

**My SDA:** <https://youtu.be/a7lkCauEycY>

### **Student Devised Assessment: Disabled or Able?**

Genetics brings up issues among many disciplines with endless ideas to explore. For my SDA, I did not want to create a simple poster. I wanted to create an experience. This experience aims to provide the visitors with a journey, to categorise their opinions and then have those challenged. As they walk through the exhibition, the intention is that they question their current beliefs. The intended audience is adults as it tackles some challenging ideas, demanding an open mind.

Something that stuck in my mind from taking part in the module was that people would argue that disability is costly to society. As someone with a disability myself, this is quite hurtful to hear and can be interpreted as people thinking of you as a cost, not a person. With my exhibition, I have designed it to remind people that having a genetic difference, does not make someone any less human and doesn't mean we can see them as only a cost to society. My goal is to illustrate the issues surrounding this thinking by estimating the costs involved, then highlighting the people whom it affects.

### **Entrance to the Exhibition**

Upon entry to the exhibition, visitors walk through a short corridor where celebrities who all have genetic conditions or conditions thought to be linked to genetics. This exhibit features the achievements of the respective celebrities, paired with a wallpaper featuring strings to represent DNA. There is also a mirror, in which you can see the title of the exhibition reflected from behind you. The idea of this is for the visitor to reflect on themselves, as well as reflecting on these celebrities' achievements as a precursor to an introduction to screening.

### **Prenatal Screening Exhibit**

This part of the exhibition depicts a child's bedroom, with children's toys beside it. A starry theme was used to entice the visitor, with the hopes they will consider dreams and aspirations. In doing so, they can think back to the previous display. This is designed to guide people to remember that those who have genetic diseases have dreams just like everyone else and that they can achieve these dreams. An infographic is provided to inform the visitors of the process of screening, including invasive and non-invasive procedures. It also gives some examples of conditions that would be identified for screening out.

### **Cost of Disability Exhibit**

This is the main exhibit, and what would have been the chosen topic my SDA. I created a display analysing the facts and figures available to the public. I chose to use infographics as these are often a lot more accessible to people, regardless of how well they understand numbers. Pictures and pie charts allow for people to see a visual representation to put statistics into perspective.

The first infographic is placed on a red background, mirroring the motif used in Gattaca, to characterise what is widely accepted as fitting with the narrative society wants you to see. I chose this colour because all of the statistics and figures used were direct, with no calculations involved. It felt like this was what society wanted you to see. These are the statistics people are exposed to and have used to build their opinions of the screening out of disability. I would have liked to have discussed more of the government's statistical results, including one that particularly stood out to me about how disabled people are more likely to experience domestic violence [16]. I also would have liked to have featured general statistics

on schooling for people with disability. The figure I chose to write down was the highest cost for the schooling of a child with a disability. However alternative options, such as well-maintained special schools or mainstream schools can cost significantly less. In a sense, this makes the figure on schooling misleading [13].

The next infographic leads into the first stages of calculation to estimate the cost of conditions we can screen out. This is placed on a green wall to complete the Gattaca motif. I used this to display the negatives of screening. Using the values from various sources (listed in the bibliography), I was able to estimate at there are roughly 85000 people in the UK currently suffering from genetic conditions which amount to 3.6% of people with a disability in the UK. I used many different sources to calculate this number and could not seem to find an accurate estimate for this value, limiting its accuracy. These different sources could have collected data from different dates, and none of the sources were perfectly up to date. However, using this crude estimate I was able to calculate how much of government funding goes to genetic disability.

The next infographic introduces the gendered nature of screening. I focus on the effect of amniocentesis, as the procedure is invasive and hence has the most associated risks. The nature of this procedure means that the chance of miscarriage is higher than the chance of the foetus having a detectable chromosomal abnormality, which is shocking. This can lead to a whole range of psychological burden on the woman, and the procedure can also be painful or result in further complications to the pregnancy. Many of the sources I used mentioned how more support and counselling needs to be given if we are to continue the screening programme, a notable mention being Don't Screen Us Out [15]. This would be to give the parents an understanding of what the condition means for the life of the child, as well as to properly support them in any decision they make. To help with this idea of understanding and awareness, I made the 'A Person with a Disability is not a Disability' Exhibit.

I was able to calculate an estimate for the cost of screening to the NHS based on the number of pregnancies [25] and the estimated cost of NIPT [26] based on private healthcare rates. Similarly, in the final infographic, I was able to calculate the amount of money each condition 'costs the taxpayer' if the support provided is equal no matter what disability you have. This assumption may completely invalidate figures calculated, as people with the genetic condition may not cost the government the average amount given to people with a disability. However, there were few sources available to say how much monetary support is average for each condition. Due to the money being the main feature of the exhibition, I put the figures in neon so they would stand out.

