

# REPRESENTING DOWN'S SYNDROME IN DOCUMENTARY

Exploring independence, relationships and  
prenatal screening in the documentary genre

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## **Abstract**

This thesis considered the role and significance of documentaries in public debates surrounding Down's syndrome and the impact they may have on the personhood of individuals with Down's syndrome. Cultural representations of Down's syndrome within documentaries were explored to consider how they might shape or contribute to understanding Down's syndrome, as well as people's lived experiences. While there has been a significant shift in the visibility of people with Down's syndrome in mainstream media, misrepresentation remains an issue. An analysis conducted with co-researchers revealed that representations based on normative, ableist ideologies construct distorted, often stereotypical images of what a life with Down's syndrome might be like. Using arts-based methods and a collaborative approach provided a space for co-researchers to consider and discuss in(ter)dependence, relationships and prenatal screening and how these themes were represented in documentaries. The collaborative aspect of this thesis demonstrates with unequivocal certainty that people with Down's syndrome can and should be included in cultural conversations no matter their complexity. Consideration of the lived experience of people with Down's syndrome is imperative in shifting attitudes concerning Down's syndrome towards an affirmative understanding of the condition that reflects their valued lives, moving away from stereotypes anchored in dependency and deficit. In turn, such a shift, enacted by people living with Down's syndrome, might make prenatal screening less routine and reactions to it more considered. This thesis illustrates how this can be done in practice, providing an inclusive approach is taken, and complex, sensitive issues are handled with the utmost care. This thesis engages with several interconnected, complex theories, including vulnerability, biopolitics, normalcy, ableism and cultural disability representation, adding to existing bodies of knowledge surrounding these concepts and how they relate to people with Down's syndrome. In so doing, this helps us to open up critical discussions of Down's syndrome and documentary and provides a framework for those working within the realms of disability and media.

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## List of Abbreviations

ARC (Antenatal Results and Choices)

ABR (arts-based research)

BAFTA (British Film Academy Film Awards)

BBC (British Broadcasting Corporation)

BMA (British Medical Association)

CRPD (Convention on the Rights of Persons with Disabilities)

DSA (Down's Syndrome Association)

ESRC (Economic and Social Research Council)

NHS (National Health Service)

PNS (prenatal screening)

SA (selective abortion)

SAG (self-advocacy group)

SRV (social role valorisation)

TV (television)

UK (United Kingdom)

## Accessible Executive Summary

# Down's Syndrome and Documentary Project Summary

This document will tell you what happened in our project about Down's syndrome and documentary.

Thank you to the co-researchers who worked on this project with me.

I hope you had as much fun working on this as I did!



### What was the project about?

Our project was about how people with Down's syndrome are shown on TV – especially in documentaries.

We watched three documentaries:



1. The Specials



2. The Undateables



### 3. A World Without Down's Syndrome?

We wanted to find out what these documentaries said about independence, relationships and prenatal screening.

#### **What did we find out?**

We found out that some people think if you have Down's syndrome, that means you cannot be independent.

The Specials documentary showed how people with Down's syndrome can be independent and live away from home.



This is the cast of The Specials sitting outside the home they share.



They have support and live independently, doing their own shopping and making their own decisions.

We thought The Specials was good because "it's saying that Down's syndrome can have their own place if they wanted, and going out, everyday life".

We found out that some people think people with Down's syndrome cannot have relationships.

The Undateables showed people with Down's syndrome going out on dates.

We watched two people on The Undateables go on first dates.



Sam and Kate



Sometimes, Sam and Kate were made to look childish. We noticed that Sam talked about sex, but Kate didn't. Watching The Undateables made us think about our own love lives.

We think it is good to have shows like The Undateables because it lets people with Down's syndrome "prove themselves".

We also found out that some people have tests to find out if they are going to have a baby with Down's syndrome. Some people don't want a baby with Down's syndrome, so they have a termination.

A World Without Down's Syndrome? is a film about these tests and what it might be like if no more babies with Down's syndrome are born.

The language in this film was hard to understand, so we used Emmerdale to help us understand the choices women

make when they find out their baby has Down's syndrome.



We made our own documentary trailer. Because we directed the trailer, we were being shown exactly how we wanted to be.

It is important that people with Down's syndrome are included in things about us. This includes:



Research,

Media (films and TV),



and public debates.

The images used in this document come from the People First (Self Advocacy) Picture Bank

## ~ Chapter One ~

### Introduction

Just under fifty years ago, many people with Down's syndrome were institutionalised at birth, consigned to reside in long-stay hospitals, denied an education or meaningful employment and stripped of many fundamental human rights.<sup>1</sup> Today, we watch actors with Down's syndrome in award-winning drama series (*Line of Duty*, 2021) and films (*The Peanut Butter Falcon*, 2019). Models with Down's syndrome have become the face of high-end fashion campaigns (River Island, 2018; Gucci, 2020), and we witness activists with Down's syndrome in public governmental debates over discriminatory abortion laws. Mattel® released their first Barbie with Down's syndrome earlier this year in a bid to 'further increas[e] representation in the toy aisle' (Mattel, 2023, no pagination). Down's syndrome is more visible now than ever before.

In the UK, noticeable strides have been made in disability equality. Legislation now prohibits discrimination on the basis of disability (Equality Act, 2010), and the overt marginalisation or rejection of people with Down's syndrome would now be frowned upon or at least questioned. Despite this seeming progress, 90% of pregnancies where Down's syndrome is identified are terminated in England and Wales (Thomas, 2017). This poses quite a predicament. If, as a society, 'different' bodies and minds are now accepted and welcomed, as the examples cited above would suggest, why are termination rates of babies with Down's syndrome predominantly high? Why do people with Down's syndrome encounter significant difficulties obtaining employment in comparison to their non-disabled peers? Moreover, why do inaccurate stereotypes of Down's syndrome still exist?

This thesis makes the case that while there has been a significant shift in the visibility of people with Down's syndrome in mainstream media, misrepresentation remains an issue. The coming chapters will validate this claim and demonstrate how representations based on normative, ableist ideologies construct distorted, often stereotypical images of what a life with Down's syndrome might be like. The central aim of this thesis is to consider the role and significance of documentaries in public debates surrounding Down's syndrome and the impact they may have on the personhood of

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<sup>1</sup> 'In 1976 there were just over 51,000 recorded NHS long-stay hospital 'beds' for people with learning disabilities in England. By April 2002 this number had decreased by 93% to 3,638' (Emerson and Hatton, 2005, p.36). The most recent statistics suggest that in 2023 there were 2,045 people with a learning disability and autistic people living in long-stay residential facilities (Parkin et al., 2023).

individuals with Down's syndrome. Specifically, I will examine three British documentary films and series (*The Specials*, *The Undateables* and *A World Without Down's Syndrome?*) that feature people with Down's syndrome in order to answer the following research questions:

- 1) What are the dominant discourses surrounding Down's syndrome within documentaries? Do documentaries, and the form they take, contribute to dominant discourses surrounding Down's syndrome?
- 2) Do representations in documentaries directly impact individuals with Down's syndrome and their sense of self? How do individual narratives of those with Down's syndrome relate to collective societal discourses surrounding ableism and normalcy?
- 3) How might people with Down's syndrome revise or transform documentaries about living with this condition?

The design of these research questions is concerned with prevailing Down's syndrome discourses within the documentary genre and what, if any, impact these narratives might have on people with Down's syndrome. In order to examine the impact documentaries might have on people with Down's syndrome, I worked closely with a small team of adults with Down's syndrome and conducted a co-analysis of excerpts from the selected documentaries. I will comment further on this towards the end of this chapter and in Chapter Four.

## **Terminology**

Before continuing any further, it is important to outline and rationalise some of the terminological choices I have made throughout my thesis. Within disability research, especially research about people with learning disabilities, the preferred terminology differs between individuals and institutions. I will now provide a short glossary of terms where this might be the case and explain the reasoning for my chosen terms.

### ***Down's syndrome:***

This research adopts the term 'Down's syndrome' as opposed to 'Down syndrome'. The non-possessive spelling is most commonly used in the US; however, in line with the UK Down's Syndrome Association, the apostrophe 's' will be used. Down's syndrome is also sometimes referred to as Trisomy 21. Trisomy 21 refers to the chromosomal anomaly that causes Down's syndrome, meaning there are three copies of chromosome 21.



### ***People with a learning disability/learning disabled people***

In the UK, the preferred terminology ('learning disability' or 'learning difficulty') continues to be debated, and terms are often used interchangeably. While some self-advocacy organisations use 'learning disability' (People First Merseyside, 2021; Manchester People First, 2021; Leep1, 2021), others use 'learning difficulty' (People First, 2021). The term 'learning disabled people' is often used when discussing groups of people that you do not know and cannot ask what terms they prefer (Inclusive Employers, 2023). Throughout this thesis, I will use their pseudonyms when talking about the co-researchers. When referring to a group of people that I do not know, in line with the self-advocacy group with whom I conduct this research, I will use the term 'learning disabilities' or 'learning disabled people' unless citing the work of others.

### ***Disabled people***

I use the broad term 'disabled people' when referring to the population of people with an impairment, health condition or chronic illness which impacts how they experience the world. In line with Oliver (1999, p.164), I define disabled people in terms of the following: (a) they have an impairment; (b) they experience oppression as a consequence; and (c) they identify themselves as disabled persons. I recognise that different people with different impairments and conditions will experience disability in myriad ways, and my use of the term 'disabled people' is not intended to discount this.

### ***In(ter)dependence***

Throughout the thesis, I will discuss dependence, independence and interdependence. When I am referring to both independence and interdependence, this will be displayed as in(ter)dependence.

### ***Selective abortion***

The term 'selective abortion', as it is being used in this thesis, refers to the termination of a previously wanted pregnancy on the grounds of disability.

The remainder of this chapter will explore some of the pressing social issues people with Down's syndrome currently face to provide the rationale behind this research. Attitudes towards Down's syndrome and prenatal screening for this condition will then be discussed in order to contextualise the debates. Before introducing these discussions, I will provide a brief historical overview of the medical classification of Down's syndrome and the characteristics of those labelled with this condition.

## **A brief history of Down's syndrome**

Down's syndrome is a chromosomal condition first medically classified over 150 years ago by English physician John Langdon Down. Down's syndrome is one of the most common genetic conditions globally. In England and Wales, it is reported to affect approximately one in every 1,000 live births. In the UK, approximately 750 babies with Down's syndrome are born each year, and the most recent statistics suggest that there are approximately 47,000 people with Down's syndrome living in the UK (Down's Syndrome Association, 2023). It would be traditional in an overview of Down's syndrome to reiterate a standard medical description of the condition; however, I wish to diverge from this convention and have instead written a non-medicalised description of what are some common characteristics in people with Down's syndrome:

Many people with Down's syndrome bear a close resemblance to other members of their families, have beautiful almond-shaped eyes, experience a wide range of emotions (including pain), have expectations and aspirations in life, live independently, have jobs, get married, have children and live full and happy lives. Down's syndrome is not a disease, and the medical label does not denote illness or suffering.

The above definition is in stark contrast to the dominant medicalised descriptions of Down's syndrome, which are often prefaced with a long list of all possible medical conditions people with Down's syndrome may be at an increased risk of. Such definitions present a troubling and distressing picture of Down's syndrome and serve to uphold many inaccurate and damaging stereotypes, such as:

- Individuals with Down's syndrome all look alike
- All mothers of children with Down's syndrome are old
- All individuals with Down's syndrome are always happy and affectionate
- People with Down's syndrome die young
- People with Down's syndrome do not feel pain
- All people with Down's syndrome are overweight
- Adults with Down's syndrome are childlike and never grow up
- Adults with Down's syndrome cannot live independently, have jobs, relationships or have children

Many histories of Down's syndrome show how a number of the myths, as mentioned above, and stereotypes have been part of cultural imaginaries since the condition was first medically classified. Histories of Down's syndrome dating as far back as the Ancient Greek era exist (Stratford, 1989; Stiker, 1999; Yong, 2007). However, for the purpose of this thesis, I offer only a brief historical overview of conceptions of Down's

syndrome from the late eighteenth century onwards. This was the period when the field of medicine began to show interest in this particular condition, coinciding with a time that Foucault (1973) identifies as the birth of social medicine. Before Down's syndrome was medically classified, people with this condition were generally categorised as 'idiots'. The contemporary equivalent to this medical label most frequently used in the UK is the umbrella term 'learning disabilities'. The late eighteenth and nineteenth centuries witnessed a rapid growth in the 'construction of categories of disease and deviance' (Turner, 1995, p.84). Prior to the beginning of the nineteenth century, the medical field did not possess the necessary language or 'gaze' to express its 'knowledge'. By the turn of the nineteenth century, medical discourses began to define and classify 'what had previously been below and beyond their domain' (Foucault, 1973, p.xii).

The first written medical description of Down's syndrome, although it was not named at this point, was presented by French physician Jean-Etienne Esquirol and pronounced people thought to have this condition as 'incurable ... the final stage of human degradation' and whose 'intellectual and moral faculties are devoid' (Esquirol, 1838, cited in Stratford, 1989, p.25). Esquirol's colleague, Édouard Séguin, went on to develop Esquirol's work, publishing a book in 1846 dedicated to the classification and 'moral treatment' of children with Down's syndrome in order to help them socialise and contribute to society, typically through physical labour (Thomas, 2017, p.26).

As medical inquiry into 'lunacy', 'imbecility' and 'idiocy' intensified, so too did interest in the classification of patients within asylums for 'mental defectives'. Dr John Langdon Down was the resident medical superintendent at the Earlswood Asylum for Idiots (Surrey, UK) between 1855 and 1868. Two years prior to leaving Earlswood, in 1866, Down formally categorised 'mongolism' in his paper 'Observations on an Ethnic Classification of Idiots', published in the *British Medical Journal* in 1867. His original paper was first published in the *London Hospital Reports* (1866) and re-published by *The Journal of Mental Science* in 1867. This publication was the first attempt to categorise people with Down's syndrome as distinct from other 'idiots' and proposed the existence of a certain 'class of idiots' that could be ethnically classified (Down, 1867). The common narrative running through this paper presented people with Down's syndrome as Mongolian degenerates who have departed from a different ethnic class, and Down (1867, p.122) concludes that these characteristics are so frequent in his patients at Earlswood that 'there can be no doubt that these ethnic features are the result of degeneration'. Although Down's work was soon shown to be unrelated to the Mongolian race, the term he coined remained in use for several

generations (Wright, 2011, p.10). The naming of this condition marked the beginning of a scientific discourse concerning Down's syndrome, and Downs' framing of research subjects as belonging in a 'class of their own' is evident, not only in medical literature but also in contemporary cultural discourses, which we will see throughout this thesis.

Down's classification made a clear connection between learning disabilities and race using the descriptor 'Mongolian', referring to people of north-eastern Asian heritage (Davies, 2021). This classification was 'loaded with implications of racial inferiority to white, Western, non-disabled subjects', and in his works, Down often compared 'congenital idiots' to animals (Davies, 2021, p.109), a phenomenon we will later return to in Chapters Two and Three. As the century progressed, eugenic principles were applied to 'primitive' people (disabled and colonised populations) in attempts to 'progress' humankind (Davies, 2021, p.110). Despite this racialised classification being rejected by the scientific community, the medical label 'Mongol' remained in use until the 1960s when it was traded for 'Down's syndrome' due to its racist and outdated connotations (Wright, 2011; Thomas, 2017), but variations of the term 'Mongol' are still used as derogatory slurs in the present day.

The work of Langdon Down formally marked the beginning of this medical categorisation and, subsequently, the emergence of Down's syndrome within social and medical discourse (Wright, 2011; Thomas, 2017). Since the 1860s, the language of medicine has been relied upon in order to describe people with Down's syndrome. Additionally, the use of this language was no longer the sole domain of medical professionals, as society more broadly began to view people with Down's syndrome through a 'medical gaze' (Foucault, 2003, p.9). It did not take long for the medicalisation of Down's syndrome to 'turn in increasingly ominous directions', as evidenced by the development of scientific technologies 'designed to deal with the problem of imbecility', such as IQ tests, sterilisation, eugenics and, in later years, termination (Yong, 2007, p.50).

As this cursory historical overview has demonstrated, numerous myths and tropes regarding Down's syndrome and people living with the condition have arisen since, if not before, its medical classification. Many of these assumptions have been scientifically debunked (such as the myth that Down's syndrome is the result of incestuous marriages (Binet, 1876)). However, myths, such as people with Down's syndrome cannot walk or talk, have only been seriously challenged due to the work of activists and families of people with Down's syndrome. That said, anecdotal evidence suggests this trope is still used in medical settings. Cultural imaginaries of Down's syndrome often still involve many of the stereotypes listed above despite such stark

counter-evidence. Such erroneous assumptions as those discussed above can have severe consequences for people living with Down's syndrome, especially in terms of access to services and life outcomes. The following section will discuss some important aspects of contemporary life with Down's syndrome and the specific issues I focus on in this research.

## **Down's syndrome in the contemporary world**

As we have already seen, life in the modern world for people with Down's syndrome is very different to what it would have been forty or fifty years ago. The 1970s saw an increase in living standards (due to the period of economic growth in the 1960s) and increased attention on defending the human rights of more 'marginal' groups (as a result of the human atrocities that took place during World War II), which provided the momentum for the deinstitutionalisation movement in many parts of the world (Emerson and Hatton, 2005, p.36). The process of deinstitutionalisation meant that people with learning disabilities (including those with Down's syndrome) were now being supported in the community rather than in state-run institutions. The 1970s also saw the passing of the Education (Handicapped Children) Act 1970, which meant that in England and Wales, it was no longer permitted to classify disabled children as 'unsuitable' for education at school.

Fast forward to today, and people with Down's syndrome are 'living much longer, enjoying lives included in their community, with greater independence, which might encompass paid employment and living in their own accommodation' (Down's Syndrome Association, 2021b). As stated in the opening paragraphs of this chapter, the visibility of people with Down's syndrome in mainstream media has also considerably improved. Yet, despite the progress that has been made, people with Down's syndrome still face many inequalities in terms of their health, housing, sexual rights and education and indeed, their very existence. As we know, in England and Wales, where abortion is legal, 90% of pregnancies identified as being affected by Down's syndrome are terminated (Thomas, 2017). This means that 9 out of 10 pregnant people who discover that their previously wanted baby has Down's syndrome make the difficult decision to terminate. The current UK law (the 1967 Abortion Act as amended by the Human Fertilisation and Embryology Act 1990) states that the termination of a foetus after 24 weeks is *not* permitted unless:

- the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman; or
- the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated; or

- there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.

The final provision in this list means that if a foetus is diagnosed with Down's syndrome (or any other impairments or genetic conditions that fall under the vague classification of 'seriously handicapped') after 24 weeks, it is legal to terminate the pregnancy, providing two independent doctors authorise it.

The discriminate nature of this law has been challenged by many within the disability community and Heidi Crowter (who lives with Down's syndrome) and Máire Lea-Wilson (whose son Aidan has Down's syndrome), supported by the disability rights campaign, 'Don't Screen Us Out', have been taking legal action against the UK Government, calling for a review of the 1967 Abortion Act (Perrot and Horn, 2023). The case was heard in July 2021 by the UK High Court of Justice, and in September 2021, the case was dismissed. This legal action coincided with the introduction of non-invasive prenatal testing (NIPT) into NHS screening programmes.

### ***What is NIPT?***

Non-invasive prenatal testing (NIPT) is a screening test that involves taking a pregnant person's blood sample. NIPT (unlike previous screening tests) can now inform prospective parents that their unborn child is likely to have Down's syndrome with 91% accuracy (NHS, 2021). The current NHS screening pathway consists of four different screening tests: screening for infectious diseases (hepatitis B, HIV and syphilis), screening for inherited conditions (sickle cell, thalassemia and other haemoglobin disorders), screening for Down's, Edward's and Patau's syndromes and a 20-week scan that screens for eleven physical conditions (NHS, 2018). A person's reproductive choices begin with whether or not to undergo any of these screening tests. Depending on this initial choice, the reproductive decisions continue. For those who choose to undergo screening for Down's syndrome, they will receive a higher or lower chance result of having a baby with this condition. Anyone with a higher chance result must decide whether or not they undergo further testing. NIPT is offered at this stage, which will give a more accurate screening result and can help patients decide if they will undergo diagnostic tests - or there is the option to skip NIPT and opt straight for the diagnostic test. Diagnostic tests (usually amniocentesis or chorionic villus sampling)<sup>2</sup> can definitively diagnose Down's syndrome, but in rare cases (1 in 100) can cause

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<sup>2</sup> Amniocentesis is a medical procedure whereby a long, thin needle is inserted through a mother's abdominal wall, guided by an ultrasound image. The needle is passed into the amniotic sac that surrounds the foetus, and a small sample of amniotic fluid is removed for analysis. Chorionic villus sampling is a procedure that involves removing and testing a small sample of cells from the placenta.

miscarriage. Upon receipt of a diagnosis of Down's syndrome, women are given one final choice – continue with the pregnancy and prepare for their child with Down's syndrome, or have a termination.

The typical response to 'foetal deviation' in England and Wales is selective abortion (SA) (Thomas, 2017). The most recent statistics from the Department of Health and Social Care tell us that in 2021, 859 babies prenatally diagnosed with Down's syndrome were aborted in England and Wales (Office for Health Improvement & Disparities, 2021). This figure has increased from 2020 by 23.95%. In addition, the statistics showed a 71.43% increase in abortions performed after 24 weeks (Office for Health Improvement & Disparities 2021). Why termination rates for Down's syndrome might be predominantly high is one of the central queries underlining this thesis. If cultural imaginations of Down's syndrome involve dependency and poor life outcomes (such as the inability to get a job or enjoy romantic relationships), and this is being reinforced in cultural representations of people with Down's syndrome, this could be one potential reason for high rates of SA in pregnancies affected by Down's syndrome.

Against a backdrop of discriminatory abortion laws (which the UK Government are unwilling to revise) and the implementation of NIPT (and subsequent concerns that the Down's syndrome population will decrease), as well as broader concerns regarding access to education, healthcare and justice, some members within the Down's syndrome community, along with Conservative MP Liam Fox, introduced the Down Syndrome Act 2022. The Down Syndrome Act applies only to England and is 'a short piece of legislation with one substantive section which does one thing – requires the Secretary of State to issue guidance, to which various public bodies must have 'due regard' relating to matters of health, education and social care (Down's Syndrome Association, 2022, no pagination). It passed into law in April 2022 and stipulates that 'relevant authorities' (including the NHS and social care) are required to take the necessary steps to ensure they meet the specific needs of people with Down's syndrome, 'under guidance from the secretary of state (Corcoran, 2022, p.10). The guidance has not yet been developed at the time of writing (18 months since the Act passed into law). It is clear that the introduction of NIPT has sparked much-needed debate around how society values (or devalues) people with Down's syndrome and has captured not only academic attention but cultural attention. For this reason, it is important to explore cultural understandings of PNS for Down's syndrome and whether they could be based on media representations of Down's syndrome, which I will discuss in more detail in the following section.

