IL905 Genetics: Science & Society

SDA: Accompanying Explanation

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Amplifying The Voice of 'Lived Experience': Accompanying Explanation

Purpose and Key Questions

The purpose of my infographic is to argue that UK society is failing to engage with disabled people's 'lived experience', and that this can and should change. To do this, the key questions considered are: What is society's prevailing attitude towards disabled people? Why is there currently a lack of understanding about disabled people's personal experience of disability? What are the implications of this on bioethics? What does the limited research suggest about disabled people's 'lived experience'? How can one contribute to developing a societal 'philosophy of inclusion'? If these five questions can be answered after reading my infographic, its purpose will be fulfilled.

Motivation and Relevance

It is intuitively obvious that we ought to include the voices of those with personal experiences of disability in bioethics debates, yet in practice their opinions are either absent or under-valued. 'Lived experience' embodies the relationship between science and society, which is the essence of this course. My SDA was influenced by my interaction with two mothers of children with Down's Syndrome in the Week Nine session, who shared their experiences of bringing up their children in a society which increasingly considers Down's Syndrome an 'undesirable and preventable condition'. They spoke about being judged as irresponsible because they had their child when options of screening and termination exist, and how people frequently react to their children with pity or awkwardness. These responses conflict with the mothers' 'lived experience' of disability, which is that their children are unique blessings who are both happy and healthy. This moving conversation with people with 'lived experience' of disability, emphasised the need to involve those with personal experiences of disability in bioethics debates, rather than exclusively relying on debates using 'expert' opinions. However, reflecting on Felicity Boardman's research (Boardman et al., 2017a, p.69) and NIPT guidelines (NCB, 2017), made me realise that the 'lived experience' of disability is virtually absent from bioethics discussions. My SDA is an attempt to understand why personal experiences are being excluded and to amplify disabled people's voices.

Audience

My infographic's audience is UK young people and adults (16+), with particular emphasis on prospective parents. These individuals are likely to be familiar with the term 'lived experience' and are mature enough to understand its complexity, but are unlikely to have reflected on its value. They would also relate to the data presented, which is mostly from UK samples. It would be particularly relevant to prospective parents because they will be offered routine genetic screening and perhaps genetic counselling, both of which would likely overlook the views of those personally affected by the disabilities under consideration, in favour of purely medical evaluations (NCB, 2017, p.6). Therefore, this infographic may encourage them to seek a more balanced view of disability. The infographic is relevant for disabled and non-disabled people; the 'key lessons' are designed to encourage non-disabled people to create a culture where disabled people's 'lived experience' is valued, as well as encouraging disabled people to increase their expectations of society. I polled a sample of 20 young people and adults about what they knew about the 'lived experience' of disability, to act as a 'baseline' knowledge to build upon: I found that the majority had heard of the term but had never had conversations with disabled people about this or read relevant research. The infographic is intended for mass communication, being distributed in relevant, high-traffic areas such as GP surgeries, government offices and children's centres as part of a wider movement to amplify disabled people's voices in societal decisions.

Medium

I presented my SDA as an infographic because I wanted to convey complex theories and research to the UK public, an audience who I assume does not have intimate experiences of disability or a scientific background. Therefore, my medium must be engaging, convey new information in an accessible, quick and clear manner and be suitable for mass communication. Given these requirements, an infographic is the most effective medium because it allows me to transmit complex information and data in the form of digestible graphics and bite-sized text, thereby allowing me to engage the reader without having to be superficial in my argument. Infographics' aesthetic presentation attracts the reader and encourages them to show it to more people, making it ideal for mass communication (Ovans, 2014). The brain processes visuals 60,000 times faster than it does text, therefore I use graphs, pie charts and statistics to demonstrate key ideas with just a glance (3M Corporation, 1997). I also use some text in order to engage different parts of the reader's brain, and allow the information to be disseminated at different levels of detail.

Design

My infographic is designed with the purpose of normalising disability and genetic technologies, highlighting how both are part of people's everyday realities. Therefore, it purposely lacks both the serious feel of 'disability rights' documents, and the dramatic imagery associated with futuristic dystopian worlds. The colour scheme is yellow/orange which symbolises happiness, an objective which unites those with and without disabilities (Colour Psychology, 2018). The illustrations are simple and seem hand-drawn, giving the infographic an informal and accessible feel. The specific illustrations represent aspects of life shared by both disabled and non-disabled people, such as holidays, family and homes, which further break down the barrier between disabled and non-disabled people.

