genomes of embryos to conceive a child, but that the research is available and useful, and can “inform the debate over deploying gene-editing in embryos for therapeutic uses in the clinic.”<sup>9</sup> Indeed, the policy is that the researchers must halt the experiments after 7 days, after which the embryos will be destroyed. This is a peak of genetic research but is not used for the mass public to create a developed human life. It has been made evident that this research *can* be done, but its use to create developed human life is illegal in UK because deemed that it *shouldn't* be done by various policies echoing mass opinion and evaluation into the ethics.<sup>10</sup> (Although it is interesting to note that this way of testing on embryos and then destroying them is in contention to many religious beliefs that life starts at conception).

I am going to focus on the ethical implications in this report of ‘designer babies’ and explore the following notion: Is using technology to manipulate the human genome ethical? This will be discussing intervention in order to create desired properties and characteristics, such as: no disabilities, intelligence, sex, physique, empathy, hair colour.

I am going to note some responses discussion points that are sceptical of genetic selection; from this we can procure discrepancies and contentions with the view:

- What is selection *for*? A general answer would be to create children who are as well off as possible,<sup>11</sup> but there are discrepancies as to what constitutes as ‘well off’ and the best prospects. For instance, intelligence is widely regarded as a desirable trait in offspring; but intelligence does not necessarily mean happier or more fulfilled. The desirable traits are inherently subjective. Are preferences for traits in offspring a parent’s right?
- Altering the offspring might therefore take away the autonomy of the offspring, the capacity to act freely (to a large extent) and to thrive on own merits, not the ones they have been chosen to have.

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<sup>9</sup> Callaway, Ewen. “UK Scientists Gain Licence to Edit Genes in Human Embryos”. *Nature* 530:18. 2016. Print.

<sup>10</sup> Rodriguez, E. “Ethical Issues in Genome Editing using Crispr/Cas9 System.” *J Clin Res Bioeth* 7:266. 2016. Print.

<sup>11</sup> Savulescu, Julian. "Deaf Lesbians, Designer Disability, and the Future of Medicine." *BMJ: British Medical Journal* 325:7367. 2002. Print.

- Manipulating the genetics in offspring makes humans accustomed to 'perfection' and instant gratification. What will happen if this is common practice in the future and there is an anomaly? Humans will be unequipped to sufficiently deal with the anomalous characteristics, leading to an inability to deal with difficulties and undesirable traits.
- Favouring perfection over diversity and inclusivity contends that there will be less resources for people who already have a certain condition. E.g.: less demand for certain resources for those with Down's Syndrome, less resources available for those with anger management and some mental illnesses, so therefore the quality of their care will decrease.
- Does Reproductive Engineering encourage potentially harmful mentalities? For example, in a country that favours male children, there may, not only be a shortage of female children, but also a heightened sense of sexism. Likewise, for skin colour encouraging racial bias.
- The pressure to produce desirable offspring may be pressured by society/government. For instance, one of the more extreme examples of which, was the Nazi eugenic programme, imposing their own agenda on couples, thereby removing a couple's reproductive freedom and autonomy.<sup>12</sup>
- There are religious tensions with genome manipulation, with notions that one will be going against nature, and 'appropriating God'. Indeed, the Vatican released a statement in 2002, stating, "But this would imply that man has full right of disposal over his own biological nature. Changing the genetic identity of man as a human person through the production of an infrahuman being is radically immoral."<sup>13</sup>

Some of these points lead to ask the vital question of 'how far is too far?' If we deem Reproductive Engineering as unnatural, what then does this imply about other medical tests, surgery, medicine, and technology? Sheldon and Wilkinson describe in intricate detail the notion of the 'slippery slope'.<sup>14</sup>

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<sup>12</sup> Savulescu, Julian. "Deaf Lesbians, Designer Disability, and the Future of Medicine." *BMJ: British Medical Journal* 325:7367. 2002. Print.

<sup>13</sup> Communion and Stewardship: Human Persons Created in the Image of God. Retrieved 30/04/17. Web.

<[http://www.vatican.va/roman\\_curia/congregations/cfaith/cti\\_documents/rc\\_con\\_cfaith\\_doc\\_20040723\\_communion-stewardship\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/cti_documents/rc_con_cfaith_doc_20040723_communion-stewardship_en.html)>

<sup>14</sup> 534. Should Selecting Saviour Siblings Be Banned? Author(s): S. Sheldon and S. Wilkinson Source: *Journal of Medical Ethics*, Vol. 30, No. 6 (Dec., 2004), pp. 533-537 Published by: BMJ

The ethics are extremely important to interrogate in depth to procure a measured consideration of the implications involved. This is especially important in countries with healthcare available and paid by the tax-payer. What if a tax-payer has justifiable contentions with a policy but then must pay taxes to contribute to its research? This consolidates the necessity for such exploration into these ethical issues in depth.