## **Contemporary understandings of screening for Down's syndrome**

NIPT was first introduced in clinical practice in Hong Kong in 2011; technologies for NIPT have since evolved rapidly and become widely implemented worldwide (Allyse et al., 2015; Minear et al., 2015). With this fast-moving technological development comes ethical, legal and social concerns (Minear et al., 2015), and research in this particular area is continually emerging. Much of this literature focuses on key stakeholders' views, such as medical professionals and pregnant persons and not the targets of NIPT – disabled people. For instance, pregnant women and their male partners in the Netherlands were asked about their attitudes towards NIPT and the widening of the scope of prenatal screening (Van Schendel et al., 2014), which prompted a variety of viewpoints. All participants agreed that the ease and accuracy of NIPT was a positive advantage when compared to more invasive diagnostic procedures, as it meant there was no risk of miscarriage (Van Schendel et al., 2014). While general attitudes appeared positive, many participants raised concerns over NIPT. Several respondents worried that the ease and convenience of the NIPT procedure would lead to some pregnant people feeling pressured to undergo PNS, as there would be no justifiable reason to decline it with the risk of miscarriage 'excuse' being removed from the equation (Van Schendel et al., 2014, p.1348). Therefore, the routinisation and ease of NIPT could result in the informed consent of many pregnant people being questionable and prospective parents thinking through their screening options less thoroughly (Van Schendel et al., 2014; Kater-Kuipers et al., 2020). Many of the prospective parents in this study also problematised NIPT in terms of fewer babies with Down's syndrome potentially being born, which could also lead to further stigmatisation for those parents who chose to decline NIPT and kept a baby with Down's syndrome (Van Schendel et al., 2014).

Van Schendel et al. (2017) conducted a further study on attitudes to NIPT, this time from the perspective of parents of children with Down's syndrome. The participants' personal experience of Down's syndrome did not appear to diminish positive attitudes towards NIPT, and the majority acknowledged that NIPT is an improved, safer option for prenatal diagnosis (van Schendel et al., 2017). Many respondents did, however, raise concerns regarding the impact of NIPT in terms of a loss of human diversity, less 'acceptance' of children with Down's syndrome, and a negative impact on the care and facilities made available to children with Down's syndrome (van Schendel et al., 2017, p.522).

Similar studies with parents of children with Down's syndrome imply that much work is to be done to change the view that NIPT is 'a predetermined pathway to termination'



(How et al., 2019, p.290). In the United States, Acharya (2011, p.27) asserts, 'prenatal testing has become synonymous with Down syndrome'. It would seem the UK also shares this worrying correlation. Evidence points to a 'hierarchy of disability', which suggests that some impairments are more stigmatised than others (Lawson and Walls-Ingram, 2010, p.556). Within this hierarchy of disability, there appears to be more inclination to terminate a baby with Down's syndrome than a baby that is prenatally diagnosed with a 'serious physical disability' (Lawson and Walls-Ingram, 2010, p.556). Therefore, it is imperative that studies evaluating attitudes towards PNS and NIPT continue if we are to better understand attitudes towards Down's syndrome. I would argue, however, that such studies must include the views of people with Down's syndrome as, ultimately, it is their lives being most affected by attitudes (positive or negative) towards PNS, NIPT and SA.

The correlation between NIPT and termination and the concerning lack of input from the Down's syndrome community when it comes to screening practices and genetic counselling is troubling. This lack of involvement with the targets of PNS and NIPT is evident, not just in practice and procedures but within academic research itself. Research measuring the attitudes of many different stakeholders: parents and siblings of children with Down's syndrome, prospective parents, young child-free individuals, and medical professionals is available. Yet, nowhere in the literature was research investigating the attitudes of people with Down's syndrome towards PNS and NIPT to be found. This, again, highlights the relevance of this thesis in terms of hearing the voices of those with Down's syndrome and investigating the impact that misinformation and commonly held assumptions can have on their lives. One medium that can potentially amplify the voices of people with Down's syndrome is film, which relates to my research both in terms of the texts being analysed as well as the research methods used with co-researchers, which I will explain in due course.

The current pressing issues within the Down's syndrome community that appear within the public realm are, as we have seen from the above discussion, discriminatory abortion laws and the potential threat of NIPT on the Down's syndrome population. This is reflected in the amount of research being conducted in relation to prenatal screening and testing. This thesis addresses these contemporary issues in terms of how mainstream Down's syndrome representations deal with narratives around in(ter)dependence and romantic relationships and to what extent dominant discourses may influence decisions around PNS and SA. The stories being told about Down's syndrome in the media are often the only connection the wider public might have with Down's syndrome. For example, a study measuring the attitudes of young child-free

adults towards Down's syndrome and PNS found that the more first-hand experience with, and knowledge of, Down's syndrome, the more positive attitude participants had towards parenting a child with Down's syndrome, and the less likely they would be to consider selective abortion following a prenatal diagnosis of Down's syndrome (Lawson and Walls-Ingram, 2010, p.555). Approximately half of the participants in Lawson and Walls-Ingram's study had no personal experience with individuals with Down's syndrome; therefore, their attitudes towards Down's syndrome, PNS and selective abortion were potentially based more on stereotypes and misconceptions (communicated through the media) than any experiential knowledge of this condition (Lawson, 2001; 2006; Lawson and Walls-Ingram, 2010). This indicates the need for not only increased representations of people with Down's syndrome, but these representations need to be based on experiences from within the Down's syndrome community, ideally people with Down's syndrome themselves, and less on non-disabled perspectives of what life with Down's syndrome might be like.

Norms and values determine and shape what research is conducted about Down's syndrome. More research about PNS, NIPT and the ethics of screening exists than research focused on the lives of people with Down's syndrome. The importance of this thesis lies in the analytical work being co-produced with people with Down's syndrome. Still, more importantly, people living with the condition have been given the space to weigh in on some of the contemporary debates affecting their lives. Societal norms and values determine what research is being conducted about Down's syndrome and who gets to conduct the research. This project is unique in that it includes people with Down's syndrome in conversations that, due to their sensitive nature, are generally avoided. There is little doubt that discussions around relationships, sexual intimacy, screening for Down's syndrome and SA are incredibly sensitive and could potentially be upsetting. I argue, however, that this is not reason enough to avoid having these critical conversations with people with Down's syndrome. This group of people are the most affected by the attitudes, policies and debates under discussion (publicly and privately); therefore, they should not be sheltered from them. As we will see in Chapter Seven, challenging subjects can be dealt with in considerate, sensitive ways, and fruitful discussions can take place, provided the information is handled appropriately. The co-researchers in this project were not aware of the practice of PNS or SA for Down's syndrome, let alone the new technologies being developed that will detect more Down's syndrome pregnancies and potentially result in fewer people with Down's syndrome being born, which only confirms the relevance of this thesis. People with Down's syndrome must be given the opportunity to learn about complex ethical issues that directly or indirectly affect their lives and sense of self.

## Mapping the thesis

As this chapter has shown, the legacy of historical narratives of Down's syndrome continues to impact people with Down's syndrome in the contemporary world. Despite the efforts of many parents and advocates of children with Down's syndrome, several myths and tropes about the characteristics of people with Down's syndrome, as well as speculative projections on the life course of an individual with Down's syndrome, exist. This thesis will consider the role and significance of the documentary genre in cultural understandings of Down's syndrome and the impact they may have on the personhood of individuals with Down's syndrome. The narrative themes being focused on in this research are in(ter)dependence, relationships and sexuality, and PNS and SA in relation to babies identified as having Down's syndrome. These are highly contentious (potentially divisive) issues and must be handled with utmost care, especially discussions around PNS and SA.

My thesis is underpinned by three core concepts – normalcy, ableism and disability representation. Chapter Two is dedicated to outlining the conceptual framework of this thesis, unpacking normalcy, ableism and disability representation within the context of Down's syndrome. I then go on to conceptualise 'vulnerability', specifically in terms of how people with Down's syndrome have often been ascribed this label in terms of their assumed dependency, their sexuality and in discussions around the ethics of PNS.

Chapter Three supplements the theoretical literature review and discusses representations of Down's syndrome in contemporary culture, drawing from literature within novels, social media, and parental memoirs about Down's syndrome. The final part of this chapter rationalises my choice of the documentary genre, examines the relationship between disability and documentary and discusses the potentiality of the documentary genre to generate alternative narratives of a life with Down's syndrome.

Chapter Four will outline my methodological considerations throughout this research, discussing positionality, the principles of inclusive research, and sampling and data collection processes. This chapter also discusses the benefits of utilising arts-based research methods before outlining the three-stage process of my fieldwork. The ethical considerations I have made in relation to the project will be discussed, as well as the potential limitations of this research.

My analytical chapters, Five, Six and Seven, will explore the three documentaries under analysis: *The Specials* (2009-2014), *The Undateables* (2012-) and *A World Without Down's Syndrome?* (2016). Each documentary will be handled separately – Chapter Five discusses the theme of in(ter)dependence and how this is framed in *The*

*Specials*. I combined my multimodal analysis with the co-analysis conducted with my team of co-researchers during the Film Club. In Chapter Six, I discuss the theme of romance, relationships and sexuality and how this is mis/represented in the docuseries *The Undateables*. The final analytical theme is discussed in Chapter Seven, exploring discourses surrounding PNS, SA and Down's syndrome in the documentary film *A World Without Down's Syndrome?*

Before concluding the thesis, Chapter Eight will reflect on the co-production process and provide further context for the arts-based methods incorporated in my research. My reflections serve as a supplementary chapter to the analyses conducted in Chapters 5-7. I will explain how I used arts-based methods to capture how the co-researchers might imagine a documentary about their lives and discuss how developing a blueprint for a documentary film became the vehicle for exploring the co-researchers' perceptions, desires and experiences.

My concluding chapter will reflect on what was learned from the co-analysis of *The Specials*, *The Undateables*, and *A World Without Down's Syndrome?* as well as the co-production of a mock documentary trailer. I discuss the value and contribution of the research findings and the methodological contributions. I will conclude the thesis with a discussion of the potential of the documentary genre in transforming narratives about Down's syndrome (and disability) and propose opportunities for future research and collaborations.

## ~ Chapter Two ~

### Theorising Down's Syndrome

#### Introduction

In the last chapter, I showed that the history of Down's syndrome is a complicated one, and contemporary issues surrounding this condition are just as complex and problematic. In order to better understand this and to substantiate why I have chosen to focus specifically on the themes of in(ter)dependence, sexual relationships and prenatal screening for Down's syndrome, it is necessary to consider some of the theoretical concepts underpinning my work. This chapter will discuss the three foundational concepts upon which I base my thesis: disability representation, normalcy and ableism.

Before introducing these concepts, I will discuss the field in which this work is located (disability studies) and provide a brief overview of this discipline, from its conception to the thought-provoking work being done in disability studies today. I will conclude the chapter by examining how vulnerability is conceptualised in relation to Down's syndrome. I will present arguments that elucidate how people with Down's syndrome are constructed as 'vulnerable' in terms of their in/dependence, their sexual relationships and in respect of their very existence.

An extensive review of the literature pertaining to social, political and medicalised issues concerning Down's syndrome is necessary in order to mirror the complexity of these issues. The next chapter (Chapter Three) will provide a supplementary literature review, focusing specifically on representations of Down's syndrome in contemporary culture. Meanwhile, this chapter will focus solely on theoretical concepts concerning Down's syndrome and will begin by discussing the interdisciplinary field in which this thesis is situated.

#### Disability Studies

This thesis is located within the interdisciplinary field of cultural disability studies, a subset within the broader field of disability studies. Disability studies is by nature interdisciplinary, engaging with different perspectives and theoretical frameworks, for example, queer theory, affect theory, and historical, sociological, psychological, cultural and postcolonial perspectives. Johanssen and Garrisi (2020, p.2) suggest that the field of disability studies is the result of 'a rejection on the part of many scholars regarding the

mistreatment of disabled people in society' and a desire to shift focus from the 'problem' of disability to the improvement of social structures that oppress disabled people.

In the UK, disability studies was established as an academic discipline in the 1970s, with firm connections to the disability rights movement during this period (and beyond) (Meekosha and Shuttleworth, 2009; Watson and Vehmas, 2019). Disability activists rejected the medicalisation of disability, institutionalisation, poverty and the exclusion of disabled people in employment and society more broadly (Barnes, 2019). In 1974, two years after Paul Hunt invited fellow disabled people to join a group that confronted disability issues, the Union of the Physically Impaired Against Segregation (UPIAS) was officially founded. It was through the work of UPIAS that 'disability' was redefined in social relational terms, which presented disability as 'a form of socially created oppression' (Thomas, 2004; Lawson and Beckett, 2021, p.348). This redefinition was to have a significant impact on the disabled people's movement. The early work carried out by UPIAS was an attempt to shift understandings of disability from a personal tragedy to a form of social oppression:

Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS, 1976, pp.3-4).

The 'offspring' of UPIAS's 'social relational conceptualization of disability' was the social model of disability (Thomas, 2004, p.570). In the 1980s, Mike Oliver articulated UPIAS's distinction between impairment and disability and named it the social model of disability, whereby:

*Disability* is the disadvantage or restriction of activity caused by the political, economic and cultural norms of a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity. (Therefore disability, like racism or sexism, is discrimination and social oppression). *Impairment* is a characteristic of the mind, body or senses within an individual which is long term and may, or may not, be the result of disease, genetics or injury. (Oliver et al., 2012, p.16, emphasis added)

The social model was juxtaposed with an alternative model that Oliver termed the individual model but is more commonly referred to as the medical model of disability. Within the individual model, disability is classified as a personal defect or 'abnormality' located within the individual, focusing on the 'functional limitations of individuals in attempting to use their own environment' (Oliver et al., 2012, p.16). In the UK, the combined efforts of thinkers such as Hunt, Finkelstein and Oliver, as well as the work of other disability activists throughout the 1970s and 1980s, led to the introduction of legislative and policy measures that addressed disability issues. This eventually led to an increase in academic interest and the formation of disability studies as a discipline

in its own right. My understanding of disability is that it is a relational concept that signifies 'the negative aspects of the interaction between an individual (with a health condition) and contextual factors' (Barron et al., 2017, p.12).

In the 1990s, an offshoot of disability studies emerged: literary and cultural disability studies. As the name suggests, this applies a disability studies approach to literature and cultural texts. At this time, literary disability was absent from literary criticism despite the prevalence of disability within literary works (Bolt, 2007; Barker and Murray, 2017). A critical approach to cultural texts, from a disability studies perspective, can offer up 'new accounts of canonical texts' and bring 'new critical paradigms through which to consider disability representation' (Barker and Murray, 2017, p.3). To borrow Waldschmidt's (2017, p.20) phrasing, much can be gained from the 'incorporation of disability into the toolbox of literary criticism'. Indeed, Waldschmidt (2017, p.20) contends that incorporating culture as an analytical tool is beneficial to disability studies and enables the 'shedding of new light on our contemporary societies, cultures and histories'.

My research draws on literary and cultural disability studies, particularly in my approach to the textual analysis of documentaries representing Down's syndrome (see Chapter Three). I explore how people living with Down's syndrome negotiate selfhood and identity through such cultural representations and, using the tools available from a cultural disability studies perspective, conceptualise how representations of Down's syndrome in the documentary genre operate, their origins, their consequences and, in turn, how they form understandings.

This thesis is underpinned by several foundational concepts that have emerged from cultural disability studies: disability representation, normalcy and ableism. The remainder of this chapter will consider some of the key theoretical writings about ableism, normalcy and disability representation, as well as conceptualising vulnerability in terms of the independence of people with Down's syndrome, their right to intimate relationships as well as the vulnerability caused by prenatal screening policies and laws. Before concluding the chapter, I will outline and discuss the bioethical debates surrounding screening for Down's syndrome.

## **Normalcy**

### **'Enforcing Normalcy'**

The concept of normalcy is crucial to disability research, particularly as it emphasises an understanding that fixed ideas of what constitutes normality are at the root of the oppression of disabled people. Lennard Davis, a prominent theorist of texts about

disability and normalcy, suggests in his history of normality (*Enforcing Normalcy*, 1995) that how we conceive what 'normal' is and why we think of something as such is a fundamental part of understanding the disabled body and mind. His argument outlines how impairment is a universal feature in the human experience, but because we live in a world of norms, disabled bodies and minds are understood in terms of deviance and disruption (Davis, 1995; 2013).<sup>3</sup> Davis draws upon Foucault's notion of biopower and explains how normalcy can be thought of as a location of biopower (Thomas and Sakellariou, 2018). Foucault's (1973) notion of biopower refers to the technologies of power used to exert control over individual bodies and populations, the likes of which began in institutions such as prisons, hospitals and factories. A contemporary example of biopower is a country's governmental law or policy on reproduction. For example, in the UK, it is against the law to terminate a pregnancy after 24 weeks unless 'there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped' (Abortion Act, 1967).

Foucault's notion of biopower reconstitutes the body as a 'site affected by the government of the population' (Campbell, 2013, p.27). In the nineteenth century, the development of statistics, or what Rose (1985, p.42) would call 'the science of the state', was the turning point in which populations became 'governable in the way we understand it today' (Campbell, 2013, p.28). The rise of modern medicine and the emergence of the new industrial political economy during the nineteenth century are inextricably linked (Davis, 1995; Campbell, 2013). Strategies of measurement, such as statistics, were invented to cultivate and govern individual bodies and populations. Technologies of power were driven by capitalism: political and economic conditions in society shifted. Consequently, the 'type of labour that individuals undertook had changed' (Campbell, 2013, p.29), shifting the way bodies and populations were understood and subsequently measured. Campbell (2013, p.31) skilfully elucidates this phenomenon in his genealogy of dyslexia:

This shift in tactics and techniques of government, and economic conditions, began to centre around a new mechanism: the norm ... a device that allowed for the cultivation of attributes in a population to be measured, acted upon and the success of the act to be judged. The normal body created a double problematic: normality was something to be exceeded if one was successful, but failure to attain the standards set by the norm marked bodies as unfit for purpose.

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<sup>3</sup> In *Enforcing Normalcy* (1995), Davis uses the terminology 'disabled' to mean 'impaired'. Davis does not adopt the social model distinction between disability and impairment, despite its sociological relevance.



In a world of norms, individuals continuously measure themselves against what is constructed as the 'norm'. The concept of the norm permeates every aspect of our lives – from what we think, what we buy, what we weigh to what we earn – these comparisons are always made in relation to a 'narrow spectrum of normality' (Campbell, 2013, p.37). In terms of disability, a 'demarcation as less than normal is a diagnosis that may, of course, lead to technological, moral or social support, but commonly it will come hand in hand with a life-sentence of domination, where capillaries of resistance become clogged' (Campbell, 2013, p.37). This means that challenging or resisting technologies of power becomes difficult, if not altogether impossible.

### **Normalcy vs normalisation**

In a review of scholarship theorising normalcy, it would be remiss to overlook the work of Wolf Wolfensberger spanning from the 1970s onwards. Wolfensberger's scholarship focused, in particular, on people with learning disabilities and challenged the institutionalisation of those to whom this label was ascribed. Wolfensberger's normalisation theory (which he later revised and renamed social role valorisation, or SRV) confronted the medicalisation of people with learning disabilities on the basis that long-stay hospital care and service provisions within institutions resulted in 'death-making tendencies' (Sullivan, 2009, p.71). Death-making, for Wolfensberger (1994, p.395), describes any human actions that 'abbreviate' the lives of other humans, and he draws attention to disability-selective abortion as an example of death-making.

Wolfensberger's normalisation process refers to policy and practice that makes available to disabled people the everyday patterns of life that are the same as (or at least close to) the everyday ways of life of their culture and communities (Nirje, 1999). Nirje (1999, p.17) summarises the principles of normalisation/social role valorisation (SRV) as:

1. A normal rhythm of the day.
2. A normal rhythm of the week.
3. A normal rhythm of the year.
4. The normal experiences of the life cycle.
5. Normal respect for the individual and the right to self-determination.
6. The normal sexual patterns of their culture.
7. The normal economic patterns and rights of their society.
8. The normal environment patterns and standards in their community.

Nirje (1999, p.34) articulates the principles of normalisation as the arrangement of social, medical and educational services that enable people with learning disabilities to 'attain an existence as close to the normal as possible'. He argues that this can only be successful by abandoning the concept that people with learning disabilities are 'always children and planning help for them to live through

a complete life cycle' (Nirje, 1999, p.34). In the US, Wolfensberger was instrumental in broadening the influence of normalisation, drawing attention to the exposure of inhumane institutional conditions at the time and proposing 'an alternative to accepted institutionalised practice' (Mann and van Kraayenoord, 2011, p.204). Normalisation and SRV theories demonstrated not only that 'normative' lifestyles with similar rhythms and patterns as everyone else were possible for people with learning disabilities but that they were desirable and would enhance the social status of disabled people (Mann and van Kraayenoord, 2011, p.204).

Wolfensberger's normalisation and SRV theories drew considerable academic criticism, particularly from proponents of the social model of disability (Mann and van Kraayenoord, 2011). From a social model perspective, normalisation dismisses the idea that social environments need to change and places emphasis on disabled people changing to fit within a disabling society (Culham and Nind, 2003). Critics of normalisation interpret the theory as normalcy, where the expectation is for individuals with impairments to 'normalise' their differences and conform to ideological norms to gain societal acceptance. Advocates of normalisation vehemently rejected this comparison:

Probably the most common misinterpretation of the normalisation principle is the mistaken belief that it means mentally handicapped people must be expected to, indeed be forced to, act 'normal', to conform in all respects to society's statistical norms for all dimensions of behaviour . . . normalisation does not mean normalcy; it does not mean that people should be normalised . . . normalisation means the acceptance of a person with their handicap within 'normal society'. (Perrin and Nirje, 1985, pp.69-70)

Mike Oliver (1999) strongly opposed normalisation and SRV, especially the theory underpinning these concepts. Oliver (1999) argues that the social theory of disability, based upon a Marxist political economy, is a much better model for describing and explaining experiences of disability than normalisation theory (which is underpinned by interactionist and functionalist sociology). For Oliver (1999, p.163), all social theory must be determined by three interconnected elements: its ability to *describe*, *explain* and *transform* experience, which he suggests a materialist social theory of disability rooted in Marxism already does, and normalisation interactionist and functionalist theories could never do. Oliver (1999, p.163) is steadfast in his critique of normalisation and goes as far as to suggest that materialist social theory:

has had a far greater influence on the struggles that disabled people are themselves currently engaged in to remove the chains of that oppression

than Normalization, which is, at best, a bystander in these struggles and, at worst, part of the process of oppression itself.