### **Quotations Exhibit**

This exhibit was designed so that as the visitor walks from the first half of the exhibition to the other side, it would feel like they were travelling to a new place. I used simple quotes to illustrate the importance of ethical and social considerations. The previous exhibition spends a lot of time regarding people as numbers, but the next half of the exhibition is designed to bring back humanity into this debate. As part of our ethics session, I learnt that people will always have their ways of assessing whether something is right or wrong. Some people will be very much pro-choice, while others will value the ethical impacts of their actions more than their feelings. Regardless of the way you choose, these decisions need to be informed, and not based on stigmatised beliefs on certain genetic conditions. These quotes are designed to get the visitor in the mindset of considering the ethical implications and to understand that a disability is just something different- differences don't make anyone less human.

## **The Endless Ability of a Person with Disability Exhibit**

I found some non-copyright royalty-free images taken by Cliff Booth [28] and thought this would be the perfect way to remind others of the humanity of people with a genetic disability. I found these photos inspiring, and we can see the lady in the photo is enjoying experiences in life, just as anyone else would.

## **A Person with a Disability is not a Disability Exhibit**

This exhibit is designed to encourage people to be proactive with their research. In doing this project, I learnt so much about the genetic conditions we would screen out. Historically, conditions like these, especially those with a clear physical difference, caused people to assume the worst. Being able to single people out like this made the eugenics movement particularly endangering to the disabled community. At one point, these physical indicators were used to pick up children off the street and institutionalise them [6].

This is not unlike what I believe happens today, and I remember this thought being echoed by Nicola in our session. Another key point brought up in this exhibit is the legal issue of screening violating the Convention on the Rights of Persons with Disabilities. This asserts that people with disability should be supported, included and accommodated within society, however, there is evidence suggesting that parents of diagnosed children are not given adequate information required to make an informed decision on continuing pregnancy [15].

## **Conclusion**

My exhibition aimed to introduce the issues of screening to adults, through giving them facts and figures at first, and then to reintroduce the humanity behind these numbers. To improve the exhibition, I would have liked to find some more up to date and reliable statistics. This may have involved contacting organisations to get their estimates for the figures I used to improve accuracy. I think that the video format of the essay was well suited to the times we are in now, however, it would have been more impactful if I were able to make the exhibition in person.

## **Bibliography**

Most of the references involved in the creation of my SDA are found on the posters and infographics throughout the exhibits.

### **Entrance to the Exhibition**

[1] Biography. 2021. [online] Available at: <<https://www.biography.com/news/celebrity>> [Accessed 20 April 2021].

*This was used to find out about Selena Gomez and Abraham Lincoln's lives and careers.*

[2] ESPNcricinfo. 2021. *Lewis Hatchett profile and biography, stats, records, averages, photos and videos*. [online] Available at: <<https://www.espncricinfo.com/player/lewis-hatchett-404458>> [Accessed 20 April 2021].

[3] IMDb. 2021. *Gaten Matarazzo - IMDb*. [online] Available at: <<https://www.imdb.com/name/nm7140802/>> [Accessed 20 April 2021].

[4] Celebrity Net Worth. 2021. *Tionne T-Boz Watkins Net Worth*. [online] Available at: <<https://www.celebritynetworth.com/richest-celebrities/singers/tionne-tboz-watkins-net-worth/>> [Accessed 20 April 2021].

[5] *The Lion's Mouth Opens*, 2015. [TV programme] HBO.

*This gave an insight into Marriana Palka's journey finding out whether she has inherited Huntington's. I would recommend this!*

[6] *Eugenics: Science's Greatest Scandal*, 2019. [TV programme] BBC4: BBC.

*A programme co-presented by Adam Pearson, explaining his condition and looking at the history of eugenics.*

[7] Rose, A., 2021. *AdaliaRoseBud Channel*. [video] Available at: <<https://www.youtube.com/c/AdaliaRoseBudd/videos>> [Accessed 20 April 2021].

[8] Motability Scheme. 2021. *A day in the life of Jack Binstead*. [online] Available at: <<https://news.motability.co.uk/inspiration/a-day-in-the-life-of-jack-binstead/>> [Accessed 20 April 2021].

### **Prenatal Screening Exhibit**

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### **Cost of Disability Exhibit**

[11] John, E., Thomas, G. and Touchet, A., 2021. *The Disability Price Tag 2019*. [ebook] Scope. Available at: <<http://file:///C:/Users/Student/Downloads/disability-price-tag-report-2019.pdf>> [Accessed 20 April 2021].

*This was used to find out the extra costs and hardships faced when living with a disability.*

[12] Boulton, S., 2017. *Does the government spend £50 billion a year on disabled people? - Full Fact*. [online] Full Fact. Available at: <<https://fullfact.org/economy/does-government-spend-50-billion-year-disabled-people/>> [Accessed 21 April 2021].