It is evident that the two disciplines of genetic research and society should be intertwined in practice, because in society, there is no such distinction. Mass implementation of legislation, policy and praxis demands a multi-disciplinary approach. There are controversies and complexities which require both. This leads to some concluding questions:

- Is it ethical and permissible to intervene with the human genome? If so, to what extent?
- Which intervention methods are deemed permissible?
- What are the implications of eliminating a disability from humanity? Does it procure more harm than good? Why, or why not?
- If one is against the ethics of genetic manipulation, are they also against medicine or other technological or scientific advances/progress?
- What are the implications of the spectrum of answers for society?

### Genetics (and the Myth of?) Ethnicity

Before this particular seminar, I was unsure of the genetic facts surrounding race and ethnicity. The exploration into this assisted my understanding for its implications for critical theory and praxis.

First of all, it is important to acknowledge that race and ethnicity carry complex connotations of history, identity, and socio-economic and political notions. In the differentiation of different ethnicities, this has historically lead to ideologies that legitimise colonialism, exploitation, and slavery. Edward Said, in his pioneering exploration into Orientalism, explores mentalities that lead to the mentality of western superiority, by portraying the East as exotic, barbaric, intrinsically different, and therefore Othered, stating that Orientalism is a western “will to govern over the Orient.”<sup>15</sup> This is particularly corroborated by post-colonialist discourse by rejecting the claims of western canonical

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<sup>15</sup> Said, Edward. “Crisis [in Orientalism]”. *Modern Criticism and Theory: a Reader, 3<sup>rd</sup> Edition*. Ed. David Lodge and Nigel Wood. 2008. Routledge. New York. 2013. Print.

literature by exposing its limitations, examining the treatment of cultural difference, and exploring the conditions of western imperialism.<sup>16</sup>

However, modern genetics helps to deconstruct racist claims of some groups, by contending that 99.9% of genes in humanity are identical.<sup>17</sup> This is particularly supported by the genetic support for the 'Out of Africa' hypothesis contending the origin of modern humans.<sup>18</sup>

If the westerner asserts superiority over the notion that another race is intrinsically different, then this discovery is vital. Ethnic classification systems promote a struggle for territorial independence, and can encourage hyperbolic nationalism. The only way to secure this superiority historically is by insisting there is an inherent difference. Therefore, now, there is no excuse of making these groups conform to traditional paradigms and power structures.

It can therefore be concluded that ethnic and national identities are socially constructed, and are becoming increasingly diverse. These discoveries lead to some concluding topics to consider:

- Is the notion of 'race' becoming less intrinsic to our identity as new knowledge regarding genetic similarities is discovered?
- Are there any intrinsic differences in 'race' apart from social constructions?
- Is there any difference in being proud of one's own ethnicity/race, as opposed to culture? If so, what are the consequential implications for society?

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<sup>16</sup> Ashcroft, Bill, et al. *Post-Colonial Studies: The Key Concepts*. Routledge. London. 1998. Print.

<sup>17</sup> Angier, Natalie. Do races differ? Not really, genes show. *The New York Times* Aug. 22, F1 (2000) Web. (Retrieved 01/05/17)

< <http://www.nytimes.com/2000/08/22/science/do-races-differ-not-really-genes-show.html>>

<sup>18</sup> Support for the Out-of-Africa Theory of Human Evolution Author(s): Masatoshi Nei Source: *Proceedings of the National Academy of Sciences of the United States of America*, Vol. 92, No. 15 (Jul. 18, 1995), pp. 6720-6722 Published by: National Academy of Sciences

### Reflection

To conclude, it is evident that these topics that were explored in the seminars are more complex than first anticipated. Often a topic does not merely concern the main subject, but also must include aspects of others, due to the intrinsically interdisciplinary nature of scientific and genetic research and progress. It is important to explore these notions because they offer indications of the nature of genetic issues and praxis.

The use of conceptual analysis in feminist theory, post-colonialist discourse, and exploration into ethical dilemmas consolidated the interrogation and consequential conclusions with the further concluding questions and notions to explore.

As a result of studying this interdisciplinary module of Genetics: Science and Society, I have learned to critically reflect upon issues in science and research and implementation into genetic research. The consideration of critical theory is vital to further understand and critique policies and why they are put in place. This is something that, I believe, is not explored enough and so I hope that the critical reflection encouraged in this piece invites deconstruction and analysis of research and topics and inventions that are happening all the time in 21<sup>st</sup> century, and to be engaged with the consequential implications about these issues, and what it suggests about culture, prejudices, and preconceptions, and how to critically evaluate them in society

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