The crux of his argument is that normalisation/SRV theory 'offers disabled people the opportunity to be given valued social roles in an unequal society that values some roles more than others' (Oliver, 1999, p.172). In contrast, materialist social theory 'offers disabled people the opportunity to *transform their own lives* and in so doing to transform the society in which they live into one in which *all* roles are valued' (Oliver, 1999, p.172, emphasis added). In his response to this article, Wolfensberger (1999, p.176) states that Oliver's critique is 'utopian and naïve', as humans can never entirely 'perfect' society, and to suggest otherwise is a 'denial of the most basic realities of human nature'. Wolfensberger (1999, p.176) maintains his argument that 'how people relate to each other will be very heavily influenced by what is in their minds' and suggests that economics is not the only way to influence how a person thinks. Regardless of who is in power (and irrespective of economics), a stratification of control will exist, according to Wolfensberger (1999, p.177). Therefore, the value of disabled people needs to be enhanced in order for their social conditions to improve.

Wolfensberger (1994, p.400) states that people with learning disabilities are regarded as 'defective bodies' and deemed less able to experience a good quality of life and are often believed to be 'expensive consumers of resources'. For this reason, Wolfensberger (1994, p.400) attests, from a 'modernistic' perspective, it makes complete sense to:

seek out and abort them [people with learning disability/disabled people] before birth, make sure they do not survive after birth, reduce the likelihood that they never recover from illness, and increase the likelihood that they die before they become too old and even more dependent.

The bioethical culture that Wolfensberger describes leads to the devaluation of different bodies and minds to the point where the very existence of particular groups of people is called into question (an issue I will return to in the next chapter). Readers could consider the tone of Wolfensberger's arguments and his work to be dated. As demonstrated by this review, his work certainly drew its criticisms. Nonetheless, his work has made a significant contribution to bioethical debates surrounding the value of disabled people, and his ideas have been said to directly influence the formation of social policy in the western world, particularly the United States (Mann and van Kraayenoord, 2011; Mathews, 2017). Moreover, his ideas still resonate with more contemporary scholarship surrounding bioethics. Burke's (2021) work on economic genetic fictions, existential vulnerability, and hostile environments (to be discussed in Chapter Three) is an excellent example of this.

## Neoliberalism

How impairment and disability are classified in contemporary neoliberal western society is changing, according to Davis (2013). Rather than enforcing normalcy, where the imperative is for people to 'conform to some white, Eurocentric, ableist, developed-world, heterosexual, male notion of normality', diversity is instead being promoted/enforced (Davis, 2013, p.3). The elevation of diversity over normalcy, Davis (2013) suggests, can be found in Eurocentric institutional, legislative and political contexts and is prevalent in cultural and media discourses. In order for the concept of diversity to be sustained within a capitalist, neoliberal context, 'disability (and poverty) represents that which must be oppressed' (Runswick-Cole, 2016). For Davis (2013, p.3), 'diversity imagines a world without a ruling gold standard of embodiment'. This does not discredit such progress, but Davis (2013) questions where disabled bodies and minds fit within this diversity paradigm. He argues that while '*diversity* is the new *normality*', normalcy still holds sway when it comes to disability, in that, unlike race, class and gender, disability is still perceived as a fixed identity through a medical lens (Davis, 2013, p.1, original emphasis; Runswick-Cole, 2016). Davis (2013) questions whether diversity in a neoliberal world can ever fully encompass disability.

Goodley (2014, p.21) writes extensively on disability and neoliberalism, referring to the 'logic that pursues the hyper normal' as 'neoliberal-ableism'. The 'logic' of ableism, or at least one of its logics, is encapsulated in the following quotation:

Ableism's psychological, social, economic, cultural character normatively privileges able-bodiedness; promotes smooth forms of personhood and smooth health; creates space fit for normative citizens; encourages an institutional bias towards autonomous, independent bodies; and lends support to economic and material dependence on neoliberal and hyper-capitalist forms of production. (Goodley, 2014, p.21)

The concept of ableism will be discussed in greater detail in the following section; however, Goodley (2014, p.26) proposes that neoliberalism is a 'discursive register' that 'provides an ecosystem for the privatisation of ableism'. Goodley defines this phenomenon as neoliberal-ableism. In societies governed by biopolitics and biotechnologies, the 'valued citizen' is 'biologically and psychologically stable, genetically and hormonally sound and ontologically responsible' (Goodley, 2014, p.23). Where, then, does neoliberal-ableism position people with Down's syndrome? Against such ruling standards as identified by ideological norms, people with Down's syndrome would be categorised as devalued citizens, unable to contribute to a capitalist labour market. The 'crucial role that capitalist economy plays in shaping the experience of groups and individuals' cannot be underestimated (Oliver, 1999, p.165).

## **Inclusionism**

Both Davis's (2013) and Goodley's (2014) arguments resonate with Mitchell and Snyder's (2015, p.4) concept of 'inclusionism', a term used to describe 'practices of neoliberal tolerance'. As neoliberalism has developed, disabled people have simultaneously been welcomed and shunned by society. In an age of neoliberalism, where market-driven societies are organised around consumer identity, there is little space for disabled people. Yet, at the same time, diversity is high on the social agenda. For Mitchell and Snyder (2015, p.4), inclusionism (which is very different from inclusion) 'obscures at least as much as it reveals' in that diversity-based practices include some differences but simultaneously make them unapparent. In their discussion of inclusionism, Mitchell and Snyder (2015) point to public education as the site most well-known for pro-diversity initiatives and state that one of the key objectives of inclusionism is to produce disabled students who 'submerge their disability experiences in order to pass as non-disabled' (Mitchell et al., 2014, p.295; Mitchell and Snyder, 2015). The significant message in Mitchell and Snyder's (2015, p.5) account of inclusionism is that 'meaningful inclusion is only worthy of the designation "inclusion" if disability becomes more fully recognized as providing alternative values for living that do not simply reify reigning concepts of normalcy'. The superficial inclusion of disabled people (in any context) only serves to further reinforce normative assumptions and expectations (Houston, 2020).

## **Summarising normalcy**

The concept of normalcy leads to one-dimensional narratives of a disabled life. St Pierre and Peers (2016), in their disruption of normate discourses of disability,<sup>4</sup> perfectly underscore the problematic nature of 'normate narratives' in their introduction to *Telling Ourselves Sideways, Crooked and Crip*:

Stories about us are boring. As predictable and ubiquitous as they are dangerous, normate narrations of our lives are as straight as they come: one-dimensional narratives of tragic loss and/or progressive normativity. We are dying or overcoming. We become a burden or an inspiration. We desire vindication or marriage. Our entire narrative worlds are defined by our Otherness, yet revolve around the normates and the normative. These stories cut straight to the point, using—and used as—well-steeped, easily readable metaphors bolstered by the requisite piano-based musical cues. If we didn't know us better, we would bore us. (St. Pierre and Peers, 2016, p.1)

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<sup>4</sup> The term normate comes from the work of Rosemarie Garland-Thomson who defines it as 'the idealised and culturally constructed notion of what an ideal body or mind should be' (Bê, 2019, p.181).

As this review of the literature theorising normalcy has shown, interrogating normalcy in the context of disability (and producing embodied knowledge(s) that reject normalcy) is paramount to disability studies and also crucial to this research. As Mallet *et al.* (2016, p.3) confirm: 'normalcy sketches out the do-able and the say-able, it cajoles, polices and decides, sometimes with mundane, and sometimes with devastating consequences'. This thesis explores how and if the documentary genre resists or subsumes notions of the norm, focusing on the everyday, taken-for-granted nature of 'normal'. The objective of using the concept of normalcy within this research is twofold: to reveal the specific risks to individual and collective futures that normalcy brings and to explore the potentiality of alternative imaginaries of Down's syndrome (Mallett *et al.*, 2016, pp.3-4).

## **Ableism**

The second key concept to inform my research is ableism, a phenomenon Wolbring (2008, p.253) defines as:

A set of beliefs, processes and practices that produce – based on abilities one exhibits or values – a particular understanding of oneself, one's body and one's relationship with others of humanity, other species and the environment and includes how one is judged by others.

For Siebers (2008, p.8), 'at its most radical, [ableism] defines the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons'. Ableism has been prevalent throughout history (Wolbring, 2008), and taken-for-granted assumptions surrounding the notion of ability are 'steeped in ideology' (Siebers, 2008). Studies in ableism are arguably more vital now than ever before, especially for the many marginalised members of the Down's syndrome population. This research is located in a world where ableism is ubiquitous. There are several terms used to describe this 'problem': ableism (Wolbring, 2008; Campbell, 2009), the ideology of ability (Siebers, 2008), normality-which-is-to-be-assumed (Shakespeare, 1996), compulsory able-bodiedness (McRuer, 2006). These scholars direct our attention to the ableist world in which we live, defining ableism as a preference for able-bodiedness and organisation of social environments according to an idealised notion of able-bodiedness. Although the term is most often used in correlation to the adverse treatment of disabled people, ableism often parallels other isms, such as ageism, racism or sexism (Wolbring, 2008, p.252). For example, sexism also favours certain abilities, and the assumption that women do not possess particular physical or psychological abilities is often used to justify sexism and male dominance (Wolbring, 2008). For the purposes of this research, however, the focus will be on

ableism against disabled people and, more specifically, ableist notions and representations of individuals with Down's syndrome.

The term ableism is often used interchangeably with disablism; however, this thesis works from the understanding that ableism and disablism are two distinct concepts. In a UK context and in accordance with the British social model of disability, disablism refers to the 'barriers, exclusions and discriminatory practices' that disabled people experience in everyday life (Bê, 2019, p.181). Disablism is the 'equivalent term to sexism or racism in that it allows us to express how an oppressed population is affected in particular ways' (Bê, 2019, p.181). Ableism, on the other hand, is a term used to describe the 'large framework that governs our society's understanding of ability and disability' and is, therefore, more comparable to the concept of whiteness or patriarchy (Bê, 2019, p.181). Bê (2019, p.181) defines ableism as a 'system of beliefs that privileges normative notions of the body/mind and ability that are culturally constructed and views disabled people as inferior and lacking'.

In line with Campbell (2009), I take the term disablism to describe the negative treatment of disabled people, with an implicit emphasis on disabled people as Other. Like Campbell (2009), I understand disablism and research in this arena to focus predominantly on practices based on assumptions (realised or unrealised) that foster the unequal treatment of disabled people based on their actual or perceived impairment. Such oppressive practices 'threaten to exclude, eradicate and neutralise those individuals, bodies, minds and community practices that fail to fit the capitalist imperative' (Goodley, 2014, p.xi). On the other hand, studies drawing on ableism emphasise discriminatory practices in favour of non-disabled people and allow for critical investigation into how ableism reproduces and reinforces normative notions of the 'ideal' body and mind.

The theoretical frameworks of ableism and normalcy will intertwine throughout my research; these are not concepts that can be separated and studied independently:

Ableism cuts across all of our movements because ableism dictates how bodies should function against a mythical norm – an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability. (Mingus, 2011, no pagination)

This assertion from Mingus (2011) chimes with Wolbring's (2008) and Campbell's (2009) definitions of ableism, and, as Mallet *et al.* (2016, p.8) outline in their description of normalcy: 'the disabled body is always living at the intersections of many other forms of oppression ... and it is not only disabled people that are threatened under the conditions of normalcy' and ableism. McRuer (2006) and Goodley (2014) adopt a

similar stance, acknowledging the intersectional nature of studies in ableism and how it cannot be considered distinct from other Othered identities. As Goodley (2014, pp.2-3) points out:

disabled people, women, children, queer people, people of colour and poor people share an Other space to that of the dominant same founded upon ableist, heteronormative, adult, white European and North American, high income nations' values.

In his seminal text, *Crip Theory*, Robert McRuer (2006) radically critiques the concept of normativity by questioning *how* ableism has been created.<sup>5</sup> Building on queer theory's 'critical tradition of norms', crip theory questions how 'physical ableism' is constructed (Löfgren-Mårtenson, 2013, p.414). McRuer (2006, p.15) coined the term 'compulsory able-bodiedness' to describe the processes that *produce* disability, claiming these processes are entwined with the system of compulsory heterosexuality, which in turn produces queerness. Crip theory questions previously unquestioned assumptions around disabled and non-disabled bodies. Compulsory able-bodiedness:

ensure[s] the survival of the normate, society learns to tolerate the deviant up to a certain limit, whereas the identity of the normate remains flexible. The flexibility is necessary to maintain the dichotomy of normal/abnormal and ability/disability. (Löfgren-Mårtenson, 2013, p.415)

For Goodley (2014, p.xi), 'compulsory ableism is to disablism what compulsory heterosexuality is to homophobia' and to a certain extent, and even more so than heterosexuality, compulsory ableism masquerades as 'the natural order of things', leaving it unquestioned and widely accepted (McRuer, 2006, p.1). An ableist stance might suggest that disabled people are entitled to fair treatment on the basis of toleration but fails to consider disability as a welcome human variation (Campbell, 2012, p.213).

## **Transhumanism**

Failure to recognise disability as a welcome human variation can also be found in the concept of transhumanism. Transhumanism is a philosophical and socio-political movement that promotes the enhancement of the human condition through science and technology. The pursuit of human advancement encourages the use of 'biotransformative technologies' (such as genetic engineering or artificial intelligence) to

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<sup>5</sup> The term 'crip', short for cripple, is intentionally provocative. Analogous with the term queer, in that it is generally considered derogatory, when adopted by people with an impairment, the term crip problematises ableism, 'embrace[ing] and actively appropriat[ing] the stigma' that disabled people face (Löfgren-Mårtenson, 2013, p.414).



'modify the human organism so radically as to overcome fundamental human limitations' (Porter, 2017, p.238). According to the transhumanist movement:

a "transhuman" is a "transitional human" who aims at becoming posthuman and takes appropriate steps (e.g., technological enhancement) toward that end—whereas a "posthuman," the ideal for and goal of transhumanists, is a being so radically different in physical, cognitive, and emotional capacities from normal or current humans as to be no longer unambiguously human. (Porter, 2017, p.238)

Levin's (2021, p.1) critique of transhumanism stresses the importance of further debate within the transhumanist movement, stating:

The human stakes of how we respond are immense both because transhumanists urge humanity's own self-transcendence via science and technology and because their arguments state or suggest that bioenhancement may be morally required.

Indeed, the moral implication of bioenhancement, as described above by Levin, has ties with ableist notions of perfect or ideal functioning bodies and will inevitably further problematise the processes of compulsory able-bodiedness. Disability critiques of the pursuit of the posthuman highlight the ableist footings upon which transhumanist thinking is founded, as well as the danger and damage that transhumanist discourse holds in terms of existing disabled people and those yet-to-exist (Hall, 2020). The transhumanism movement and proponents of human enhancement 'make arguments that rely on the denigration of disabled embodiment and lives' and ultimately 'link disability with risk' (Hall, 2020, p.633).

Stemming from their work on ableism, Campbell (2009), Wolbring (2008) and (Goodley, 2014) problematise transhumanism and its tendency to promote ableist principles. Campbell's (2009) concerns of technological enhancement and the irrefutable shift towards transhumanism raise fundamental questions regarding how this movement will impact concepts of normalcy. Wolbring (2008, p.254) refers to the 'transhumanized version of ableism' as giving 'preference to going beyond human species-typical abilities and sees humans as in a diminished state of being if they are not enhanced beyond human species-typical abilities'. The boundaries of what constitutes the human norm are being pushed through rapidly emerging enhancement technologies, and what happens to those who fail to meet newly formed 'ableist standards of super health and wholeness' through transhumanism is of grave concern (Goodley, 2014, p.26). It is for this reason, Goodley (2014, p.161) states, 'there is an urgent need for disability/ability studies to become more and more involved in the ethics and project of transhumanism'.

An example of a transhumanist strategy is the reproductive genetic technologies that allow prospective parents to choose to give birth to particular children (and not others). This strategy is increasingly becoming an option for parents-to-be. These strategies are currently available through either combining in-vitro fertilisation and preimplantation genetic diagnosis (which will later be referred to when discussing the documentary film *A World Without Down's Syndrome?*) or by combining prenatal screening and diagnostics with selective abortion (Hall, 2020).

An even more extreme example that directly pertains to Down's syndrome can be found in the quest to improve cognitive function in foetuses. With the aim of 'improving the future child's intellectual development and independent life skills', medical professionals in the field of foetal therapy are currently invested in developing therapeutic strategies that could become an option for pregnant people carrying a child with Down's syndrome (de Wert et al., 2017, p.222). This transhumanist endeavour is a troubling example of the downside to celebrating normativity of which Goodley (2014, p.25) warns in his problematisation of 'the idealisation of some forms of life over others'. In this example, ableist notions of acceptable forms of humanness steer the transhumanist movement – to the extent that people with Down's syndrome are being targeted (and enhanced) before they are born. Such ethical dilemmas will be explored further in the thesis, particularly in Chapter Seven, when discussing non-invasive prenatal screening, using both ableism and normalcy to intervene in these debates. I will now turn to a discussion of the final concept underpinning this thesis – disability representation.

## **Disability representation**

### **Theorising representation**

Representations of disability in art, literature, and on-screen are omnipresent and far more prevalent than one might think (Bérubé, 2016a). In many ways, disability can be thought of as one of the 'sub-specialities' of visual media, in that we see a lot of disabled people in film and television (Davis, 2017, p.39). The different ways in which disabled people are represented within literary and cultural texts have been extensively researched, with disabled people being rendered in undesirable terms as: 'monstrous' (Hughes, 2009), 'freaks' (Garland-Thomson, 1996), 'cultural spectacles' (Bogdan, 1990), as 'Others' (Goodley, 2000; Oliver, 2009), either as 'scroungers' or 'superhumans' (Hollomotz, 2013; Crow, 2014), as dependent and burdensome (Morris, 1993; Shakespeare, 2000b), and as 'biologically deviant' (Snyder and Mitchell, 2006). Against this backdrop, this thesis problematises dominant representations of Down's syndrome in connection with critical theories of literary and cultural representation,

utilising the toolkit available through this field of inquiry as well as theories in disability studies more broadly.

Given that cultural representations construct meaning (Hall, 1997), it is unsurprising that representations of disability continue to be widely researched in literary and cultural disability studies. A recent edited collection from Johanssen and Garrisi (2020, p.1) explores cultural representations of disability, seeking to analyse 'how bodies are presented as strange, shameful, wrong, impaired, wounded, scarred, disabled, lacking, different or "other" in the media'. It is equally important to reveal *how* disabled people are represented in disparaging ways, as it is *why* they are represented. The political force behind cultural representations should not, as Davis (2013, p.130) states, be overlooked:

In talking about power and politics it has been too often easy to exclude culture or to see culture as either the handmaiden of power and/or the site of resistance to that power. In either case, culture is peripheral and marginal, aleatory.

Indeed, the very purpose of literary and cultural disability studies is to reveal the power and politics behind cultural representations and understandings of disability and to question why, culturally, the voices of disabled people are being overlooked or suppressed. In his description of disability studies, Fraser (2016, p.2) states that it is:

a disciplinary formation whose sustained political force require constant methodological innovation and political commitment if it is to respond to struggles that appear, morph and reappear in specific places and at specific times – always with specific human consequences.

To exclude culture and representation from the foundations of disability studies is, as Davis (2013) stated above, perilous.

This thesis works from the understanding that 'culture is about shared meanings' and that 'language is central to meaning and culture' – therefore, representation is 'central to the processes by which meaning is produced' (Hall, 1997, p.1). While the term *culture* can be thought of as a vague word, capacious in its meaning, for the purposes of this research, culture is understood as a variety of signs, symbols, tools and ideologies, or signifiers (Williams, 1981), working from the basis that cultural meanings organise and regulate social practices and influence societal conduct (Hall, 1997). My understanding of culture, in line with Hall (1997, p.2), is that it is not a word to describe certain *things*, such as a painting or even a documentary series (which we might instead call cultural productions or texts), but, rather it describes *practices* – the processes 'concerned with the production and exchange of meanings'.

According to Hall (1997), there are three main theories of representation. The first is the reflective approach, whereby language functions as a mirror, reflecting 'true meaning as it already exists in the world' (Hall, 1997, p.24). Contrasting the reflective approach is the *intentional* approach, whereby the speaker/author/producer imposes their 'unique meaning on the world through language' (Hall, 1997, p.25). Finally, there is the *constructionist* approach, whereby 'neither things in themselves nor the individual users of language can fix meaning in language' – that is, we construct meaning using representational systems (concepts and signs) (Hall, 1997, p.25). Convincing arguments are made within each of these approaches. While this research largely fits within the constructionist approach to representation and contends that we use signifiers in representation organised into different forms of languages to meaningfully communicate with others, the three approaches do not necessarily have to be mutually exclusive (Hall, 1997, p.28).

The ways in which disabled people are represented through cultural texts is an area of inquiry widely researched in the field of literary and cultural disability studies. Previous scholarship draws attention to misrepresentations of disabled people within fictional and non-fiction literature (Mitchell and Snyder, 2000; Cheyne, 2012; Bradshaw, 2016), news media (Titchkosky, 2005), cinema (Norden, 1994; Snyder and Mitchell, 2010; Markotić, 2008; 2016), television (Grue, 2015), advertisements (Bolt, 2014a; Houston, 2019; 2020; 2023), and charity campaigns (Waltz, 2012; Bolt, 2016), highlighting the ways distorted portrayals can be harmful to the already marginalised groups of people being represented. The above list of works, which is by no means exhaustive, supports Benjamin Fraser's (2016, p.3) unambiguous assertion that 'representations matter'. This thesis will add to the growing body of literature, drawing attention to how Down's syndrome is represented within the documentary genre and considering how these portrayals impact the co-researchers with Down's syndrome. My analysis identified two dominant representational approaches to disability texts – supercrip and freakery, concepts I will now discuss in more detail.

### **'Freakery'**

Many scholars in disability studies and literary and cultural disability studies have illustrated how past and present cultural texts often represent disabled people as 'monsters' and 'freaks' (Bogdan, 1990; Hevey, 1992; Garland-Thomson, 1996; Shildrick, 2002). Before the nineteenth-century, bodies that were anatomically, neurologically or developmentally different to those considered average or acceptable would have been categorised as 'monsters' (Richardson, 2017, p.330). Scientific and medical advancements in the early nineteenth century meant that scientists were able to debunk any ideas around 'abnormal' births being a 'result of divine intervention' and

understand them as the result of 'atypical foetal development' (Richardson, 2017, p.331). According to Richardson (2017, p.331, original emphasis), the result of these key advancements is 'that it changed the position of the "monster" from something unfathomable to something that was *almost* human'. The birth of the 'freak show' in the early 1800s saw dominant social categorisations of disabled people as monsters being replaced with the category of 'freak' (Bogdan, 1990). The 'history of freakdom' began before the birth of the freak show but was at its pinnacle during the mid-1800s and mid-1900s, a time when the popularity of the freak show soared (Clare, 2015, p.84). The various terms used to describe the people being exhibited in freak shows varied over time and space but often represented a 'hodgepodge of medical terminology and show-world hype' due to the fact that showmen 'exploited scientific interest in constructing freaks' (Bogdan, 1990, p.3). 'Freaks', 'oddities', 'nature's mistakes' and 'curiosities' were just some of the terms Bogdan (1990, p.6) listed as examples.