[13] House of Commons, 2020. *Special Educational Needs and Disability Funding*. Available at: <<https://www.local.gov.uk/sites/default/files/documents/29012020%20LGA%20briefing%20-%20SEN%20support-WEB.pdf>>

*This government document was used to find information about the cost of schools for students with special educational needs.*

[14] Genetic Disorders UK. 2020. *About Genetic Disorders UK*. [online] Available at: <<https://www.geneticdisordersuk.org/about-us/#:~:text=It%20is%20estimated%20that%201,living%20with%20a%20genetic%20disorder>> [Accessed 21 April 2021].

*This website gave the number of people living with genetic disorders in the UK.*

[15] Don't Screen Us Out. 2021. *Don't Screen Us Out campaign*. [online] Available at: <<https://donscreenusout.org/>> [Accessed 20 April 2021].

*This website highlighted many of the disabled community's concerns with allowing screening as well as proving figures used in my project.*

[16] Putz, C., Sparkes, I. and Foubert, J., 2021. *Outcomes for disabled people in the UK - Office for National Statistics*. [online] Ons.gov.uk. Available at: <<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020>> [Accessed 22 April 2021].

*Gave an understanding of the disparity between the life of the average person with a disability versus without. Provided graphs included in the exhibit.*

[17] Fridovich, I., 1998. *Human genetic disease*. [online] Encyclopedia Britannica. Available at: <<https://www.britannica.com/science/human-genetic-disease>> [Accessed 21 April 2021].

*Provided statistics on genetic defects and gave rates of incidence for chromosome abnormalities.*

[18] Sickle Cell Society. 2021. *About Sickle Cell*. [online] Available at: <<https://www.sicklecellsociety.org/about-sickle-cell/#:~:text=3%20in%2076%20babies,in%20the%20UK%20every%20year.&text=7%20Children%20with%20SCD%20are,ages%20of%202%20and%2016.>> [Accessed 22 April 2021].

*Used to create a charity poster on sickle cell society and to find out how many people are affected currently.*

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,How%20common%20is%20cystic%20fibrosis%3F,in%20every%20%2C500%20babies%20born.> [Accessed 22 April 2021].

*Used to find out how common cystic fibrosis is.*

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*This website contains many statistics related to the number of genetic related conditions in the UK.*

[23] Campbell, A., 2021. *Vital statistics in the UK: births, deaths and marriages - Office for National Statistics*. [online] Ons.gov.uk. Available at: <<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/vitalstatisticspopulationandhealthreferencetables>> [Accessed 22 April 2021].

*This was used to find information about the number of live births in the UK.*

[24] nhs.uk. 2021. *NHS screening*. [online] Available at: <<https://www.nhs.uk/conditions/nhs-screening/>> [Accessed 22 April 2021].

*This website was very useful in gaining an understanding of the screening process and the extra procedures that occur like amniocentesis.*

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*This was used to estimate the number of pregnancies in the UK.*

[26] Chitty, L., 2016. *Uptake, outcomes, and costs of implementing non-invasive prenatal testing for Down's syndrome into NHS maternity care: prospective cohort study in eight diverse maternity units*. [ebook] BMJ 2016;354:i3426. Available at: <<https://www.bmj.com/content/354/bmj.i3426>> [Accessed 22 April 2021].

*This study evaluates the benefits and costs of NIPT, focusing particularly on Down's Syndrome.*

## **Quotations Exhibit**

[26] BrainyQuote. 2021. *Inspirational Quotes at BrainyQuote*. [online] Available at: <<https://www.brainyquote.com/>> [Accessed 20 April 2021].

*Found the quotes from Stephen Covey and Potter Stewart here.*

[27] Kind Over Matter. 2021. *Life gets better when you're kind to yourself*. [online] Available at: <<https://kindovermatter.com/>> [Accessed 20 April 2021].

*Audre Lord quotation was found here.*

### **The Endless Ability of a Person with Disability Exhibit**

[28] Photo by Cliff Booth from Pexels

*Used images as pictures for this exhibit.*

### **A Person with a Disability is not a Disability Exhibit**

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[31] MuscularDystrophyuk.org. 2021. *Muscular Dystrophy UK*. [online] Available at: <<https://www.muscularDystrophyuk.org/>> [Accessed 22 April 2021].

*Used this to create the poster on muscular dystrophy.*

### **Software Used Within Project**

[32] 2018. *House Flipper*. Poland: Frozen District.

*This video game was used to provide the platform to create the exhibition, allowing me to place objects and change the format of the building.*

[33] 2021. *Lightworks*. LWKS.

*Lightworks is a video editing software that I used to create a YouTube video with the recordings I took.*