Content

My argument is that UK society is failing to engage with disabled people's 'lived experience', and that this can and should change.

I first investigate what society's prevailing attitude towards disabled people is and why this is: the statistics I cite, such as that 67% of non-disabled people feel uncomfortable talking to disabled people (Aiden &

McCarthy, 2014), suggest that there is a lack of understanding about the reality of living with different disabilities. This deficiency in communication is largely because society is understanding disability through the medical model rather than incorporating the social model, i.e. understanding disability as being caused solely by medical impairments, rather than by socially-constructed barriers caused by ignorance, prejudice and/or stereotypes of disabled people (disablism) (Disability Nottinghamshire, 2018). Disablism hinders society from engaging with disabled people's 'lived experience', which results in 'the Disability Paradox': non-disabled people assuming that disabled people's quality of life is much lower than they self-report (Albrecht & Devlieger, 1999, p.977). I highlight that often well meaning, empathetic people fall into this trap, to make people more likely to reflect on their own behaviour. I also use a pie chart to highlight how commonplace disability is (Papworth Trust, 2016, p.6).

I then consider the implications of disabled people's exclusion on bioethics and explore what the limited research suggests about disabled people's 'lived experience'. Disablist attitudes are detrimental to bioethics; advancements in reprogenetic technologies mean it is increasingly possible to permanently eradicate genetic conditions, but our failure to include disabled people's 'lived experience' in debates means that we are making assumptions about the quality and value of disabled people's lives, which are over-simplistic and often wrong. This is contemporarily relevant, as screening tests have become part of routine antenatal care and the new screening test NIPT will make it easier to screen for conditions like Down's Syndrome. However, our ability to screen for conditions is greater than our ability to 'fix' them. Current genetic counselling tends to present a one-sided view proposing that any deviations from normality ought to be prevented to minimise suffering, and overlooks how the disability is actually experienced, therefore it is likely that more sophisticated screening tools will result in more pregnancy terminations (DSUO, 2017). Therefore, even after accepting the argument that it is good to give prospective parents more information through screening, thus more choice, there is still a need to follow up this screening with accurate and balanced information to help parents to make fully informed decisions about conditions they are unlikely to have any experience of (Murray, 2017). This 'balance' requires learning about the rich and varied lives of disabled people (Shakespeare, 2017, vii). Therefore, I then communicate research about the 'lived experiences' of different genetic conditions: the overwhelmingly positive experiences of children with Down's Syndrome and their families (Skotko, Levine & Goldstein, 2011a, p.2348; Skotko, Levine & Goldstein 2011b, p.2360); the differences in the opinions of those living with 'spinal muscular atrophy', their families and the general public, with respect to the value and quality of their lives and support for screening (Boardman et al., 2017b, p.207-208); and the challenges faced by people living with 'cystic fibrosis' (Jamieson et al, 2014, p.1683). These additional perspectives are likely to complicate prospective parents' decisions, however, complexity is a necessary feature of balanced information. Some (Raeside, 2016) argue that it is wrong to focus on the views of those with personal experiences of disabilities, as the personal nature of 'lived experience' makes accounts too emotional and anecdotal to give a balanced assessment of disability. This may be true, but my infographic's objective is not to give a balanced assessment, it is to ensure that bioethics debates are informed by all relevant stakeholders, and since the stakeholders currently lacking contribution are disabled people and their families, these are the voices being amplified.

I conclude by summarising key lessons which can help individuals to amplify the voice of 'lived experience'. These are: to actively seek disabled people's personal experience of disability, rather than assuming they have a low quality of life; to oppose disablism and find ways to involve disabled people in societal decisions, rather than assume you are immune to being disablist; and to consider 'lived experience' when making personal decisions, rather than assuming that medical perspectives give a balanced view of disability.

Limitations and Further Research

One limitation of my SDA is that I refer to 'disabilities' generally, without acknowledging that the severity of any given condition varies and appreciating that individual experiences are heterogeneous. This simplification was a necessary trade-off made to fulfil the infographic's purpose of being engaging and accessible to people unfamiliar with the topic. One criticism of my SDA could be that highlighting statistics such as how many people feel uncomfortable talking to disabled people, may offend disabled people. However, surveys (Aiden & McCarthy, 2014, p.10) suggest that disabled people are aware of this and more importantly, exposing issues is the first step towards overcoming them. Ideally, this infographic would encourage the public to reflect upon the value of disabled people's 'lived experience', and a supplementing document would refine the arguments presented.

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