In her exploration of American freak shows, Rosemarie Garland-Thomson (1997, p.58) enhances Bogdan's (1990) discussion around scientific and medical curiosity in difference, and she states that the emergence of freak shows coincided with a time when scientific pursuits to name and measure became the elite method of quantification, as previously discussed in relation to normalcy. This period in time was 'an era of display', and 'truth' needed to be scientifically measured, counted and controlled – objectivity was at the forefront (Garland-Thomson, 1997, p.58). This, Garland-Thomson (1997, p.58) argues, is one of the reasons the American freak show was so prevalent throughout 1830-1940: 'exhibits challenged audiences not only to classify and explain what they saw, but to relate the performance to themselves'. The freak show is a 'spectacle' that 'institutionalizes the relationship between the spectacle and the spectators' (Garland-Thomson, 1997, p.60). For Garland-Thomson (1997, p.17), this institutionalised relationship consists of a spectacle that allows spectators to stare at difference and reassure themselves of their own normalcy – their identity was (through the staging of the spectacle) verified as 'ordinary, tractable, and standard'. In other words, the freak show is entirely fabricated – the people being exhibited are *not* 'freaks', but the way in which they are costumed, presented and made to perform is what enfreaks them. This is particularly relevant in my discussion of *The Undateables* in Chapter Six, where I argue that the framing of characters with Down's syndrome in this docuseries involves 'strategies of enfreakment' (Richardson, 2017, p.330). I will explore how contemporary disability representations have repackaged the freak show into more palatable forms for present-day audiences, arguing that *The*

*Undateables* serves as an interesting case study of how this is subtly (and not so subtly) executed.

Freak shows were overwhelmingly lucrative, and endless streams of paying customers would come to 'gawk at the "freaks", "savages" and "geeks"' (Clare, 2015, p.86). Showbills would promise audiences a front-row seat to real-life 'freaks of nature'. Eli Clare's (2015, p.86-87, emphasis added) historical account of the freak show confirms that four different groups of people were constructed as 'freaks' and the one thing they shared in common was that '*nature* did not make them into freaks ... The freak show did'. Garland-Thomson (1996, p.10) first made this argument, correcting the phrase 'freak of nature' with 'freak of culture', emphasising the culturally constructed nature of the 'freak'. The four groups as described by Clare (2015, p.86) were disabled people (including various races and ethnicities), non-disabled people of different races and ethnicities, 'nondisabled people of color from the United States' (who would be referred to as 'Natives from the Exotic Wilds') and finally, non-disabled people with visible differences (such as 'fat' or 'bearded' women or 'very thin men'). The racial and ethnic differences between these four groups were melded together (Clare, 2015) and abridged under a 'single sign of the freak-as-other' (Garland-Thomson, 1997, p.62).

Against a backdrop of ableism and racism, the freak show produced (and exploited) many 'freaks', both disabled and non-disabled and of various racial backgrounds. For Clare (2015, p.99), the American freak show was closely associated with racial politics at that time, and their displays of Black (and white) 'cognitively disabled people' bolstered the 'missing-link evolutionary theory' that was prevalent during the freak show era. Clare (2015, p.99) states that medical professionals and politicians would reference cast members from freak shows as 'living proof' of their theories and in so doing, 'they were reaffirming the less-than-human status of people of color' and justifying the racist politics and ideologies they professed. Clare (2015, p.99) summarises this as follows: 'simply put, the freak show both fed upon and gave fuel to imperialism, domestic racist policies, and the cultural beliefs about "wild savages" and white superiority'. In any analysis of Down's syndrome representation, this entanglement of racism and ableism is significant and harks back to Dr Downs' medical classification of the condition. As we saw in Chapter One, when Down's syndrome was first medically classified, descriptions of this specific form of 'idiot' were laden with racism and speciesism.

By the mid-twentieth century, the freak show era had ended. It was instead overtaken by the medical scrutiny of disabled people: 'Thus the wondrous monsters of antiquity,

who became the fascinating freaks of the nineteenth century, transformed into the disabled people of the later twentieth century' (Garland-Thomson, 1997, p.58). The passing of time condemned the freak show as 'an oppressive institution from the bad old days', but, as Clare (2015, p.100) argues, quite how 'dead' the freak show remains is questionable, an issue that I will return to in Chapter Six when I discuss the freakery conventions used within *The Undateables*. While it was no longer socially acceptable to exhibit freaks in the capacity of a freak show, this did not stop the process of freakery or enfreakment. For instance, Stevens (2010) argues that freakery is imbued in contemporary supercrip narratives, which brings us to the concept of the 'supercrip' and its relation to representing Down's syndrome.

### **Supercrip**

Eli Clare (2015) rejects the connection between freaks and supercrips. For him, freaks 'did not *overcome* disability; they *flaunted* it' (Clare, 2015, p.98). For Stevens (2010, p.71), however, 'freaks and "supercrips" share a common rhetorical strategy; both attempt to inspire the normate to feel better about their body in relation to the "Other"'. Portrayals of disabled people as 'supercrip', inspirational or extraordinary are commonly found within cultural representations and have been influenced by the history of the freak show. The inspirational and supercrip stereotypes represent the direct opposite of the 'sentimentalized, pathetic poster child wheeled out for telethons and tearjerkers', and they defy pity and inspire awe from their non-disabled audiences (Alaniz, 2014, p.31), reminiscent of the freak show era.

The term 'supercrip' became popularised in the 1990s and is most often used to describe either inspirational disabled people who have 'overcome spiritual and physical challenges to perform everyday tasks' (Fahn, 2020, p.6) or competitive or professional sports people at the top of their field, 'despite' their impairment. Not only does this descriptor of disabled people highlight the low expectations society holds for disabled people, but critics of the supercrip narrative also argue that it 'represents a sort of overachieving, overdetermined, self-enfreakment that distracts from the lived daily reality of most disabled people' (Alaniz, 2014, p.31). Eli Clare (2009, p.2) encapsulates Alaniz's point effectively, using Down's syndrome as an example in their definition of the supercrip:

An adolescent girl with Down's syndrome learns to drive and has a boyfriend ... Supercrip stories never focus on the conditions that make it so difficult for people with Down's to have romantic partners. I don't mean medical conditions. I mean material, social, legal conditions. I mean lack of access, lack of employment, lack of education, lack of personal attendant services. I mean stereotypes and attitudes. I mean oppression.

To defy expectations and to 'overcome' challenges as a disabled person (because of the low bar set for anybody whose minds or bodies deviate from a perceived norm) is considered inspirational and exceptional. Beth Haller (2000, no pagination) argues that putting disabled people on a pedestal because of their 'inspirational quality in doing ordinary things' is, in fact, condescending praise and, in reality, is just another form of pity. Most critiques of the supercrip narrative discuss how these representations:

rely on concepts of overcoming, heroism, inspiration, and the extraordinary. Additionally, most scholarship also mentions how these representations focus on individual attitude, work, and perseverance rather than on social barriers, making it seem as if all effects of disability can be erased if one merely works hard enough. (Schalk, 2016, p.73)

The phenomenon of the supercrip is saturated in the concepts of normalcy and ableism and certainly has 'conceptual connections' with freak shows since 'supercrip narratives ... rely upon the visual rhetoric of wonder' (Schalk, 2016, p.73). In this sense, supercrip narratives predate the term itself (Schalk, 2016).

Almost all disability scholars agree that the supercrip narrative emphasises over-compensation for the 'perceived "lack" created by disability'; however, Schalk (2016, p.71) argues that if we are to 'understand the production, consumption, and appeal of supercrip narratives in popular and mainstream culture', there must be further scholarly inquiry into the supercrip 'narrative mechanisms, type and context'. Focusing on supercrip as a 'critical device' allows disability studies to engage more with 'mainstream genres that are often dismissed as too normative, regressive, or uncomplicated to be of value to improving the lives of people with disabilities' (Schalk, 2016, pp.71-72).

Building on Kama's (2004) supercrip typology, Schalk (2016) contends that there are three distinct yet related types of supercrip representation:

- 1) Regular supercrip narrative (where everyday tasks are perceived as exceptional because of impairment). For example, getting married or playing on a sports team.
- 2) Glorified supercrip narrative (where disabled people achieve feats even non-disabled people rarely attempt). For example, becoming a famous musician or competing in the Paralympics.
- 3) Superpowered supercrip narrative (where fictional, and sometimes non-fictional, characters in visual media have abilities, or 'powers', that are either connected to or contrasting their impairment). For example, a Marvel superhero or renowned Paralympic runner, Oscar Pistorius.



Schalk's (2016, p.84) concluding arguments suggest there is a 'future for supercrips' and that to 'dismiss outright all representations of supercrips as "bad" is to disregard potentially entire genres of popular cultural productions, ones which tend to have vast audiences'. Schalk's (2016) claim reflects Foucault's outlook on dangerous discourses:

My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a hyper- and pessimistic activism. I think that the ethico-political choice we have to make every day is to determine which is the main danger. (Foucault cited in Dreyfus et al., 1983, pp.231-2)

The point I believe Schalk (2016) is making is that representations (particularly supercrip representations) do not always have to be designated as either 'good' or 'bad'. Sometimes, as Foucault (1983) suggests, supercrip narratives might not be 'bad'; rather, they might be dangerous. If we assess something as dangerous or problematic, the intent becomes to change or work through the risks rather than dismiss the narrative altogether. I approached the documentaries under analysis from a similar stance – for example, in Chapters Six and Seven, rather than simply identifying and labelling scenes or characters as supercrip, I have considered why the supercrip narrative is being relied upon and what cultural work is being performed as a result (Schalk, 2016).

Having introduced the conceptual underpinnings of this thesis, I will now turn to the concept of vulnerability in relation to the thematic components of the project – in/dependence, relationships and screening for Down's syndrome.

### **Conceptualising vulnerability**

As outlined in Chapter One, the three thematic strands of this thesis are Down's syndrome and in(ter)dependence, dating and Down's syndrome, and the ethics of prenatal screening (PNS) for Down's syndrome. These three themes are interconnected in that all of them are widely discussed issues within the Down's syndrome community, but also because they are all in some way linked to the concept of vulnerability. Vulnerability is often closely associated with the experience of disability, with disabled people frequently assumed to be vulnerable. Usage of the term in this context often denotes a lack of 'ability' (Beckett, 2006) as well as dependence on non-disabled people. The concept of vulnerability informs how certain groups of people are governed and classified and functions to justify 'state intervention in citizens' lives', allocating resources and defining social responsibilities (Brown, 2011, p.313). The 'vulnerable' label is often ascribed to those with learning disabilities, and I would argue

that individuals with Down's syndrome are especially susceptible to this label as a result of their often assumed 'childlike' characteristics.

Who 'belongs' to the vulnerable and privileged groups is dependent upon and determined by 'operations of power' (Butler, 2016, p.26). Butler (2016, p.26) politicises vulnerability, arguing that 'if certain lives do not qualify as lives or are, from the start, not conceivable lives within certain epistemological frames, then these lives are never lived nor lost in the full sense'. While much of Butler's work centres around war and does not overtly discuss disability, her arguments can be applied in the context of disability and vulnerability and the operations of power that frame these concepts (Butler, 2016). If the lives of those with Down's syndrome and disabled people more generally are not conceived as valued lives, this calls into question 'their humanity, their personhood, their place alongside other humans' (Goodley, 2020, p.33). As Goodley (2020, p.23) states: 'some humans appear to be more precariously so than others', with some humans denied rights and privileges and others unaffected by such disparities. As we will see in Chapter Three, people with Down's syndrome often have their personhood questioned, and it is not uncommon within philosophical and bioethical circles to find people with learning disabilities being associated with non-human animals.

Licia Carlson's (2010, p.134) work traces the philosophical journey of 'intellectual disability' and discusses this common association with non-human animals, suggesting it manifests itself in one of two ways – a comparative approach or a definitional approach. The first approach she describes as the perceived condition or status of people with learning disabilities being compared to animals – their mental or intellectual capacity is deemed comparable to that of an animal (Carlson, 2010). The second manifestation is definitional in that people with learning disabilities, 'by virtue of certain qualities and capacities (or lack thereof), are placed in the same moral category as non-humans' (Carlson, 2010, p.134). With the moral worth and personhood of people with learning disabilities in a constant state of interrogation, it is unsurprising that people with Down's syndrome are categorised as vulnerable. As the remainder of this chapter will reveal, however, the vulnerability of people with Down's syndrome is complex and works on many different levels.

First, however, it is important to continue unpacking why people with Down's syndrome (and disabled people generally) are classified as vulnerable and what consequences the label of vulnerable might have on the lives of people with Down's syndrome. Many authors contend that vulnerability is a shared condition (Butler, 2004; 2016; Fineman, 2019) and that the term should not be reserved exclusively for disabled people (Zola,

2005; Beckett, 2006; Macintyre, 2009; Garland-Thomson, 2012; Knight, 2014; Vehmas and Shakespeare, 2014). These writers, and many more, have asserted that impairment is unavoidable and that at some point during the human life course, we will all encounter injury or become ill (physically or mentally). We will all age, and we are always, therefore, vulnerable. In her work on the precariousness of life, Butler (2004, p.31) calls this 'the condition of primary vulnerability'.

In philosophical literature, 'mirror roles' are often used as a device to understand ourselves in other humans – Others are positioned as mirrors for the reassurance of the non-marginalised, to gain comfort in knowing 'this could have been us' (Carlson, 2010, p.190). In *Dependent Rational Animals*, Macintyre (2009) suggests, in a similar fashion to the thinkers listed above, that vulnerability is universal and argues that we should not devalue our dependency and vulnerability – if we value it, then we might see ourselves in the individual with an impairment. In this sense, the mirror role is deployed to dispel the us/them dichotomy. In making the case for universal vulnerability and implying that we are or will all in some way become disabled, humans are not categorised on the basis of impairment. Carlson (2010, p.193), however, warns of the potential for obfuscation in declaring we are all disabled – namely, the threat of the Other being obscured to the point that they 'literally lose face, or disappear if they are simply a means for the non-disabled to recognize their own limitations'.

The mirror role, as it is used by writers such as Macintyre (2009), while encouraging and certainly more in line with a human rights-based approach to disability, does not reflect the current status of a life with Down's syndrome, certainly not in the context of the UK. People with Down's syndrome in the UK do not have access to equal rights in terms of education, employment or healthcare. As Knight (2014, p.18) suggests (and in line with Butler's vulnerability theory), 'while human vulnerability is a shared condition, it is not shared equally in a context of inequality'. The ways in which political, social and economic institutions are structured make some populations more vulnerable than others (Fineman, 2005; Brown, 2011; Hollomotz, 2011; Knight, 2014). A recent and devastating example of this can be found in statistics surrounding COVID-19-related deaths.

As we have already established, to belong to the vulnerable population, in the context of disability, is to be at increased risk of harm, wrong-doing or exploitation as a direct result of impairment (Cameron, 2014), this being especially significant in the age of COVID-19. At the start of the pandemic, any individual with an underlying health condition was medically branded as 'vulnerable'. This further classification of vulnerable (in addition to any previously assigned medical labels) is underpinned by the

individual/medical model of disability and implies that vulnerability is an inherent and unavoidable trait in disabled people (Cameron, 2014). Beckett (2006, p.3) stresses that 'one of the ways disabled people are vulnerable is with regard to negative assumptions made about their abilities by some non-disabled people'. The language used to describe and classify people with impairments is instrumental in the way meaning is ascribed to disability.

Throughout the pandemic, people with impairments or, to use the UK government's preferred terminology, those with 'underlying health conditions', were perpetually described as 'clinically vulnerable' and 'the most vulnerable'. This sparked debate among the disability community, with concerns being raised over the 'deadly discourse' used to 'other' any individuals with pre-existing health conditions and the message such discourses convey about citizenship, human worth and exclusion (Abrams and Abbott, 2020, pp.168-170). During the first wave of the pandemic, it was reported that the death rate of people with learning disabilities was over six times higher than that of the general population (Public Health England, 2020). These statistics demonstrate the deadly discourses Abrams and Abbott (2020, p.170, original emphasis) warned of early on in the pandemic and support their point that ableist discourses surrounding underlying health conditions (ergo disabled people) is, in fact, making people more vulnerable, blurring the value of 'the flourishing lives of disabled persons' and diminishing 'the care that goes into sustaining *all life*'.

Within disability studies, vulnerability is not generally understood as an outcome of impairment. Many disabled people experiencing vulnerability do so as a result of social policies and service provisions embedded within the medical model (Beckett, 2006; Cameron, 2014). The coronavirus pandemic and subsequent framing of disabled people as the 'most vulnerable' is the quintessential example of vulnerability being *caused* by ableist discourse. The social and political construction and subsequent categorisation of disabled people as vulnerable, as well as physical, environmental, economic and cultural barriers, are what make disabled people 'vulnerable' and prevent them from exercising personal autonomy (Davy, 2019, p.101). People with learning disabilities, in particular, are marginalised by the 'conception of the autonomous individual', as they often have support needs that require assistance in several aspects of life and 'lack the capacity for independent linguistic agency privileged in dominant understanding of personhood' (Davy, 2019, p.101). If people with learning disabilities are doubly bound by normative expectations of dependency, as the literature would suggest, an exploration of how this is represented in documentary films and series is all the more timely.

## **Down's syndrome and dependency**

As the historical overview in Chapter One outlined, prior to the 1950s, people with Down's syndrome in the UK (and many other countries) were confined to institutions and resided under the protection of medical professionals. It was not expected that children with Down's syndrome would reach adulthood, and 'those who did survive were very often accommodated in mental hospitals where they could be quietly forgotten by all except those who were immediately responsible for their care' (Stratford, 1989, p.129). The 'burden' of caring for a child with Down's syndrome was taken from parents and placed in the hands of professionals. The institutionalisation of people with Down's syndrome was often portrayed as being in the best interest of all involved – families, the individual with Down's syndrome and society more broadly. It was during the 1950s and 1960s that the confinement of people with learning disabilities began to be questioned by professionals and parents, and the process of deinstitutionalisation commenced. The consequences of deinstitutionalisation were 'improved health care, increased services and community participation' – people with Down's syndrome (and others with learning disabilities) were now being extended life opportunities they were once denied (Jobling and Cuskelly, 2002, p.109).<sup>6</sup>

In a present-day context, people with Down's syndrome (in the UK) are protected by legislation that is supposed to ensure their equal rights and protect them from disability discrimination, such as The Equality Act (2010) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 3 of the CRPD outlines the 'full and effective participation and inclusion in society' as an equal right. Article 19 stipulates the right to live independently and be included in the community, with disabled people being afforded choices equal to others. Across-the-board, this article is intended to ensure that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs. (Article 19, United Nations, 2007, no pagination)

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<sup>6</sup> Children with Down's syndrome would have to wait until the 1970s before they were legally entitled to an inclusive education (Stratford, 1989).

Interestingly, the right for all disabled people to live in the community almost did not happen and was only incorporated into Article 19 at the very last negotiation session in January 2006 (Leibowitz, 2013). The hesitation, Leibowitz (2013, p.46) suggests, may be in part because of the fundamental changes that would be required to social structures and 'deep-seated legal constructs'. How successful Article 19 has been and will prove to be is yet to be seen.

While the deinstitutionalisation of learning disabled people is less common in the present day, it has not been completely abandoned, and many learning disabled people are currently institutionalised. According to a UK Parliament Report, in 2021, there were at least 2,055 people with a learning disability (including neurodivergent people) being held in secure institutions, 'where they are unable to live fulfilled lives and are too often subject to treatment that is an affront to a civilised society' (The Health and Social Care Committee, 2021, p.3). Several disturbing reports of abusive conditions within housing facilities for people with learning disabilities have come to light in recent years, including The Winterbourne View Hospital case, whereby people with learning disabilities and neurodivergent people were subjected to physical and psychological abuse, with systematic failing being exposed by an undercover BBC *Panorama* journalist. Another distressing example can be found in the preventable death of Connor Sparrowhawk, affectionately known as Laughing Boy or LB. LB, who had autism and epilepsy, was found dead in a specialist NHS unit where he drowned in a bath, having been left unattended (Ryan, 2018). These cases demonstrate the drastic improvements required if we are to ensure the protection of learning disabled people's human rights.

Discourses of Down's syndrome often involve a narrative of encumbrance – the assumption that raising a child (and eventual adult) with Down's syndrome is an emotional, physical and financial burden for parents and family members (Alderson, 2001). As we will see in Chapter Three, many parental narratives recounting initial concerns following the birth of their children with Down's syndrome describe anxieties over what will happen to their adult children once they have passed. This apprehension is legitimised in a context where austerity measures and welfare cuts are drastically limiting housing options for many disabled people. As we will see in Chapter Five, the housing provisions in place for the subjects of our analysis (*The Specials* housemates)

were hard-won but do not represent the reality for most people with learning disabilities in the UK who live with family and friends.<sup>7</sup>

In addition to a lack of housing provisions in the UK, the two devastating examples discussed above (which were widely covered in news media) will undoubtedly lead many families of people with learning disabilities to opt out of securing group housing accommodation, knowing that their adult children would be safer staying at home. Regardless of whether adults with Down's syndrome remain living at home or embark upon the independent living route, meaningful participation within the community should still be accessible to them. 'Community participation is an essential dimension of human functioning', and therefore, social policies and programmes should be structured in a way that facilitates community participation in the daily lives of people with learning disabilities (Verdonschot et al., 2009, p.304). The denial of access to meaningful participation in the community is what makes people with Down's syndrome vulnerable, not their chromosomal difference.

In the UK, there are inclusion policies in place that are intended to 'enable people with learning disabilities to lead a "life like any other" person' (Power and Bartlett, 2018, p.562), such as the *Valuing People* white paper (Department of Health, 2001). In a context where social inclusion is high on the government's agenda (as policy and legislation would suggest), social policies in practice can often contradict their objectives. In their study examining the realisation of such policies in the UK, Power and Bartlett (2018, p.562) found that although their respondents (people with learning disabilities who have experienced policy-driven inclusion schemes) reported 'moments of inclusion' in their communities, 'these were situated amidst wider experiences of exclusion and harassment'. It would appear that social narratives of dependency and assumptions that people with Down's syndrome are unable to live independent lives in adulthood are widespread. In contrast, the ineffectiveness of inclusion policies to support the independence of disabled people goes relatively unseen, with one enforcing the other in a positive feedback loop.

### **Sexual vulnerability**

The ways in which people with learning disabilities are presented as sexually vulnerable will also be explored with co-researchers through an analysis of *The*

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<sup>7</sup> *The Specials* housemates lived together in a shared house with 24/7 support funded by their combined welfare provisions. The housemates have been friends since childhood and have chosen to live together. In the UK, it is reported that the majority of people with learning disabilities live in one of three types of accommodation: with family and friends, in care homes, or in supported accommodation (Mencap, 2012). Waiting lists for supported housing are significant and people are often placed in residences out of their area (Mencap, 2012).

