

## **SDA Accompanying Piece**

This piece features 'fact files' of 11 people; 5 men, 5 women, and 1 non-binary individual. There are people of different ethnicities, sexualities and with different mental and physical differences. It is designed to represent the great diversity of our modern society. The individuals shown on the cards are all of a similar age, of late teens and early 20s. The red line through 10 of the 11 people is designed to show the loss of these individuals in a world where eugenics is a fundamental part of reproduction and there are genes which are attributable to those characteristics. It shows that when people start altering their children, the wonderful diversity of people will ultimately be lost, and the world will be filled with billions of people, all of whom are very similar. The only card without a red line through it is one of a white, heterosexual, cis-gender male who is good looking, athletic, intelligent and funny. Some of these characteristics, such as being funny, would generally be considered to be 'desirable'; however, some of them, such as gender, race and sexuality are still a source of discrimination. In a world of eugenics, characteristics which are still being discriminated against would ultimately stop being chosen by parents for their children, so they would fade out of existence altogether. This could be used at a lower education level to help young children to understand why discrimination isn't acceptable, and that diversity is a wonderful part of life, so different characteristics need to be embraced. It can also be used for older children and adults as a simple way of demonstrating the dangers of gene editing. In essence, it is designed for people who do not have a scientific background or a high level of scientific knowledge as this is a problem for everyone in society to be made aware of and to understand from a young age, as the opinions that we form as children affect how we behave later on, even after those initial influences are removed because habits have been formed (Loewenstein, Price, & Volpp, 2016).

Eugenics, as a word was coined by Francis Dalton in 1883 and derived from the Ancient Greek εὖ- (eu-), meaning 'well', and -γενής (genēs) meaning 'born' (English, 2016). Despite the seemingly innocent etymology of 'well-born', eugenics in practice has always meant encouraging people with better characteristics to reproduce, in what is known as 'positive-eugenics' and anyone who is deemed unfavourable would be discouraged to reproduce, for example, by encouraging the use of contraception, all the way to sterilisation, this is known as 'negative-eugenics'. However, with the discovery of CRISPR Cas-9, scientists now have an ability to cut strands of DNA; this could mean cutting out a gene that would result in a genetic disease such as cystic fibrosis, which the DNA repairs this hole with genes that wouldn't cause cystic fibrosis (Doudna, 2015). This has been seen by many as a huge leap in the medical side of human reproduction, as this gives the potential to ensure people aren't born with certain genetic diseases or make them immune to other chronic diseases. The first case of editing human genes in an embryo, thus creating a 'designer baby' was conducted by He Jiankui in 2018 (Greely, 2019). The thinking behind this was to ensure, that even with an HIV positive father, that the children would be resistant to catching HIV themselves. An initial reaction might be to think how brilliant this is given that HIV is a life-long disease; however, this gene-editing wasn't strictly necessary, as in cases where a pregnant mother has HIV, antiretroviral drugs can be taken to reduce the viral load to an undetectable level, which enables most individuals with HIV to live a relatively normal life, and reduces the chance that a mother passes on HIV to her child to less than 1% (NHS, 2018). Even in cases where the pregnant mother isn't on antiretroviral drugs at the time of labour, a drug called Viamune® can be taken to prevent HIV being passed on to her child (Boehringer Ingelheim, 2010-2020).

In earlier years of eugenics, when genetic technologies were not as sophisticated as they are today, the ways of trying to control who was born was very problematic. In cultures that are male-favoured, parents would seek to have male children as they would be able to help in rural areas with manual labour and be able to look after his parents financially in their old age. This has meant that for centuries, families in China have killed their daughters, given them up for adoption, or just abandoned them (Chan, et al., 2002). In some cases, families who had a girl, but didn't want to kill or abandon her but who also wanted a son, chose to not register the girl. As a result, the girl would be a 'black child' (黑孩子); with a lack of registration, this girl would not be able to access education, or healthcare as they are not actually recognised as someone who exists. Without education or healthcare or any identification, it would be impossible to live a normal life (Laogai Research Foundation, 2010) This was so problematic during the era of the Chinese one-child policy, that the policy had to be changed so that families that had a girl as their first child were allowed to have a second child (White, 2006, p. 167). China has one of the highest male:female ratios in the world, with the Jiangsu province in China having a ratio of 192 boys per 100 girls born. It is clear that if the selection of characteristics, not limited to gender, was unregulated, that there could be huge gender imbalances, as well as decreases in populations of non-white races and LGBTQ+ individuals.

Before the ultimate eradication of certain traits and characteristics, there would be a decrease over the span of many generations. Initially, individuals who are not genetically modified would be in the majority of the population, but over time, they would become the minority and not only a minority, but one which has characteristics that the population have deemed so undesirable that they actively choose for their children not to have them. This

phenomenon is currently happening in Iceland, where only 2-3 children are born in Iceland with Down's Syndrome in a whole year and this has been the case for the last decade (Embassy of Iceland in London, 2018). With such a small number of people with Down's syndrome in Iceland, the general awareness around the condition will not be as well spread across the population, and with a lack of awareness comes ignorance which may result in the spreading of false information about people and their conditions and lifestyles as well as negative attitudes of those who have disabilities (Lindsay & Edwards, 2013). In circumstances where humans could edit genes to make their children hyper-intelligent, those who are left behind whose genes are not modified in this way will struggle for places in higher education and may be forced into lower-skilled jobs as they have lower qualifications and lower skill levels than their genetically modified counterparts. Even one round of regular IVF, which isn't new technology anymore, costs on average £5000 (NHS, 2018). For technology which is this new and this significant, the price would be much higher, resulting in lower-income families being forced to conceive their children in a more traditional way, and in doing so, putting their child at a lifelong disadvantage.

In conclusion, gene editing in eugenics is a route to high levels of discrimination and elitism, which despite the obvious advancement in genetic technology, would be a huge backwards step in the way that humans interact with and view each other. Editing genes to eradicate diseases that are incompatible with life, such as infantile Tay-Sachs is, in principle, a good idea as there is no treatment for it and throughout the child's very short life, they would be in pain due to seizures and severe difficulties due to deafness, blindness and paralysis (Genetics Home Reference, 2020). However, the slippery slope of gene editing is so severe, that to allow human gene editing for certain circumstances would be naïve; as if it is successful, it will spread in its use in non-medical situations. This is reiterated in a TED talk

by Paul Knoepfler where he asks 'what would you do?' in a world where genetically modified children have better opportunities than those who aren't (Knoepfler, 2015). The answer is clear. Those who could afford this technology would use it to ensure the best possible future for their child. Therefore, the only way to avoid a huge detriment to human diversity would be to introduce a blanket ban on all human gene editing.

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