*Undateables*. There is a long history of people with learning disabilities being 'denied the right to express their sexuality', and paternalistic, protectionist and patronising attitudes towards the sexual wants and needs of people with Down's syndrome (and learning disabled people generally) have resulted in this population of people being characterised as either asexual, sexually deviant or as victims (Winges-Yanez, 2014, p.107). People with Down's syndrome are often framed as sexually vulnerable in terms of either their susceptibility to sexual abuse or their sexual innocence, resulting in their sexual desires and right to sex and relationships being disregarded. Disabled people, particularly those with cognitive impairments (and especially those with Down's syndrome), are 'often cast into the role of the eternal child' (Dóra, 2004, p.79), and there is, therefore, often an assumption that people with Down's syndrome are asexual. Sexual innocence or disinterest is presumed, and as a result, many adults with Down's syndrome live without access to or exposure to intimate relationships.

There has been some progression in the realisation that people with learning disabilities have a right to romantic and sexual lives, which will be demonstrated in Chapter Three with a discussion of a campaign called *Just The Two of Us*. Attempts are being made to disrupt the idea that people with Down's syndrome either cannot, should not or do not want an active sex life, and the issue of families, caregivers and professionals controlling the sexual desires of people with a learning disability has now made its way into academic and public debate (Hingsburger, 1995; Shakespeare, 2000a; Cuskelly and Bryde, 2004; Swango-Wilson, 2008; Rohleder, 2010; Shuttleworth and Sanders, 2010; Bates, 2020; Shuttleworth and Mona, 2021). That being said, on the whole, academic studies examining the lived experience of disability and sexuality remain 'thin on the ground', as Shakespeare and Richardson (2018, p.82) state. Research on the sexuality of people with Down's syndrome is even more scant. Although learning disabled people have the same sexual desires and sexually mature at the same rate as non-disabled people (Winges-Yanez, 2014), they face sexual discrimination in that they often do not have the same opportunities to explore their sexuality due to a 'lack of access to privacy, lack of accurate information, and lack of acceptance of individuals exhibiting their sexuality' (Winges-Yanez, 2014, p.108).

In an attempt to address the scarcity of research in the field of disability and sexuality, Shakespeare et al. (1996) published *The Sexual Politics of Disability: Untold Desires*, which explored the emotional and sexual experiences of disabled people from a disability rights-based perspective. This edited collection predominantly focused on the narratives of disabled people, countering existing work in this area that was traditionally based on the accounts of medical professionals. While the omission of any input from



people with learning disabilities is evident in this publication, it was the first of its kind and sparked much-needed critical debate in the area of disability and sexuality, paving the way for further exploration into the right to sexual fulfilment for all.

Two decades after this publication, Shakespeare and Richardson (2018) attempted to track the academic progress that had been made concerning disability and sexuality. They reviewed five relevant academic journals (*Scandinavian Journal of Disability Research, Disability and Society, Alter, Sexuality and Disability, and Sexualities*). They found that save for a few exceptions, disability, sex, and sexuality did not play a significant part in any of the journals' content since the release of *The Sexual Politics of Disability* (1996). Shakespeare and Richardson (2018, p.82) interviewed eight of the original participants who were involved in the 1996 research and found that 'respondents generally felt that social attitudes to disabled sexuality had not changed sufficiently, but also that UK austerity policies risked undermining hard-won independence and wellbeing'. Clearly, there is still much room for improvement in challenging the taboo around disability and sexuality and a quarter of a century on from this seminal work, the issues remain just as relevant.

Ruth Garbutt's work with people with learning disabilities contends that the barriers they face in relation to sex and relationships 'contribute to wider conceptual frameworks of social exclusion' (Garbutt, 2010, p.80). Drawing on her work on the Sex and Relationships Project, Garbutt identifies the need for better sex education for people with learning disabilities and argues that the realisation of social inclusion for this marginalised group is contingent on the following:

The empowerment of people with learning difficulties to take action, be political and campaign for better services/attitudes; the disability movement needs to be more inclusive of people with learning difficulties; and people with learning difficulties need to be more visible and valued members of society with positive role models and images. (Garbutt, 2010, p.97)

Garbutt's final point on the visibility of people with learning disabilities and access to positive role models reflects Margaret Shildrick's (2009) work on the dangerous discourses of disability, sexuality and subjectivity. Shildrick (2009, p.66) discusses the general public's uneasiness with disability and sex and posits that while media portrayals of disabled people are increasing ('in the interest of diversity'), they very rarely 'provide positive representations of disabled people in a sexual context'. What is perhaps most troubling about this lack of representation, she argues, is that many disabled people internalise this negativity and become accustomed to a societal context that 'silences, devalues, and distorts their sexuality' (Shildrick, 2009, p.66). The sexual politics of disability are enveloped by dangerous discourses that are subtle yet

powerful and indicate, as Shildrick (2009, p.1) argues, 'the depth of anxiety that engagement with disability elicits'. Shildrick (2009) queries how, in a world where much weightier global concerns exist, disability and human difference can provoke such anxiety. Normative narratives continue to discriminate and alienate disabled people, meaning that, despite the progress being made in the integration of disabled people in the realm of sexual expression, they are still in a precariously vulnerable position (Shildrick, 2009).

The sexual violence experienced by people with learning disabilities is also an issue that has been widely covered in the academy (Franklin and Smeaton, 2017; Helton et al., 2018; Bourke, 2020; Tomsa et al., 2021) and for good reason – people with a learning disability are disproportionately more likely to experience sexual abuse than people who do not have a learning disability (Majeed-Ariss et al., 2020). A recent study conducted by Tomsa et al. (2021) suggests that one in three adults with a learning disability is a victim of sexual abuse in adulthood, and their analysis also revealed that the UK has the highest prevalence of sexual abuse experienced by adults with learning disabilities. These statistics confirm the troubling reality for many people with learning disabilities and go some way to explaining why they are so often framed as vulnerable. They also explain why many parents, caregivers and professionals 'protect' people with learning disabilities from relationships and sexual liberation – within the 'prison of protection', to borrow Hingsberger's terminology (1995, p.27), they are safe from harm but are deprived of sexual experiences and intimate relationships, which are fundamental human rights.

As this literature review has demonstrated, the sexual needs and desires of people with Down's syndrome and how they are understood and upheld are highly controversial social, moral and legal issues (Foley, 2012, p.383). The concept of vulnerability and the subsequent ascription of the label 'vulnerable' have consequences for those assigned the label. Despite often being with sound intentions, attributing vulnerability sometimes does more harm than good. Chapter Six will illustrate how sexual vulnerability transpires in representations of people with Down's syndrome and explore what impact this has on people living with this condition.

### **Existential vulnerability**

Notions of vulnerability and risk are also evident in bioethical debates around Down's syndrome. That some lives (including those with Down's syndrome) are not valued and that certain people are not considered fully human is seemingly presented in the current UK law, which states that any child at 'risk' of being born with 'such physical or mental abnormalities as to be seriously handicapped' (1967 Abortion Act c.1(1)(d)) and

can be aborted up until full gestation. Thankfully, although 'disabled people struggle to be recognised as human in contemporary society', the work being done by disabled people and their allies is 'reclaiming their humanity', offering alternative re-imaginings of what it means to be human and welcoming other ways of being human (Goodley, 2020, p.26). In this spirit, my research seeks to question and disrupt the assumed vulnerability and affirm the humanity of individuals with Down's syndrome, serving as a further reminder that other ways of being human are just as valuable. As Fineman (2019, p.52) suggests, if the concept of vulnerability were to be normalised, it could offer a 'powerful and inclusive conceptual tool' that could help 'define individual, professional, and institutional responsibility in situations of inherent inequality'. Acknowledging and recognising the universality of vulnerability, as well as avoiding the 'othering' of certain groups, underscores the idea that we are all vulnerable to disability and various other forms of social exclusion (Beckett, 2006, p.195). Dependency, like vulnerability, is both universal and contextual in that it can be experienced episodically, individually, and is subject to change (Fineman, 2019, p.57). It is upon this understanding of vulnerability (and dependency) that this thesis is based.

The existential vulnerability of people with Down's syndrome is an issue that many bioethicists, philosophers and sociologists have been grappling with for some time. Indeed, bioethical debates surrounding Down's syndrome have taken up space in political, medical, legal, and cultural dialogues since the end of the twentieth century. These conversations/contentions are complex and multifaceted, and for that reason, this section (*Existential vulnerability*) will be somewhat lengthier than the sections above that discussed in/dependence and relationships. In the coming section, I will outline some of the arguments surrounding screening for disability (and Down's syndrome) and the issue of selective abortion, looking to bioethics in order to critique the cultural power of medicine and screening.

In the broadest sense, the two sides of the bioethical debate involve arguments that either oppose screening for Down's syndrome on the grounds that detection of this medical condition predominantly results in selective abortion and arguments that advocate the use of genetic technologies on the grounds that a person's reproductive freedom relies on access to prenatal screening (PNS) and the option to terminate the pregnancy on the basis of disability. This is a somewhat crude overview, however, and bioethical debates surrounding Down's syndrome (and disability more generally) are convoluted, with no straightforward 'solution'. Tensions between the feminist pro-choice perspective and the disability-rights-based perspective become even more challenging to navigate when one agrees with both standpoints, a position I find myself in. As Burke

(2021, p.194) states, this area of inquiry is difficult to navigate, and it is important that I acknowledge the ‘profoundly “messy”, complicated and contextual nature’ of researching PNS and SA for Down’s syndrome, especially in ‘an ableist, economically unequal culture dominated by neo-utilitarian premises about human value’.

Deliberations around the ethics of screening for Down's syndrome (and other genetic conditions) began around 1968 when the first prenatal diagnosis of Down's syndrome was made, and subsequent ‘therapeutic abortion’ was carried out (Valenti et al., 1968, p.220; Boyd et al., 2012). Since that time, the recognised branch of PNS has advanced at an exponential rate, in the UK at least, and screening for Down's syndrome has become a routinised aspect of pregnancy (Suter, 2002; Boyd et al., 2012). As medical and genetic technologies have evolved, prenatal detection rates for a variety of medical conditions have improved, and uptake rates for PNS have increased (Boyd et al., 2012; Thomas, 2017). In England, as of June 2021, non-invasive prenatal testing (NIPT) was added to the existing National Health Service (NHS) screening programme (UK National Screening Committee, 2023), meaning that all pregnant people, regardless of their age, will be offered safer and less invasive screening to test for Down's syndrome, Edward's syndrome and Patau's syndrome. In Chapter Seven, our co-analysis of *A World Without Down's Syndrome?* explores NIPT in more detail, as the documentary film explores the use of NIPT in the UK and its potential consequences.

The introduction of PNS has triggered a number of public and private debates around the social value being placed upon disabled people, including those with Down's syndrome (Kuhse and Singer, 1985; Wolfensberger, 1994; Asch, 1999; Parens and Asch, 1999; Johnson, 2003; Garland-Thomson, 2012; 2015a; 2015b; Sparrow, 2015; Thomas, 2015; Thomas and Rothman, 2016; Rubeis and Steger, 2019). It is beyond the scope of this chapter to outline all of the bioethical debates in this area; however, the ensuing sections will explore some of the key debates in more depth.

### ***Determining social worth***

The social value of disabled lives is brought into question before birth – this is accomplished through genetic screening and diagnostics. Many members of the bioethics community have recognised the dangers of using prenatal technologies followed by selective abortion based on foetal sex characteristics, yet there appear to be fewer reservations regarding selective abortion based on characteristics regarding chromosomal or genetic conditions (Asch, 1999).

Pregnant people are routinely offered screening tests throughout their pregnancy in order to detect any health conditions that may affect their baby. Suppose a baby is identified as having a high chance of being born with Down's syndrome, for instance. In

that case, parents are offered an appointment with a medical professional where they will be informed of their options. Ultimately, parents have the choice to continue with the pregnancy or terminate the pregnancy, and they can legally opt for the latter up until the full gestation period (1967 Abortion Act). Ruth Hubbard (2013), in her work on abortion and disability, examines this notion of 'choice' and argues that parents faced with a decision about whether or not to continue a wanted pregnancy are placed in an impossible situation for a number of reasons. Hubbard (2013, p.82) argues that the current selective abortion regime shares the same underlying moralities as Nazi eugenicists in that they have 'similar principles of selection and eradication'. The Nazi euthanasia programme was the product of the then-highly respected eugenics movement that developed in the early twentieth century. During this era, scientists and eugenicists 'sought to clean the gene pool' (Suter, 2002, p.234) and were responsible for deciding whose lives should be valued and whose were not worth living.

In the present day, the ultimate decision of whether a disabled foetus is born or terminated lies with its parents; however, it remains the responsibility of scientists and geneticists to develop the tools and technology that detect chromosomal or genetic differences. The burden of the eventual decision, however, is passed on to the pregnant person (Hubbard, 2013). As Hubbard (2013, p.82) suggests, there is no 'force' involved; a pregnant person must 'merely "choose" whether to terminate a wanted pregnancy'. Alternatively, pregnant persons also have the option to refuse PNS, meaning they must accept 'responsibility for whatever the disability will mean to that child and to her and the rest of her family' (Hubbard, 2013, p.82). Exactly what kind of 'choice' this is, Hubbard argues, is problematic, to say the least, and will be explored in greater detail in my discussion of PNS and SA in Chapter Seven.

Prospective parents are placed under tremendous pressure during this decision-making process; pregnant persons have an obligation to consider their options in terms of their own wants or needs, their partner's, other family members and, in many ways, their societal responsibilities attached to this decision. Many bioethicists have argued that to bring a child with Down's syndrome into the world (or any other genetic condition that deviates from the so-called 'norm') is irresponsible and denies the child the right to an open future (Davis, 1997; Wilkinson, 2010). According to this view, to knowingly continue with the pregnancy of an 'abnormal' foetus is considered reckless and negligent (Davis, 1997; Wilkinson, 2010). The implications of bringing a child with Down's syndrome into your family, as stated in the arguments of the bioethical debate, are often viewed as the responsibility of the pregnant person. Indeed, much of the research in this area alludes to maternal responsibilities rather than joint or paternal

obligations (Reed, 2009). Narratives around the responsibility for the health of the foetus predominantly focus on the pregnant person (Reiter, 1999) and any paternal responsibility is often thought to end with conception (Reed, 2009).<sup>8</sup> The sacrifices families face by raising a child with Down's syndrome, this argument outlines, is an assumption that 'justifies abortion' and is often central to bioethical debates advocating PNS and selective abortion (Asch, 1999, p.1653).

Moreover, the decisions prospective parents have to make in these circumstances are entangled not only with questionable assumptions around what life with Down's syndrome might entail but also with the unknown 'severity' of the condition.<sup>9</sup> While PNS cannot provide results with 100% accuracy, diagnostic tests such as amniocentesis or chorionic villus sampling will tell parents for certain whether or not their baby has Down's syndrome (NHS, 2018). There is, however, currently no way of detecting before birth whether a baby with Down's syndrome will be born with 'mild' or 'severe' cognitive delays or any associated medical conditions (National Down Syndrome Society, 2021, no pagination). So, while pregnant people can, if they consent to PNS, discover whether or not their baby will likely be born with Down's syndrome, they will not know how this medical condition will develop. From a critical disability rights standpoint, an interrogation of 'our excessive preoccupation' with genetic conditions is required (Hubbard, 2013, p.84). A perspective is required that focuses less on advancing genetic technologies that detect 'disabling trait[s]' and [places] more emphasis on disrupting the assumption that disability is 'incompatible with life satisfaction' (Asch, 1999, p.1650).

### ***'Eugenic logic'***

As previously cited, Hubbard (2013) argued that PNS and selective abortion can be considered a form of eugenics, an argument shared by several other disability rights advocates and writers. In line with Asch's (1999; 2000) work within bioethical debates surrounding genetic technologies and Mitchell and Snyder's (2003) commentary on the disqualification of disability and disabled people, Rosemarie Garland-Thomson (2012, p.339) introduces her notion of 'eugenic logic'. Eugenic logic, she affirms, is a logic that tells us the world would be a better place if disabled people did not exist within it, and this logic, she states, is based on historical ideologies regarding the meaning of disability and has a very clear objective: 'to eliminate disability and, by extension,

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<sup>8</sup> A small number of studies have been conducted that evaluate the decision-making obligations of fathers, such as How *et al.* (2019); Sheldon *et al.* (2021) and Skotko *et al.* (2011).

<sup>9</sup> The language often used within medical and educational literature to distinguish the degree of learning disability within people with Down's syndrome often contain the terms 'mild', 'moderate' and 'severe'.

disabled people from the world' (Garland-Thomson, 2012, p.340). Garland-Thomson (2012) stresses that her views on abortion are very much located in the pro-choice camp. Other renowned writers within this field of inquiry, such as Hubbard (2013) and Asch (1999), also situate themselves as pro-choice and emphasise their support for reproductive freedom. As stated earlier, my own thinking is aligned with these scholars and firmly supports a person's right to choose whether or not to continue a pregnancy. I would argue, like Garland-Thomson (2012), Asch (1999) and Hubbard (2013), however, that screening for 'defects' is perilous territory.

The historical ideologies discussed by Garland-Thomson (2012) embrace the notion that disability is an ordeal to be avoided. As we have seen throughout this literature review, dominant understandings of disability often involve assumptions about pain and suffering, poverty, dependence, stigma, and abnormality. Indeed, dominant ideologies of Down's syndrome involve many of these signifiers. People with the condition are often understood to be a familial and financial burden, unlikely to gain meaningful employment, uneducable, and childlike (Down's Syndrome Scotland, 2021). The eugenic logic thought to underpin narratives surrounding genetic screening and selective abortion is often based on such assumptions.

Clearly, the bioethical debates around screening for Down's syndrome are complex and multifaceted, with no obvious 'solution'. As this brief review of the literature has shown us, people with Down's syndrome are socially constructed as vulnerable in various ways. Relevant to this thesis, however, are the ways in which people with Down's syndrome are rendered 'vulnerable' before they are born, throughout adulthood and within their romantic relationships. It is therefore appropriate to further consider and problematise the dangerous discourses of vulnerability at play in these contexts, which our co-analysis of *The Specials*, *The Undateables* and *A World Without Down's Syndrome?* will achieve.

## **Conclusion**

As this extensive review of the literature has demonstrated, representations of disability have a historical relationship with ableism and normalcy. Society itself is structured upon ableist, normative neoliberal assumptions of human value, where able-bodiedness is privileged. As attitudes towards disability slowly improve, and inclusion and diversity are firmly located on the social agenda, it is time we reconsider what kinds of spaces are being opened up to people with Down's syndrome and disabled people more generally.

If, as Mitchell and Snyder (2015) argue, neoliberal practices refuse to or avoid embracing disability and instead only tolerate certain kinds of disabled people, an increasing number of disabled children and adults will be forced to suppress their identities and experiences as disabled people so that they can pass as non-disabled. Inclusionism quietly expects disabled people to conform to ideological norms while loudly proclaiming its inclusivity. As we have seen in this chapter, to superficially include disabled people, or to do so for only tokenistic reasons, be those social, environmental or cultural, is to further reinforce ableist and normative expectations and subsequently marginalise disabled people further.

How this issue plays out in disability representations is important. Examining how and to what extent different cultural texts reflect or reinforce normative and ableist ideologies is key to cultural disability studies. There appear to be deep-seated anxieties embedded in discussions around Down's syndrome and in/dependence, sexual relationships and personhood, which begin to permeate discourses regarding PNS and SA. This literature review has explored the basis of these anxieties, and the remainder of my thesis will demonstrate how they materialise in documentary representations of Down's syndrome.

Within the social sciences, and to some extent even within the broader field of disability studies, there has been some scepticism as to the usefulness of critiquing disability representations, especially from those working solely within the realm of disability rights (Shildrick, 2020). Like Shildrick (2020, p.32-33), I would argue that the critical work being done in cultural disability studies 'offers a new productive way of thinking' about disability that challenges us to question and 'rethink everything'. In line with Butler's (2004) theorisations of critique, Shildrick (2020, p.33) asserts that 'the work of critique is to keep alive the very process in which questioning itself generates new potential'. In critiquing documentary representations of Down's syndrome, I am not just revealing ableist and normative assumptions of life with Down's syndrome. I am questioning why representations fortify these assumptions and am generating alternative ways in which the stories of people with Down's syndrome can be told. At a time when disability (and Down's syndrome) is more visible than ever before, we cannot stop there (Wong, 2020). Visibility is not enough – more depth, nuance and embodiment in cultural representations of disability are needed. In the next chapter, I will supplement this literature review by specifically discussing how Down's syndrome is represented in contemporary culture and exploring the dynamic between disability and the documentary form.



## ~ Chapter Three ~

# Literature Review of Down's syndrome in contemporary culture

### Introduction

Having explored the theoretical concepts underpinning this thesis in the previous chapter, I will now provide an overview of some of the contemporary cultural representations of Down's syndrome and explain why I have focused on the documentary genre. Representations of Down's syndrome have reportedly existed in cultural texts since as early as 1460AD (Stratford and Gunn, 1996, p.106)<sup>10</sup>, but in today's culture, where diversity and equality are firmly on the social agenda, cultural depictions are much more ubiquitous. There has been a shift in how Down's syndrome is represented in recent years, particularly in film, television and social media.

As we saw in Chapter One, representations of Down's syndrome are more prominent in today's television. Take, for example, George Webster – the first ever children's television presenter with Down's syndrome in the UK (*CBeebies*), who then went on to be the first celebrity contestant with Down's syndrome on *Strictly Come Dancing* in their Christmas Special in 2022 (Wollaston, 2023). The framing of contemporary representations of people with Down's syndrome will be further explored in this chapter and throughout the analytical chapters that follow. Consideration will be given to whether people with Down's syndrome are treated and represented paternalistically, in line with the diversity agendas that Davis (2013) and Mitchell and Snyder (2015) critique. Undeniably, figures like George Webster and the individuals detailed in Chapter One are now celebrities, thus giving people with Down syndrome more exposure in some arenas than before, representing in itself a significant shift in Down's syndrome representation.

As the previous chapter has demonstrated, there is a significant, ever-expanding and necessary body of academic literature on disability representation. Yet, existing narratives focusing specifically on cultural representations of Down's syndrome are, to date, somewhat limited. Several scholars and authors have attempted to address this

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<sup>10</sup> Stratford and Gunn (1996) have previously made the case that the child in the painting titled *Madonna and Child* by Andrea Mantegna has suggestive facial features of Down's syndrome. Stratford (1989) also suggests the possibility of people with Down's syndrome being present amongst The Olmecs between 1500 BC and AD 300, evidenced in several sculptures and figurines.

scarcity. I will discuss some of their work in the first section of this literature review. The first half of this chapter focuses on Down's syndrome in contemporary culture, exploring various representations of Down's syndrome in novels, medical literature and social media while utilising the conceptual toolkit available through normalcy and ableism theory. I will then examine the documentary form and discuss the politicised nature of this genre, looking specifically at how disability and Down's syndrome are often represented in documentaries.

## **Down's Syndrome**

### **Hostile environments**

Lucy Burke (2021, p.193) recently published a paper which grapples with the 'complex entanglement' of advanced reproductive and genetic technologies, the economics of health, rights-based discourses, and ethical debates surrounding the value of human life. Burke's analysis focuses on representations of Down's syndrome within bioethical discourse, feminist texts on reproductive autonomy and disability studies, and a work of popular crime fiction. Her readings of these cultural texts expose and challenge ableist and neoliberal conceptions of human value (concepts previously explored in Chapter Two). Burke (2021, p.194) identifies two powerful 'genetic fictions'<sup>11</sup> in narratives about genetic screening and reproductive choice: 'the imagined but not yet/perhaps never to be born infant with Down's syndrome and the imagined but not yet/perhaps never to be materialised figure of the "mother" who suffers'. Within dominant discourses surrounding genetic testing, these genetic fictions assume that being born with Down's syndrome and being the parent of a child with the condition are inherently negative. The processes, ideologies, and 'pressures' that construct these genetic fictions create what Burke (2021, p.197) describes as a 'hostile environment'.

The genetic fictions described by Burke (2021) echo the 'grim imagined futures' Alison Kafer discusses in her introduction to *Feminist, Queer, Crip* (2013, p.2). In this publication, Kafer talks about disability in general terms, partly from personal experience (although she does not have Down syndrome, she has physical impairments). Kafer (2013, p.2) describes how she is often confronted with assumptions and predictions (from disabled and non-disabled strangers) concerning her impairments, suggesting her 'future cannot be anything but bleak'. As Kafer (2013, p.2) argues, any understanding of disability as a 'terrible unending tragedy' inevitably

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<sup>11</sup> Bolt (2014b; 2021) would refer to this as genetic 'metanarratives' – both terms (metanarratives and genetic fictions) refer to imagined stories/narratives (in this case of genetics) being told *about* (not by) disabled people that are based on myths, stereotypes and tropes.

presumes that an imagined future involving disability is one to avoid. The 'imagined but not yet/perhaps never to be born infant with Down's syndrome' that Burke (2021, p.194) describes reverberates with Kafer's (2013, p.2) 'undesired' futures. Directly citing geneticist James Watson, Kafer (2013, p.3) confirms that imagined futures specifically involving Down's syndrome are consistent with tragedy:

We already accept that most couples don't want a Down child. You would have to be crazy to say you wanted one, because that child has no future.

Within this hostile environment, the lived experiences of Down's syndrome and learning disabilities 'fail to capture the diverse realities of people's lives and compel disabled people and their families to justify their very existence' (Burke, 2021, p.197). Burke (2021, p.197) aptly points out that pressure to provide a counternarrative and justify one's very existence is an experience very few (if any) non-disabled people have to consider. Disabled people and their families are often caught in this complex entanglement of resisting continued oppression that negatively impacts their opportunities in life while simultaneously demonstrating their value and quality of life.

Discourses within reproductive ethics and public policy also present a particular genetic fiction (or imagined future), focusing on the economic benefits of genetic testing and screening. Within the field of health economics, the financial, economic and societal impact of disability is 'measured', with disabled people being understood in the abstract with what Burke (2021, p.194) states as 'no sustained ethical consideration of the value of human life'. This is evidenced by Watson's earlier comments on conceiving a child with Down's syndrome (Watson in Kafer, 2013, p.3). This genetic fiction represents children with Down's syndrome (and other genetic conditions) as 'the locus of parental suffering and strain, [a] financial and societal burden ... [a] resource consuming, energy sapping figure' (Burke, 2021, p.194). While PNS for genetic conditions is masked as a routine aspect of pregnancy that works in the interest of everyone, Burke (2021, pp.194-5) illuminates the reality that prenatal screening (PNS) is driven by economic and biopolitical logic and directly contributes to negative perceptions of Down's syndrome. In a similar vein, Kaposy (2018) also argues that reproductive selectivity is influenced by capitalism. He suggests that the 'demands and imperatives of the economic system in which we live influence many to believe that raising a child with Down syndrome is undesirable' (Kaposy, 2018, p.149). Kaposy's (and Burke's) analyses reveal the internalised capitalist, neoliberal values that oppress bodies or minds that struggle to keep pace with or contribute to market-driven, profit-making enterprises.

## **Hostile Hospitable environments?**

It is crucial not to underestimate the capacity within literary and cultural representations to re-write distorted portrayals of disability-related issues and disabled people. As Burke (2021, p.197) suggests, literary fictions have the potential to offer 'a more capacious and generous space in which eccentric or marginal voices can break through dominant and often exclusionary frameworks of the hostile environment faced by disabled people today'. Burke's (2021) reading of the crime fiction novel *Someone To Watch Over Me* by Yrsa Sigurdardóttir (2013) demonstrates this potential and offers an alternative reading of human worth (which Burke refers to as a renewed genetic fiction) than that commonly found in dominant disability discourses. In this new genetic fiction, the characters with Down's syndrome 'dismantle' the ableist premise which opens the novel because they are structured so that 'epistemic privilege' is elevated to 'trouble normative and ableist conceptions of value, and about what and who matters' (Burke, 2021, p.199).

A prominent feature in writings about characters with an impairment is that their impairment or condition is often the foundation of the character itself (Mitchell and Snyder, 2000). *Someone To Watch Over Me*, on the other hand, presents its two main characters (one who has Down's syndrome and one with autism) as central to the plot and, more specifically, fundamental to the 'revelation' of truth and justice within the novel (Burke, 2021, p.198). The novel tells the story of an Icelandic attorney assigned a case looking into the deaths of five people living in an assisted-living facility for people with learning disabilities following a fire. The characters with learning disabilities are assumed to be 'disposable and unworthy of equal recognition'; however, the text challenges this assumption and highlights the unequal legal and political system that fails to recognise their existence (Burke, 2021, p.198). Burke's (2021) analysis shows how dominant methods of presenting Down's syndrome and cognitive differences in cultural and literary texts are often bound with ableist assumptions about what lives are worth living, with neoliberal ambitions to produce 'valuable' citizens and dispose of those deemed unworthy. As *Someone To Watch Over Me* (2013) demonstrates, disrupting these dominant discourses is both paramount and plausible.

## **'The Down's syndrome novel'**

Like Burke, Sarah Kanake (2019, p.62) has written about representations of Down's syndrome in contemporary narrative fiction and has identified several recurrent themes and tropes in what she calls 'the Down Syndrome novel'. According to Kanake (2019), many mainstream contemporary fictional narratives that represent Down's syndrome do so through the experiences of the mother and the supposed trauma of having a

child with Down's syndrome. The narrative presence of characters with Down's syndrome is limited as they 'are viewed exclusively through the mother's point of view' (Kanake, 2019, p.62). The Down's syndrome novels that Kanake (2019, p.67) analyses circumnavigate three themes: acceptance, tolerance and inclusion. Moreover, the narratives within the 'typical realist' Down's syndrome novel predominantly follow a similar design:

The character with Down syndrome is born, the character is diagnosed, the narrator or protagonist begins the struggle of living with and understanding the character with Down syndrome, and the end of the novel arrives only when the narrator or protagonist has achieved that understanding. (Kanake, 2019, p.67)

Kanake is alluding to the tendency within disability fiction for stories to include characters with an impairment in order to tell the story of the non-disabled character and propel the narrative. For Kanake (2019), a character with Down's syndrome exists predominantly to support the plotline or the non-disabled character's development. Murray (2006) also found this to be the case in his work about narratives of autism. His analysis revealed how autism is often used as a narrative device and that the very presence of the neurological condition is what enables the narrative to develop (Murray, 2006). In the novels and films analysed by Murray (2006, p.41), autistic agency was absent, replaced instead with the typical portrayal of the autistic character immersed in 'sentiment, melodrama, and wonder'. Both Murray's (2006) and Kanake's (2019) readings correspond with Mitchell and Snyder's (2000) notion of *narrative prosthesis* (the idea of disability being used as a characterisation device) and demonstrate the pervasiveness of this trope in stories about disability.

How the Down's syndrome novel plot arrives at the 'inevitable' conclusion is important, Kanake (2019, p.67) states, as the majority end with either the death of the character with Down's syndrome, their being placed in a 'care situation', or their reunion with a non-disabled counterpart. Kanake (2019, p.67) suggests that many Down's syndrome novels end with the death of the character with Down's syndrome in order to protect the worldview of its readers from being threatened and, in keeping the character with Down's syndrome to the confines of the page, 'the reader does not have to deal with them'. This analysis is consistent with the arguments about endings in literary disability studies more broadly. For example, in *Narrative Prosthesis*, Mitchell and Snyder (2000) identify disability narratives that transcend into either 'cures' or 'death'. These 'cure-or-kill story endings' often relate to eugenic logic and present disabled people as 'a soon-to-be-eradicated group whose promised erasure will better society' (Snyder, 2002, p.181), in line with Garland-Thomson's (2012) description of eugenic logic as discussed in Chapter Two.

Like Burke's (2021) analysis of contemporary cultural texts, Kanake's (2019) reading of the Down's syndrome novel draws attention to how Down's syndrome is presented as a trauma or a problem in need of fixing. In Kanake's (2019, p.70) analyses of Down's syndrome novels, this trauma is predominantly experienced by the mother of a child with Down's syndrome, and representations of the condition are employed as a 'narrative device used to reach some extremity in the depiction of motherhood and women'. Plotlines often see a mother struggling to include the child with Down's syndrome, both within the family itself and in society more widely. In this sense, mothers are portrayed as heroines or martyrs until the child reaches adulthood and is ready to live independently – reflecting societal expectations of motherhood and disability (Kanake, 2019). Kanake's 'typical' Down's syndrome novel also neglects to involve any narratives that depict a pregnant person's struggle in coming to terms with the termination of a child with Down's syndrome. Kanake (2019, p.70) suggests this could be 'in part because these narratives take a very traditional view of motherhood under the guise of creating an acceptance narrative about disability'.

### **Disrupting 'the Down's syndrome novel'**

Like Kanake, Davies (2019) questions the construction of Down's syndrome characters in contemporary novels and suggests that the ways in which certain stereotypes of Down's syndrome established by Victorian medical discourses (namely the descriptive work of John Langdon Down), often go unchallenged in contemporary fiction. Kanake's analysis of the Down's syndrome novel suggests that literary representations of Down's syndrome are often formulaic in structure and plot and fail to give any agency or depth to the characters with Down's syndrome. Kanake's (2019) argument is limited to just one genre – social realist fiction – and therefore not representative of all Down's syndrome literatures. In an attempt to unravel the 'typical' Down's syndrome novel, Kanake wrote her own disability narrative in a novel called *Sing Fox To Me* (2016). Kanake's (2019, p.71) novel rejects the low expectations routinely set for people with Down's syndrome and creates a character who thrives, 'forging a new path through an old narrative'. Unfortunately, not all critics of the novel credited Kanake's alternative Down's syndrome narrative, with one reviewer unable to accept the character with Down's syndrome, stating they thought 'he was attributed a self-awareness far beyond the ability of someone with Down syndrome' (Kanake, 2019, p.71). This review and its blanket assumptions regarding the 'abilities' of people with Down's syndrome show how deeply entrenched ableist conceptions of the condition are and just how vital it is to produce more literary and cultural texts that challenge normative depictions and present the diverse realities of lives with Down's syndrome.

Davies' reading of Kanake's *Sing Fox To Me* (2016) interprets the narrative perspective of the main character with Down's syndrome as 'self-conscious and sensitive', which in itself distances it from typical portrayals of individuals with learning disabilities (Davies, 2021, p.118). Davies' (2021) analysis focuses on the proximity to animality that can often be reiterated in literary representations of Down's syndrome. Davies (2021) draws attention to how people with Down's syndrome are often compared to animals. For example, Davies (2021) describes a recent example whereby the Canadian Down Syndrome Association launched a campaign for the equal rights of people with Down's syndrome called 'Endangered Syndrome'. In this campaign, actors with Down's syndrome are dressed as different endangered animal species in a short video, reciting the line, 'Like some animals...people with Down Syndrome are endangered' (Davies, 2021, p.106). Cultural associations between people with Down's syndrome and animals have propounded the idea that people with Down's syndrome are somehow less than human to be established in cultural discourse. As discussed in Chapter One, subhuman narratives around people with Down's syndrome are unsurprising, given that 'nineteenth-century medical discourse around "idiocy" repeatedly made comparisons between intellectual disability and animality, mired in colonial, racist, and ableist stereotypes', ideologies that continued into the succeeding century and, arguably, into the present day (Davies, 2021, p.107). Contextualising Kanake's *Sing Fox To Me* (2016) through critical animal and disability studies, Davies (2021, p.107) argues that this novel (while applying the theme of animality) does so in a way that ensures 'more productive points of connection and affiliation between human and non-human animals' are being presented.<sup>12</sup> The main character 'claims animal' and, as a result:

The additional chromosome of Down syndrome is no longer a persecuted, misunderstood pest, but a powerful spirit-animal that predates colonial exploitation of indigenous human and non-human animals, and troubles the boundaries of colonizer/colonized, disabled/non-disabled, and human/animal. (Davies, 2021, p.119)

Davies also explores cultural representations of Down's syndrome in her reading of Doris Lessing's *The Fifth Child* (1988). Davies (2021, p.107, original emphasis) argues that the character with Down's syndrome is depicted in this novel as 'having a *proximity* to animality'. Lessing does not overtly denote animality – she is not directly proposing that people with Down's syndrome are animal-like; however, the author does

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<sup>12</sup> Jane Gull's film, *My Feral Heart* (2016) applies a similar theme of animality. The male protagonist in *My Feral Heart*, Luke, has Down's syndrome and, after the passing of his elderly mother, is forced to move into a residential care home. Running parallel to Luke's new life in the care home (where he struggles with being contained having previously led such an independent life) is a plot where he cares for an injured fox - or feral girl – the viewer is left to decide the status of this character.

characterise Amy (the character with Down's syndrome) as mid-way in the 'hierarchical chain of human and non-human animals' (Davies, 2021, p.107).

Davies' reading of *The Fifth Child* was published as part of a collection on metanarratives of disability edited by David Bolt (2021). Bolt (2021, p.xvii) uses the phrase *metanarrative of disability* to refer to the 'grand expansion into the realms of myths, tropes, stereotypes, and other aspects of cultural imagination' in relation to disabled people. Metanarratives of disability (which are primarily constructed and defined by non-disabled people) replace the personal narratives of disabled people and are present in countless cultural texts, including soap operas, novels, films or social media, amongst others (Bolt, 2021, pp.xvi-xvii). Reminiscent of Carlson's (2010) critique discussed in Chapter Two, Davies' reading exposes the ableist and even 'speciesist' ideologies embedded in cultural representations of Down's syndrome – the ramifications of which render people with cognitive differences (*and* non-human animals) as 'deviant and inferior' (Davies, 2021, p.109). As discussed in Chapter One, the historical association between animals and people with learning disabilities is steeped in medico-scientific discourses. Davies argues that Amy's otherness and proximity to animality are evident in the following excerpt from the novel:

[Harriet] watched how the big dog seemed to know that Amy, the loving child in the big ugly body, needed gentleness: he moderated his exuberance for her [...] Sarah said this dog was like a nursemaid to Amy. (Lessing, 1988, 71)

The above excerpt, Davies suggests, is a classic example of characters with Down's syndrome (or any cognitive difference) being cast in the same light as non-human animals:

Amy's otherness – the 'ugliness' of her body – is reiterated; the dog is cast as having an almost superior emotional intelligence to the child with Down's syndrome. This said, it is difficult not to note the resonance between mongrel/mongol, and both are defined by their happiness. (Davies, 2021, p.114)

Persistent metanarratives of Down's syndrome that place people with the condition in close proximity to animals tend to focus on physical and cognitive differences – leaving little room for alternative imaginations of characters with Down's syndrome (Davies, 2021).

The readings of Down's syndrome presented here are crucial to this thesis for two reasons. Firstly, they all underscore and deconstruct the pitfalls of mainstream literary and cultural narratives of Down's syndrome, exposing their rootedness in ableist perceptions. Secondly, they reveal the potential and promise for other genres (such as documentary film) of representing the diverse realities of people with Down's syndrome, learning disabilities and disabled people in general. Within fictional genres,



it is often the case that the cultural texts produced are from the perspective of non-disabled people who are imagining the inferiority of someone with Down's syndrome. In contrast, documentaries allow more agency for people with Down's syndrome to express their thoughts and speak for themselves.<sup>13</sup> It is in this same spirit that this project is formulated – to offer a critique of the normative, ableist discourses around Down's syndrome in the documentary genre but, more importantly, to offer an alternative story, one that is created and authenticated by the co-researchers with Down's syndrome.

### **Parental memoirs**

As the above section shows, there has been some academic engagement with representations of Down's syndrome in contemporary fiction; however, one genre that has gone relatively uninterrogated is that of the parental memoir. A simple internet search for 'books about Down's syndrome' will generate over one million results, and the overwhelming majority of these search results are linked to books written about children and adults with Down's syndrome by parents, educators, medical professionals and charities. For many prospective parents of a child with Down's syndrome, reading the stories of other parents with similar experiences will not only be informative but reassuring. In recent years, there has been a shift in the publication of autobiographical accounts of Down's syndrome written by people with Down's syndrome themselves. For instance, Heidi and James Crowter and Tommy Jessop, mentioned earlier in Chapter One, have recently published their memoirs (Crowter and Crowter, 2022; Jessop, 2023). Parental memoirs, however, dominate the life writing genre for non-fiction literature about Down's syndrome. Amanda Apgar (2023, p.1) has dedicated an entire book to examining what she calls the 'special needs' parental memoir. In *The Disabled Child: Memoirs of a Normal Future*, she describes 'special needs' parental memoirs as 'a subgenre of disability life writing with distinct conventions'. Apgar (2023, p.1) argues that, save for a small number of exceptions:

parental memoirs reiterate a dominant cultural narrative of disability as inherent in the individual and as compromising quality of life via the foreclosure of opportunities, especially in terms of future labor, sexuality, and reproduction.

Apgar (2023, p.2) does not single out a specific impairment or condition but writes about parental stories that construct a specific image of children with 'special needs' –

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<sup>13</sup> This is not to say that fiction cannot represent Down's syndrome progressively or that documentary is inherently more progressive as a genre, but that at the current moment when metanarratives about Down's syndrome are still prevalent, documentary is one space where voices of people with Down's syndrome can be heard.

'The Figure of the Disabled Child... the child who overcomes ableist exclusions of childhood, adulthood, and "normal" life'. The memoirs she analyses are diverse in terms of the range of children's impairments but are notably similar in that they are generally produced by white, heterosexual, middle/upper-class, non-disabled parents and predominantly reflect narratives imbued in normalcy (Apgar, 2023). The stories being told in parental memoirs range from 'tragedy to overcoming, from grief to acceptance' and, although the writers are undoubtedly showing their love for their children and depicting them as both wanted and as exceptional for 'overcoming' barriers, they simultaneously reinforce the 'myth of autonomy' by avoiding dependency (Apgar, 2023, p.173). Apgar (2023, p.6) identifies four predominant narratives within her analysis:

the narrative of overcoming; the entanglement of heterosexuality and able-bodied development; the "threat" of dependency; and, perhaps most saliently, the neoliberalization of inclusion.

The themes Apgar (2023) established correlate with the social concerns I address in this thesis. In line with many of the arguments outlined in the previous chapter, Apgar (2023) has demonstrated how parental memoirs are saturated with normative, ableist, neoliberal notions around what constitutes human value. She argues that constructing their stories in such a way portrays their children as productive, 'worthy' members of society (Apgar, 2023). In so doing, parental memoirs reinforce the ableism they are actively trying to reject in their writing (Apgar, 2023). Apgar's critique of the parental memoir genre proposes the possibility of writing a different story. She suggests that it should be disabled people themselves writing these stories rather than non-disabled parents, but concedes the unlikeliness of this: 'they are compelled to account for their child's life; because a baby like theirs demands a story' (Apgar, 2023, p.173-4). For this reason, it is imperative, Apgar (2023) states, that parental memoirs are given serious academic consideration as a cultural text that produces meaning not only about disability but also about race, economy and gender.

### **Down's syndrome and social media**

The prominence of parental memoirs in contemporary literature is not the only recognisable shift in recent discourses on Down's syndrome. Social media representations of Down's syndrome have also become more prominent in recent years. The extent to which parents are involved in shaping the social media profiles of their children is unknown. Nonetheless, the presence of activists, advocates and 'internet celebrities' with Down's syndrome across social media platforms marks a

significant shift in not only contemporary digital media practices but also in disability representation.<sup>14</sup>

Social media has become an integral part of our everyday lives, especially in an age of smartphones and social media apps (Ellis and Kent, 2017). Social media platforms, such as Twitter, Facebook and Instagram, have the potential to increase social and employment opportunities for disabled people. That said, they also have the potential to 'replicate the inaccessibility and discriminatory attitudes people with disabilities regularly experience *offline*' - in other words, 'social media has the potential to both enable and further disable' the disabled population (Ellis and Kent, 2017, p.1, emphasis added). While they are an essential site of inquiry, I will not focus on accessibility barriers in social media in this chapter. While acknowledging that there is much room for improvement in the accessibility features of many social media networks and apps, the remainder of this section will pay attention to the broader social implications of social media, specifically in relation to disability representation.

In an age of 'new media', disabled people are contributing to and creating media content that allows them to 'tell new stories and old stories in a new way' (Ellis, 2016a, p.154). In doing so, they are defying the typical renderings of disabled people as pitiable and unfortunate and challenging the 'disability as inspirational' paradigm (Ellis, 2016a, p.150). Scholars have commented on the ambiguity of traditional social media representations of disability, arguing that where disability was once 'a devalued form of identity and embodiment', this is now being challenged by a wave of activists and entrepreneurs from within the disability community (Ellis and Goggin, 2015, p.37; Trevisan, 2017; Christensen-Strynø and Eriksen, 2020).

In their exploration of the 'affective economies' of social media, Christensen-Strynø and Eriksen (2020, p.35) use Madeline Stuart, an Australian fashion model with Down's syndrome, as a case study. Stuart became a 'social media phenomenon' in 2015 after her mother started a public Facebook account on her behalf (Christensen-Strynø and Eriksen, 2020, p.35). Her profile pictures gained significant online attention, and Stuart has since gone on to become an international fashion model and advocate for disability visibility and inclusion. Stuart's online fame, or what some would dub *Instafame* (Marwick, 2015), has led to an 'increased professionalization and celebrification of Stuart's self- presentation in which she has taken on a number of versatile and

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<sup>14</sup> Examples of UK-based people with Down's syndrome who are using social media for brand promotion or advocacy include Heidi Crowter (an activist with 9k Twitter followers), Tommy Jessop (an actor and advocate with 28.2k Twitter followers) and Kathleen Humberstone and Kate Grant (both successful fashion models with 12.9k and 46k Instagram followers respectively).

distinctive roles and identities as *supermodel, advocate, dancer, role model, actor* and *philanthropist*' (Christensen-Strynø and Eriksen, 2020, p.36, original emphasis). Through their analysis of Stuart's weight loss journey, as documented in her Instagram posts, Christensen-Strynø and Eriksen (2020, p.46) highlighted how, in this particular case study, Down's syndrome and disability identity had been turned into a 'valuable personal brand'. The value that Christensen-Strynø and Eriksen (2020) talk about is both monetary and in the form of social and emotional (affective) capital. Through her weight-loss and advocacy Instagram posts, Stuart has created a 'highly distinct and capitalizable brand of Down syndrome and disability', from which she can gain financially through advertisements, sponsorships and travel (Christensen-Strynø and Eriksen, 2020, p.46). Stuart's case study demonstrates 'the emergence of new forms of disability representations, in which minority identity and status may become valuable assets in the creation of effective branding strategies' (Christensen-Strynø and Eriksen, 2020, p.46). While they acknowledge the potential for the economic exploitation of disabled people via social media, citing some of the historical examples of disability being monetised and exploited, they somewhat gloss over this issue, reminding readers that the focus of their paper is on self-branding practices and understanding ways in which 'different forms of capital culture circulate and manifest' (Christensen-Strynø and Eriksen, 2020, p.47).

Katie Ellis (2016a, p.148), however, provides a more thorough interrogation of how social media has used disability for 'insidious money-making purposes'. In her exploration of 'spreadable media' (a term used to describe the sharing of images, videos, memes or links via social networking), Ellis (2016a, p.147) suggests that disability is a prominent feature in spreadable media. The emotive/affective influence of disability means it is often featured in popular culture as a way to evoke emotion (Ellis, 2016a). Ellis cites the example of 'Mallory', a young girl with Down's syndrome who was the centre of a spreadable image scam. In 2012, a Facebook page with an image of 'Mallory' was posted, accompanied by the following tagline:

This is my sister Mallory. She has Down syndrome and she doesn't think she's beautiful. Please like this photo so I can show her later that she truly is beautiful. Like if You Respect him, ignore if you don't<sup>15</sup>

Ellis (2016a, p.153) explains how this page, and many others like it, exemplifies a form of marketing strategy generated for the sole purpose of 'like farming'. If the page or

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<sup>15</sup> It is unclear what the last line of this Facebook post means ('Like if You Respect him, ignore if you don't'). I would speculate that it refers to the fictitious brother in this scenario and the post is inciting users to like his post.

image is 'liked' by another Facebook user, it will then appear in their newsfeed as well as the newsfeeds of their Facebook friends. This process continues, and the image is spread across networks. Ellis (2016a, p.153) states that once a page has garnered over 100,000 likes, they are usually sold through underground markets where prices are calculated on a '\$ per K' basis. The image of 'Mallory' generated almost 4 million likes before it was exposed as a hoax by the mother of the child seen in the post, Katie, whose image was stolen for the purposes of this spreadable media (Ellis, 2016a). The phenomenon of 'like farming' has led to countless 'fake charities' and Facebook pages using images of disability in order to dupe users into spreading media content, and, even when reported, these images often do not get taken down hastily (Facebook took six months to remove Katie's image) or frequently do not get removed at all (Ellis, 2016a).

The troubling example above shows that social media can be used for corrupt purposes. Social media can also be advantageous, and many Down's syndrome charities utilise their social media networks to raise awareness and promote inclusion. Social media has played a significant role in verifying World Down Syndrome Day (WDSD), a global awareness day to advocate for people with Down's syndrome's rights, inclusion and well-being. Launched in 2006 by Down Syndrome Association Singapore on behalf of Down Syndrome International, WDSD was established in 2012 and was officially observed by the United Nations as a global awareness day. On 21<sup>st</sup> March each year (the 21<sup>st</sup> being selected in order to 'signify the uniqueness of the triplication (trisomy) of the 21<sup>st</sup> chromosome which causes Down syndrome'), the global Down's syndrome community join together to raise public awareness of the inequalities they face (World Down Syndrome Day, 2023, no pagination). Each year Down Syndrome International selects a different theme (for example, the theme for 2023 is *With Us Not For Us*) and globally, members of the Down's syndrome community use social media to spread awareness of said theme. Many countries also recognise National Down Syndrome Day and Down's syndrome Awareness Month in October (National Down Syndrome Society, 2023).

CoorDown (the Italian national coordination of Down's syndrome associations) utilises social media in order to achieve its fundamental aims: to 'activate social communication actions to raise awareness of the potential of people with Down syndrome; promote their inclusion in school, in the workplace, and sport' (CoorDown, 2023, no pagination). Each year, they produce 'innovative and bold campaigns' and

have won several awards for their work (CoorDown, 2023, no pagination).<sup>16</sup> CoorDown's 2021 World Down Syndrome Day campaign – *The Hiring Chain* – promoted the inclusion of people with Down's syndrome in employment, and the video created for this campaign went viral, leading to a boost in hiring and training internships in Italy (Charity Stars, 2023). CoorDown's campaigns often feature satirical shorts to highlight the inequalities people with Down's syndrome face. In their 2022 campaign, *Just The Two of Us*, comedic scenes showing a couple with Down's syndrome being followed and monitored by ten other people as they try to pursue their relationship highlights the infantilisation of people with Down's syndrome and attempts to challenge the idea that dating and Down's syndrome are a taboo subject. As the image in Figure 1 shows, many people with Down's syndrome have their romantic relationships closely monitored by well-meaning family members or social workers, with the room to express their sexuality being thwarted, an issue I return to in Chapter Six during my discussions with co-researchers.



Figure 1

Still image from CoorDown's *Just The Two Of Us* campaign video

Social networking was used to share and promote this comedic short. Many other Down's syndrome organisations and networks supporting the campaign were consequently motivated to make their relationships and sexuality resources free to download (Down's Syndrome Association, 2021a).

As this overview of Down's syndrome in contemporary culture has shown, progress is slowly being made in the representation of people with Down's syndrome, and there is undoubtedly more visibility than ever before – but this should not give rise to

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<sup>16</sup> *The Hiring Chain* won awards at the Cannes Festival, the D&AD Awards, the ADC2021 Awards and the New York festivals. Other campaigns have been awarded 22 lions, including 9 golden ones, at the Cannes International Festival of Creativity (CoorDown, 2023).

complacency. As outlined in Chapter One, the inclusion of people with Down's syndrome in films, books or advertisements does not necessarily command access to equal rights for people with Down's syndrome. Thomas (2020, p.704) reminds us that 'media content alone, in the absence of concrete actions, will not ameliorate disadvantages and inequities held in place by structural forces'.

## **Documentary**

### **Why documentary?**

Representations of disabled people in any cultural text, regardless of its form, have the potential for impact, whether positive or damaging. Indeed, many varied representations of Down's syndrome are worthy of analysis, as earlier discussions around Down's syndrome in fictional novels and social media have shown. There are also now many recognised actors with Down's syndrome who have had roles in mainstream television and film (Zack Gottsagen in *The Peanut Butter Falcon*; Tommy Jessop in *Line of Duty*; Lauren Potter in *Glee*; Sarah Gordy and Leon Harrop in *The A Word* and its spin-off drama series *Ralph & Katie*), and an examination of this body of work would undoubtedly be constructive. This thesis, however, focuses solely on documentaries. The reason for this is based on the argument that this particular genre is potentially more problematic than other forms of cultural representation in that filmmakers (and audiences alike) identify documentary-makers as purveyors of 'truth' or 'reality'. The remainder of this supplementary literature review will discuss the documentary form and its social relevance in terms of representing Down's syndrome, explore the historical relationship between disability and documentary, and discuss how this relationship impacts contemporary cultural works.

### **What is documentary?**

Documentary is a film genre that 'uses real people and real situations to tell a story' (Piotrowska, 2013, p.60). John Grierson, a Scottish documentary filmmaker whom some scholars refer to as the 'British father of documentary' (Piotrowska, 2013, p.61), coined the term 'documentary' in 1926 in his review of the silent documentary film *Moana* by Robert J. Flaherty. Brylla and Hughes (2017, p.1) define documentary as 'a historically defined film and television genre, and now also an internet genre, that has been concerned with providing evidence about reality'. Often claimed to be the first genre of the cinema (Ellis and McLane, 2005; Aitken, 2006), documentary (as an artistic film form) originated in motion pictures and became an established movement by the 1930s (McLane, 2012). Bill Nichols (2017, p.90), frequently referred to as the

founder of the contemporary study of documentary film, asserts that 'both science and spectacle contribute to documentary film development but are hardly synonymous with it'. Scientists were the driving force behind early film technology developments, and the late nineteenth-century fascination with scientific 'wonders' discussed in the previous chapter was eventually capitalised on to form what we now call entertainment cinema (Gouyon, 2016, pp.18-19). Many film historians have traced the beginnings of documentary film to the works of Thomas Edison (the inventor of the phonograph) and the Lumière Brothers (inventors of the projector). Gouyon (2016, p.19) suggests that these early pioneers of film paid attention to the desire for both science and spectacle, 'capitalising on the taste of the day for combinations of entertainment and edification'. Indeed, medical practitioners, 'using a technology, whose accuracy could be vouched for by scientists', were now able to 'produce and display records of moving natural phenomena' (Gouyon, 2016, p.19) and documentary images and film were now becoming an established part of medical research.

Film historians and documentarians often disagree about definitions of documentary. There are several ways to define this genre, depending on where you look. According to the *Dictionary of Film Studies*, documentary is:

The practice of filmmaking that deals with actual and factual (and usually contemporary) issues, institutions, and people; whose purpose is to educate, inform, communicate, persuade, raise consciousness, or satisfy curiosity; in which the viewer is commonly addressed as citizen of a public sphere; whose materials are selected and arranged from what already exists (rather than being made up); and whose methods involve filming 'real people' as themselves in actual locations, using natural light and ambient sound. (Kuhn and Westwell, 2020, no pagination)

Grierson's original definition of documentary (Grierson, 1966, cited in Brylla and Hughes, 2017, p.1) describes this filmic form as 'the creative treatment of actuality'. Many of the definitions available differ semantically, and inevitably, over time, the form has progressed. However, one commonality within all definitions of documentary is that it is in some form a manipulated (or edited) version of 'reality', and it is a genre that deals with the (f)actual. Nichols (2001, p.1, emphasis added) goes as far as to state that 'every film is a documentary', meaning that, when deconstructed, both documentary and fictional film genres and the form they take are not too dissimilar. Nichols (2001, p.1) suggests that there are two types of film: '(1) documentaries of wish fulfillment [sic] and (2) documentaries of social representation', that is: fiction and non-fiction films. Elaborating on this point further, he states that:

Fiction harbors echoes of dreams and daydreams, sharing structures of fantasy with them, whereas documentary mimics the canons of expository argument, the making of a case, and the call to the public rather than private response. (Nichols, 1991, p.4)



For Nichols (2017, p.xi, original emphasis), documentaries are 'a fiction (un)like any other' and although they 'address *the* world in which we live rather than a world imagined by the filmmaker' (such as a romantic comedy or horror film), there is no 'absolute separation' between fiction and documentary. For Corner (1996, p.2), the term documentary is:

the loose and often highly contested label given, internationally, to certain kinds of film and television ... which reflect and report on 'the real' through the use of the recorded images and sounds of actuality.

Corner's perception of documentary corresponds with Nichols'; however, Corner stresses a vital point: documentaries very much intentionally look and sound like reality; this is the effect they are supposed to have. Despite documentary films sharing many of the same practices as fiction films (such as scripting, staging, performance, reenactment and rehearsal), they are generally perceived as objective and transparent (Ward, 2005; Nichols, 2017). The definitions and explanations of documentary cited thus far highlight what seemingly separates fiction from documentary: a portrayal of 'truth'. Documentaries often make certain 'truth claim[s]' that serve the purposes of 'political and social management' (Corner, 1996, p.3). Hogarth (2006, p.3) suggests that traditional documentaries, as texts, allowed for 'rigorous factual argument' and as viewing experiences, they 'elicit[ed] the sort of dedicated, undivided attention by which mass audiences might be transformed into educated citizenries'. Hogarth (2006, p.4) describes this filmic form as 'civic-minded cinema' and suggests that as well as more experimental, *avant-garde* forms, many documentarians in the twentieth century did so with the aim to produce 'civic-minded documentation' that would enact change.

McLane's (2012, p.xiii) description of the tradition of documentary suggests it was founded upon a wide-ranging set of circumstances:

The prevailing social hierarchies, the technologies, the finances, the conflicts and the distribution of personal and political power created the milieu in which the documentary developed. Sometimes it has been the films themselves that changed this order; documentaries are nothing if not a product of the shifting conditions of their own time. We today can learn much from these documentaries, not only about how reality was once recorded, but also about how to create change.

McLane's comments about the history of documentary ring true today and emphasise both the historical and ongoing cultural relevance of documentary as a form of informational or 'factual' media.

Several documentary themes exist, some of which include criminal justice, sports, travel, nature, politics, exploration, pop culture, and scientific documentaries. This

thesis, however, is only concerned with the 'social documentary' genre (Ellis and McLane, 2005, p.ix), meaning that other non-fictional documentary forms, such as those listed above, have been excluded from my analysis. In more recent years, several crossover and hybrid documentary genres have been established, such as *docusoap* (television series that combines elements of documentary and soap opera formats to tell the stories of real people over a period of time), *docudrama* (films or television series based on actual events), *animadoc* (animated documentary films, not to be confused with documentaries that incorporate animated sequences) and *reality television* (in the broadest sense, a genre that consists of unscripted shows featuring non-professional actors being observed by cameras in pre-specified environments). Indeed, two of the three documentaries I analyse in this thesis could be categorised as belonging to crossover documentary genres: *The Specials* (docusoap) and *The Undateables* (reality television). Both of these contemporary documentaries fall in line with crossover documentary genres as they 'incorporate key forms and conventions of documentary' (Kuhn and Westwell, 2020, no pagination).

Defining documentary becomes even more complicated as the documentary genre expands and offshoots into crossover genres. As Ward (2005, p.8) suggests, editing, staging, techniques and modes concerned with documentary filmmaking will always be subject to change (and, importantly, attitudes towards these approaches), yet the one unchanging thing about documentary is that 'it is a form that makes assertions or truth claims about the real world or people in the real world'.

As the many descriptions of documentary cited above have articulated, the aim of all documentaries, regardless of their mode, is to 'capture a reality rooted in the depiction of the everyday' (Biressi and Nunn, 2005, pp.35-36). How filmmakers go about this can either validate or undermine the pursuit of reality. As cited in the previous section, Grierson famously described documentary as 'a creative use of actuality', and Piotrowska (2013, p.61) suggests that the word 'creative' in this citation alludes to the controversy surrounding the documentary genre.

Theoretical writings prior to the 1960s predominantly focused on the social and educational goals and merits of documentary. Post-1960s theorists, however, began to embellish on the *form* of documentary and what is referred to in film studies as *cinéma vérité* (also known as direct cinema, both terms that describe the 'real' style of observational, documentary-style of filmmaking) (Rosenthal, 1988). Documentary theorists began to question form, and their work was based on the foundation that 'film is a language, with a grammar and semantics' and, as such, the myth that 'documentary is "truer" than the standard fiction entertainment film' began to be

deconstructed (Rosenthal, 1988, p.12). It became necessary for filmmakers to state their accountability and positionality, and very rarely did filmmakers claim complete objectivity (Rosenthal, 1988). There was a consensus that, as with all creative works, we are all 'caught up in our various cultural and ideological systems' (Rosenthal, 1988, p.13). How this translates to audiences, however, is dubious. How audiences engage with a documentary text is paramount in issues of representation and, as Ward (2005, p.28) suggests, the meaning of a documentary is a 'process of negotiation between the film, the filmmaker, their audience(s) and the social and viewing context'.

In an age when camera phones and the internet are widely available, documentary-making has become widespread, and they are now created and viewed worldwide. Many documentarians have commented on the shift taking place in the documentary genre, some of whom refer to the unprecedented increase in the production and distribution of documentaries as 'documania' (Hogarth, 2006, p.1). The demand for documentary has never wavered, perhaps because, as McLane (2012, p.389) states, 'people are always interested in seeing their own, and other, realities reflected back to them'. It has already been established that documentarians often use the seemingly obvious correlation between documentary and truth to construct and uphold arguments and to frame subjective viewpoints as fact (Renov, 2008; Debinski, 2018). Within this context, then, and as the prevalence of disability documentaries increases, it is important to question and problematise the conditions in which a documentary is formed. Who is making the documentary, who is commissioning it, who is the intended audience, and why is it being made?

Furthermore, the documentary genre comes with certain expectations: audiences anticipate that this type of film or television is representative, truthful, and possibly even educational, or at the least informative. In many ways, this genre is comparable to a textbook or a newspaper article in terms of audience expectations. Therefore, this particular genre of film functions as an incredibly powerful vehicle of representation. As Snyder and Mitchell (2010, p.195) state, 'documentary ... just like horror, melodrama, and pornography, makes bargains to demonstrate "real life" emotions – to bring forth the most credible and empirical insider account of disability truths and existence'. Indeed, Nichols (1991,p.x) describes documentary as 'the most explicitly political film form'. The political weight of representations of Down's syndrome within documentaries, especially in such a highly charged context, is therefore of great relevance.

## Disability and documentary

Unlike many other marginalised groups, disabled people have historically captured the attention of the filmmaker's lens (Beitiks, n.d). While other stigmatised social identities have been glaringly absent in film, such as lead female roles and characters representing ethnic minorities, disability has been and is continually displayed in film (Chivers and Markotić, 2010). It is a familiar yarn that to succeed in the film industry, a non-disabled actor's 'recipe for success' and critical acclaim requires landing a role playing a physically disabled character (Chivers and Markotić, 2010). Markotić (2008) and (Mitchell and Snyder, 2000) point out the irregularity that, while disability is underrepresented in film, simultaneously, it has been excessively displayed: it is both discernibly visible and equally invisible. This is especially the case for documentary film.

Documentaries about disability have become increasingly popular on mainstream television. For example, Channel 4's most recent releases include *Rosie Jones: Am I a R\*tard?* (2023), *Embarrassing Bodies* (2007-present), and *Britain's Tourette's Mystery* (2022). Debinski (2018, p.59) writes that 'inspirations, freaks, pitiable souls, and abject bodies: these stereotypes, laden with deeply affective characteristics, occupy the landscape of mainstream disability documentary'. The timeworn tradition of presenting disabled bodies and minds as 'deviant spectacles' has been analysed by many writers with an interest in disability and documentary (Snyder and Mitchell, 2006; Markotić, 2012; Brylla and Hughes, 2017; Debinski, 2018; Ellcessor and Kirkpatrick, 2019; Fraser, 2019; Sandahl, 2019), some of whose work I will now discuss further.

Despite the political and pedagogical quality of the documentary genre, not to mention the prevalence of documentaries *about* disabilities, research on documentary and disability is relatively limited. Documentary is extensively researched within the fields of media and film studies; however, it is seldom from a disability studies perspective. There are, however, exceptions to this, and since the seminal work in disability documentary from Snyder and Mitchell in *Cultural Locations of Disability* (2006), the field has grown in recognition. This is evident in the recently edited collection compiled by Catalin Brylla and Helen Hughes (2017), which assembles essays focusing on the role, production and potential power of disability documentary.

As practitioners of film, as well as critics, Snyder and Mitchell's work on disability documentary cinema began in 1994 when they began making documentary films about disability, history, art and culture. They also have their own production company, Brace

Yourselves Productions.<sup>17</sup> In *Cultural Locations of Disability* (2006), Snyder and Mitchell critique representations of disability in documentary by examining the works of renowned documentarian Frederick Wiseman. They do this through a Foucauldian lens, exploring the issue of institutionalisation within the Helen Keller Institute for the Deaf and Blind, the location for Wiseman's films. They find that Wiseman's documentaries echo entrenched 'discomfort with the topic of disability' and, in many ways, reproduce the idea that different bodies and minds are mysterious and abnormal (Snyder and Mitchell, 2006, p.155). Sometimes referred to as 'global in(ter)dependent disability documentary cinema', this genre highlights the importance of increasing public awareness about inclusion and providing audiences with 'an alternative ethical map of living interdependently with each other' (Mitchell and Snyder, 2016, p.18). They suggest that disability documentary, as a form, cannot be fully understood as a separate entity in and of itself and that it is necessary to juxtapose disability documentary alongside fictional disability films (Mitchell and Snyder, 2016). In so doing, both genres have real potential to offer alternative 'representational approaches to disability' that might radically improve audience understanding of disability (Mitchell and Snyder, 2016, p.18). Examples of recent mainstream disability documentaries that reject the 'disabled body as spectacle' mode (Snyder and Mitchell, 2010, p.180) are Lebrecht and Newnham's *Crip Camp* (2020) and Bonhôte and Etedgui's *Rising Phoenix* (2020). Both films represent the interesting complexities of lives with various impairments and speak to the politicised issues surrounding disability. Disability documentary should strive to move beyond demonstrating the somewhat modest argument that disabled people should be afforded the same rights as non-disabled people and instead present disability as 'an identity in its own right' (Mitchell and Snyder, 2016, p.18). The chief objective of disability documentary cinema is to present an 'ordinary life with disability [as] imaginable and even palatable in a society that holds a bankrupt tradition of disability imagery' (Snyder and Mitchell, 2006, p.174). For Snyder and Mitchell, representing the everyday is crucial.

This thesis works from a similar platform to that of in(ter)dependent disability documentary: it agrees that disability documentary should 'diminish feelings of audience alienation with embodied differences' (Mitchell and Snyder, 2016, p.20) and to create a meaningful space in which Down's syndrome can be presented through embodied, *cripistemic* knowledges or cripistemologies (the term used to describe a

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<sup>17</sup> Examples of Mitchell and Snyder's documentary films include: *Vital Signs: Crip Culture Talks Back* (1995); *A World Without Bodies* (2002); *Self-Preservation: Art of Riva Lehrer* (2004); and *Disability Takes on the Arts* (1996). They are also currently making a full length documentary about disability and the Nazi T4 programme.

rejection of normative epistemologies surrounding disability) (Johnson and McRuer, 2014). So often, 'real life' stories about disabled people involve the inspirational, 'supercrip' narrative, whereas, as Clare (2015, p.33) compellingly states: 'the dominant story about disability should be about ableism, not the inspirational supercrip crap, the believe-it-or-not disability story'. In order to move away from the dominant supercrip narrative, filmmakers are required to rely more on the narratives disabled people create, and their cripistemologies, which can then shape cultural disability narratives. By 'breaking down misconceptions and metanarratives' of disability, the space is created to 'de-essentialize constructions of normative disability, disrupt preconceived perspectives on disability, and help determine possibilities for crip futurity' (Kim, 2021, p.64).

As previously discussed, the blurring of 'fact' and fiction in documentary is problematic and one of the key reasons I chose this particular form of cultural text for analysis. Markotić's work on disability in documentary film also addresses the issue of 'truth' in documentary. Markotić (2016) queries how audiences of documentaries attribute 'truth' to a subject's body through an examination of the Canadian documentary *Citizen Sam* (dir Moulins, 2006). Markotić (2016, p.143, original emphasis) questions 'what, in fact, is a *fact*? And how do "facts" inform a viewer's acceptance of filmic authenticity and veracity?'. These questions, and indeed Markotić's body of work on disability in film, will be crucial to engage with in my research. If documentary viewers ascribe truth to visual representations of 'fact' about the impaired body, how does this 'betray the myriad ways we pronounce upon the body?' (Markotić, 2016, p.143). In other words, if viewers process the 'facts' they observe in a documentary as 'truth', as the literature suggests, what messages are being portrayed about Down's syndrome? How would the 'facts' according to filmmakers differ from the lived realities according to people with Down's syndrome?

As previously stated, documentary can act as a powerful vehicle of representation and has the distinct potential to transform understandings of disability. Nevertheless, any work relating to disability and documentary must acknowledge the complex relationship between the two. As Brylla and Hughes (2017, p.2) have stated: 'the photographic documentation of the body has been an integral part of defining what it means to be disabled'. The documentary genre has traditionally adopted medicalised narratives, and the objectifying gaze has scrutinised disabled bodies. It is valuable to reflect upon the history of disability cinema and acknowledge the 'wreckage left by generations of repeated representational patterns that function to the detriment of disabled people's social identity' (Snyder and Mitchell, 2006, p.172). The work being done in

contemporary disability documentary endeavours to reverse the objectifying gaze, corroborating the notion that ‘the dehumanising stare can be met with a creative look’ (Brylla and Hughes, 2017, p.2).

Much of the work discussed by Snyder and Mitchell (2006) and Brylla and Hughes (2017) relates to independent disability documentary films. Brylla and Hughes (2017, p.3) state that the reason for this is not because independent documentaries have reached a ‘utopian ideal’ in the representation of disability but because working outside of the mainstream allows for more experimentation, creativity and inclusion. They do, however, remind us that creative practices established in the realm of independent film often trickle down into the mainstream and that this is especially the case in an age of digital convergence (Brylla and Hughes, 2017, p.3). Two of the three documentaries I analysed for this project were broadcast on mainstream British television, while the third started as a web series available to stream online and was eventually aired on US mainstream television through the Oprah Winfrey Network. My analysis shows how types of broadcasting can impact the form and content of a documentary and discusses how documentaries can often be caught between traditional and contemporary representational practices.

### **Down’s syndrome and documentary**

As alluded to earlier in this chapter, scholarly literature on disability and documentary is relatively limited, and research regarding Down’s syndrome and documentary is even more so. Its scarceness could be due to a lack of cultural representations of Down’s syndrome available for critique, but as the list in Figure 2 shows, there have been several documentary films and series featuring people with Down’s syndrome in the past decade, and this list is only indicative of UK and US-based documentaries.

<b>Name of documentary film/series</b>	<b>Brief Synopsis</b>
<i>The Specials</i> (2009-14)	Series following the lives of five friends with learning disabilities who share a house in Brighton.
<i>The Undateables</i> (2012-present)	Series following adults with a wide range of impairments as they navigate the world of dating.
<i>Growing Up Down’s</i> (2014)	Film depicting the story of group of young actors with Down’s Syndrome who set out to create a touring production of Shakespeare’s Hamlet.
<i>Born This Way</i> (2015-19)	Reality TV series following the lives of seven young adults with Down’s syndrome who reside in Southern California

<i>The Special Needs Hotel</i> (2015)	Three-part docuseries following young students with a wide range of learning disabilities as they receive hands-on training in the hotel trade.
<i>A World Without Down's Syndrome?</i> (2016)	Film exploring the ethics of pregnancy screening in light of new non-invasive prenatal testing technology being implemented in the UK.
<i>Far From the Tree</i> (2018)	Film that explores the lives of children who are somehow radically different from their parents, and includes a 41-year old man with Down's syndrome and his family.
<i>My Extra Chromosome and Me</i> (2018)	Documentary short depicting the lives of three people living with Down's syndrome.
<i>Home Free</i> (2019)	Two-part series that follows a group of young people with learning disabilities as they leave home for the first time.
<i>Handsome</i> (2021)	Film following two brothers as they travel the world to discover what life is like for the siblings of people with Down's syndrome.
<i>Disability and Abortion: The Hardest Choice</i> (2022)	Film presented by Ruth Madeley (actor with spina bifida) and Ruben Reuter (actor with Down's syndrome) who question the ethics around abortion laws on the basis of disability.

Figure 2

Table detailing contemporary Anglophone documentaries about Down's syndrome

Perhaps the lack of scholarship in the area of documentary and Down's syndrome has more to do with the perception that the documentary genre comes lower in the cultural chain than fictional film, which receives far more scholarly attention within cultural and disability studies (Fraser, 2021).

One scholar seeking to address the shortage of research relating to Down's syndrome and cultural representations is Benjamin Fraser, much of whose work is based in 'cognitive disability studies'. Fraser's (2021, p.233) work highlights the inadequacy of traditional documentary in that 'disability is seldom, if at all, approached on its own terms' within this genre. While much of Fraser's work focuses explicitly on cognitive disability in Iberian and Latin American cultures, his edited collection, *Cultures of Representation* (2016), brings together discussions about disability in global cinema contexts, querying approaches to disability studies that take cross-cultural parallels for granted and attending to the specificities of embodied space/place that are often overlooked (Fraser, 2016). Bérubé (2016b, p.28) states that when it comes to media representations, physical disabilities often become a stand-in for disability generally, and intellectual disability goes 'unmarked and unremarked'.

A more recent publication from Fraser, *Cognitive Disability Aesthetics*, spotlights cognitive disability as opposed to more visible physical impairments as, he argues, 'disability scholars in the humanities have not traditionally explored the social realities



or cultural representations relevant to those with cognitive disabilities' (Fraser, 2018, p.xii). Fraser (2018) acknowledges and celebrates three seminal publications in physical disability representations in visual and literary forms – Martin Norden's *Cinema of Isolation: A History of Physical Disability in the Movies* (1994), David Mitchell and Sharon Snyder's *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000) and Tobin Sieber's *Disability Aesthetics* (2010). Fraser (2018, p.ix) praises these foundational texts for uncovering (in the literary and visual art world at least) the idea that 'physical disability has long been clothed in the normative trappings of an able-bodied society and mobilized to suit a range of symbolic, metaphorical, and perhaps even purportedly transcendent artistic purposes'.

Fraser's (2018, p.xi) intention with *Cognitive Disability Aesthetics* is to centre on material realities of cognitive impairment and move beyond the 'physical orientation of much disability studies research', in what he terms a 'second wave of disability studies'. His motivation for paying added attention to cognitive disabilities lies in his vision to 'expand the scope and impact of disability studies in the humanities' so that those with 'severe' cognitive impairment who are not able to 'communicate their needs in the way required by normative ableist power structures' are eventually able to do so without the need for others to speak on their behalf (Fraser, 2018, p.xii).

In his analysis of Alberdi's documentary film, *The Grown-Ups* (2016), Fraser (2021, p.234) commends the director for portraying the stories of four adults with Down's syndrome on their own terms, factoring into the production how biological, social, physical and intellectual characteristics each play into their lived experience. *The Grown-Ups*, which in the original Spanish-language title of the film (*Los niños*) translates to 'the children', is a reflection of the 'entrenched cognitive ableism that persists in contemporary societies' (Fraser, 2021, p.236). The choice of title was an overt political statement speaking to the ways in which adults with Down's syndrome in Chile (and many other parts of the world) are 'reduced to the social status of children', be that through governmental and public discourse, legislation and indirect forms of indiscriminate 'embedded in tropes of charity, pity and benevolence' (Fraser, 2021, p.236). Fraser (2021, p.236) states that 'the title thus reflects a documentarian's urge to capture and screen the textures of everyday experiences of marginalization', and both the English-language and Spanish-language titles call out the infantilisation of adults with Down's syndrome. The themes being explored in the film address the broader issues around autonomy and people with cognitive impairments. Fraser (2021, p.236) points out that while the protagonists live in Chile, it would be wrong to assume that the issues being raised in the film are specific only to a Chilean context: 'the fact remains

that people with Down syndrome face similar obstacles to their own autonomy across the globe’.

Fraser’s work on cognitive disability representations in the documentary genre is grounded in Mitchell and Snyder’s research in interdependent disability cinema (2006; 2015; 2016), which relocates the disabled body from ‘the site of intervention’ and instead ‘targets the social services, rehabilitation and medical industries as more a more appropriate site of revision’ (Snyder and Mitchell, 2010, p.202). Since the 1990s, Mitchell and Snyder, whose work was introduced earlier in the chapter, have ‘generated important scholarship detailing the cultural work of independent and international disability film festivals’ (McRuer, 2019, p136), referring to this new wave in disability representation as ‘The New Disability Documentary Cinema’ or ‘Global In(ter)dependent Disability Cinema’. They believe that this shift in representational practices and techniques will allow for more nuanced portrayals that establish disability as a ‘productive social identity in its own right – one that complicates previous social model efforts to merely argue disabled people should be able to live as non-disabled people do’ (Mitchell and Snyder, 2016, p.18). Indeed, Fraser’s argument throughout his analysis of *The Grown-Ups* is that the film fits within the realm of new disability documentary cinema as it ‘emphasises the bodies and faces’ of the protagonists as a way of critiquing social services that fail to secure their autonomy and interdependence (Fraser, 2021, p.239).

Fraser (2018) suggests that cognitive disabilities, unlike physical impairments, are often neglected in society and scholarship. For Davis (2013, pp.31-32), while physical impairment is often denoted in cultural representations as tragic and affective, cognitive impairments (especially, Davis suggests, depictions of people with Down’s syndrome and autism) play a different role – they ‘function in the media as states of existence designed to evoke the compassion of the viewer’. Davis (2013) argues that the personhood of characters with Down’s syndrome is often called into question – viewers are expected to feel sympathy or pity for these characters and feel a sense of beneficence towards them. The reason people with Down’s syndrome are so often assigned this role, Davis (2013, p.32) suggests, is to uphold normalcy and pacify non-disabled audiences:

The more lovable and understandable the characters become, the more likely the film or television show will succeed. And the ultimate point about the function of such narratives is that they end up making the audience feel good about itself and its own “normality”.

The idea of upholding or *enforcing* (to use Davis’s terminology) normalcy, which was covered in Chapter Two, chimes with Snyder and Mitchell’s (2006) work on disability

representations as well as Darke's (2004, p.104) critiques of 'impairment imagery', which both suggest that the concept of normality is central to understanding the nature of disability representations and critiques of these representations. According to Darke (2004, p.103), normality is 'the belief that there is an essentially correct way to have been born, look like and be', which is reflected in the images of disability portrayed in the media.

As I posited earlier, there does appear to be a shift in how Down's syndrome (and disability more generally) is being represented, with many parents of children with Down's syndrome commenting on the positive aspects of more recent media portrayals of people with Down's syndrome (Thomas, 2020). Thomas interviewed several parents of children with Down's syndrome, most of whom agreed that there has been a departure from the more damaging historical discourses surrounding Down's syndrome that depict life with the condition as a tragedy. While they mostly welcome positive public attitudes, there are concerns around 'tokenism, stereotyping, focusing upon "exceptional people", and fuelling sanitized accounts which deny, or at least obscure, the harsh lived realities for many parents of disabled children' (Thomas, 2020, p.693). This brings us back to Fraser's (2021) analysis of *The Grown-Ups*, in which he praised the director for not glossing over social and political struggles. While the film presents the everyday lives of the protagonists with Down's syndrome, including the joy, solidarity and closeness the characters enjoy, it also depicts 'moments of devastating consequences as the protagonists face their collective lack of autonomy' (Fraser, 2021, p.247).

When Darke (2004, p.100) penned his critique of impairment imagery (now almost 20 years ago), he argued that disability media representation had not changed much since the 1990s, suggesting it remained 'clichéd, stereotyped and archetypal' and lacking any recognition of the political and social consequences of living with an impairment. While damaging and hollow portrayals such as those described by Darke can unfortunately still be found, cultural representations of disability appear to be more welcoming of diversity and bodily difference, something that should not be overlooked. Recent collections such as Johanssen and Garrisi's *Disability, Media, and Representations: Other Bodies* (2020) and Ellcessor and Kirkpatrick's edited volume, *Disability Media Studies* (2017), reflect this shift in disability media representations and provide a sense of optimism that the future of this field of inquiry is progressing in the right direction. That said, and in line with Fraser (2021), I would argue that cognitive difference is currently less embraced on (and off) screen, but documentaries like *The Grown-Ups* (2016) provide a blueprint for how this can be done tastefully and authentically. It is also vital, as academics, not to become complacent in the wake of

this shift in cultural representations. As Thomas (2020, p.704) has previously cautioned, changes in representational practices and the cultivation of positive media imagery about disability are not enough – after all, ‘what good is a positive imaginary supposedly symbolic of value and worth, if society continues to create and foster disabling conditions’? As Darke (2004), Mitchell and Snyder (2006) and Thomas (2020, p.704) have all pointed out, a suitable start would be for media coverage to recognise impairment as a ‘distinct political category’ rather than a medicalised term.

## **Conclusion**

This review of the literature shows the pervasiveness of ableist and neoliberal discourses surrounding Down’s syndrome and demonstrates how narratives of Down’s syndrome are often intertwined with the idea that to be born with Down’s syndrome or give birth to a child with Down’s syndrome, is an inherently negative experience, for parents and children alike. Many of the cultural texts included in this literature review presume an undesirable imagined future for people with Down’s syndrome and their parents, and it is within this hostile environment that families and advocates of people with Down’s syndrome are challenging and resisting these damaging discourses.

Despite the hostile environment in which people with Down’s syndrome and their allies find themselves, strides *are* being made and the assumption that ‘no one wants a child with Down’s’ is now being questioned more openly within media representations, social media movements and in the public arena. In the UK, we can now find less problematic portrayals of characters and ‘real’ people with Down’s syndrome within film, television and social media. The recent television drama series aired on BBC1, *Ralph & Katie* (2022), is an excellent example of Down’s syndrome being represented in ways that counter the pitiful and tragic narratives that have historically been used to portray all disabled people. The two protagonists in this series are a married couple who both have Down’s syndrome (Ralph and Katie), and the series follows their first year living together as newlyweds. The series depicts Ralph and Katie’s journey as they ‘navigate their way through love and independence’ (BBC, 2023, no pagination). That a mainstream television series based on a married couple with Down’s syndrome has been broadcast in the UK confirms the significance of the shift in the representation of people with Down’s syndrome and is a welcome departure from ‘hurtful historical narratives’ of Down’s syndrome (Thomas, 2020, p.693). Literary and cultural texts have vast potential to rewrite the stories we tell about Down’s syndrome, learning disabilities and disability more generally. Characters or social actors within these texts should not only be exclusively included as plot devices or as a matter of non-disabled character development. As Mitchell and Snyder (2000) have shown, disabled characters can

(and do) provide much more than a narrative prosthesis, and the independent documentary cinema movement has demonstrated a myriad of ways in which metanarratives of disability can be rewritten.

One of the key points to have emerged from this literature review is the importance of politicising Down's syndrome in documentary. While positive portrayals of life with Down's syndrome are necessary, this alone is not enough if we are to stand a chance of fundamental social change. As mentioned in Chapters One and Two, the social, economic and health inequalities faced by people with Down's syndrome can be catastrophic. The figures around deaths of learning disabled people during the COVID-19 pandemic are but one example of this. Collective action is required and, as McLane (2012) states, social documentaries *can* enact social change. Filmmakers within the documentary genre need to steer away from the feel-good, stereotypical, inspirational narratives of Down's syndrome that privilege able-bodiedness and this will only be possible if more documentaries are made on the subject's own terms. Failure to include the criptestemologies of subjects with Down's syndrome will result in the reproduction of stereotypes. As Smith (2011, p.53) states in his work on the politics of Down's syndrome, if audiences only ever see the stereotypical, 'forever happy' version of a person with Down's syndrome, then society has even more justification for looking away: 'if you are genetically happy then what need is there for others to feel a responsibility to their fellow human, to involve or care, consequently you can be easily dismissed'. Fraser's work in the field of disability and documentary has demonstrated how filmmakers can achieve aesthetically pleasing works of art whilst simultaneously making important sociopolitical statements. The pairing of representing a life worth living without glossing over or dismissing the social inequalities faced by people with Down's syndrome is not a straightforward task, but it *is* possible. Documentary as a form is well equipped to confront this task – it has the exceptional advantage of presenting 'real' people with the objective of telling 'real' stories about the world. With the involvement of their subjects, not only in the filming stages of production but in the editing phase and distribution process, filmmakers have a unique opportunity to present reimagined stories about Down's syndrome, stories that are grounded in the lived experience of their documentary subjects.

## ~ Chapter Four ~

### **Methodology**

This chapter outlines my methodological considerations throughout this research and will begin with an overview of my epistemological positioning. I will then discuss positionality and reflexivity, commenting on the intricacies of researcher/respondent roles within research with people with learning disabilities and outlining my efforts to address the power dynamics imbalance. Following this, I will discuss my sampling and data collection methods and introduce the co-researchers in this project. I will then outline the stages of data analysis and generation, followed by a discussion about the practice of arts-based research. I will then review the ethical considerations underpinning this research, followed by a section outlining the potential limitations of my research methods. Before concluding the chapter, I will briefly discuss ways in which the research outputs can be disseminated.

#### **Epistemological and ontological position**

My epistemological stance is that reality and knowledge require interpretation in order for underlying meanings to be fully discovered (Berger and Luckmann, 1966; Burr, 2015). Cultural representations that are rooted in ableist notions of normalcy become engrained in societal understandings of Down's syndrome, and this thesis seeks to interpret, understand, challenge and disrupt normative representations of living with the condition.

My approach to knowledge production works from the premise that disability is not an unfortunate characteristic located within an individual body or mind. Rather, disability pertains to the social, environmental, physical, sensory and attitudinal barriers faced by disabled people on the basis of their impairment. My sociological perspective positions the 'problem' of disability with environments and social structures built to stigmatise and exclude 'deviant' ways of being rather than locating the problem in the minds and bodies of individuals with impairments (Kafer, 2013, p.6). As previously discussed, I will engage with normalcy, ableism and disability representation in order to theorise how cultural representations of Down's syndrome are embedded within the political/relational model of disability.

From this epistemological stance, I understand Down's syndrome as a chromosomal difference whereby people living with this condition do experience impairment effects, but the disabling nature of Down's syndrome is a social and cultural phenomenon based on taken-for-granted assumptions around what constitutes a 'normal' body and

mind (Davis, 1995; 2013). In other words, the problems associated with the disabling nature of Down's syndrome are not solved through medical intervention or normalisation. Rather, they are solved 'through social change and political transformation' (Kafer, 2013, p.6). In line with Kafer (2013), my positioning does not reject medicine or assert that medical intervention and treatment are not a necessity for many individuals living with Down's syndrome – nonetheless, medical-based narratives are not the only way to understand Down's syndrome. I am mindful that cultural representations based on medicalised narratives are 'imbued with ideological biases about what constitutes normalcy and deviance' and have subsequent effects on the treatment of and attitudes towards people with Down's syndrome (Kafer, 2013, p.6). My ontological stance can be defined as 'flat ontology', whereby I do not distinguish between 'different social levels or realms with distinct characteristics' (Beunen et al., 2021, p.112), enabling me to account for a range of different perspectives that transpire through varying comprehensions of reality. According to Ash (2020, p.345), a flat ontology means that 'hierarchical or binary modes of thought' can be avoided in social research. This means that, from a flat ontological positioning, different realities can co-exist and each perspective is as important and valid as the other, as 'a flat ontology implies a *relational* perspective on the nature of objects, subjects, facts, truth claims and so on' (Beunen et al., 2021, p.112, emphasis added). Throughout this thesis, I engage with various stand points, including my own, my co-researchers', documentary filmmakers' as well as wider communities impacted by the issues being discussed. Therefore, my ontological positioning needs to understand each of these multiple realities as relational. As Beunen et al. (2021, p.112) state, 'everything that is observed as real is always the contingent result of a particular relation in which something is rendered real in relation to something else'. A flat ontologist would suggest that knowledge and reality is 'always situational' and is dependent on time and place, making it 'relational to the object of research and/or the school it belongs to' (Boelens, 2021, p.5). Epistemologically and ontologically, my research takes a critical stance towards cultural imaginaries of and ideologies surrounding Down's syndrome and questions how they come to be taken as truisms (Berger and Luckmann, 1966, p.15). The intention is to lay the way for alternative realities and knowledges (cripistemologies) about life with Down's syndrome in terms of independence, intimate relationships and prenatal screening for this condition.

### **Inclusive research**

The primary aim of this research was to represent the lives of people with Down's syndrome from their own perspectives. Snyder and Mitchell (2006) discuss the

significance of embodied knowledge in disability research and argue that it is important to centralise the phenomenological experience of disabled people. This thesis is consistent with this line of argument. It explores the perceptions of individuals with Down's syndrome regarding how people living with this condition are represented within the documentary genre. While Snyder and Mitchell (2006, p.21) argue that the analysis of cultural texts has real value and that text-based research avoids subjecting disabled people to research, I believe that the objectives of this thesis could not have been achieved without including people with Down's syndrome in the discussion. This thesis is not only an investigation into the phenomenon of Down's syndrome representation; it works towards changing disabling discourses and social structures and broadening the control people with Down's syndrome have over their own lives and how they are narrated (Sullivan, 2009). In order to do this, my approach to the research problem embraced a range of research approaches within the inclusive research paradigm (Walmsley and Johnson, 2003). According to Walmsley and Johnson (2003, p.23), inclusive research has traditionally been informed by several theories and practices, including qualitative research, feminist and participatory action research (PAR). Whether a researcher identifies as working from within the parameters of inclusive, emancipatory, participatory or action research, the fundamental principles each approach shares are a commitment to social change, empowering participants, focusing on the individual, emancipation, reflexivity and translating principles into practice (Walmsley and Johnson, 2003). Though based on similar fundamental principles, the definitions of emancipatory and participatory research differ. Chappell (2000, pp.38-9) summarises the working definition of emancipatory research according to Oliver (1992), Morris (1992) and Zarb (1992) as follows:

- 1) research should be used as a tool for improving the lives of disabled people;
- 2) there should be greater opportunities for disabled people to be researchers;
- 3) researchers must adopt a more reflexive stance regarding their work;
- 4) the democratic organizations of disabled people should act as commissioners and funders of research; and
- 5) researchers should be accountable to the democratic organizations of disabled people.

Chappell's (2000, pp.38-9) definition of participatory research is based on Cocks and Cockram's (1995, p.32) description of participatory research with people with learning disabilities:

- 1) the research problem may be identified by disabled people or non-disabled researchers, who then bring it to the attention of the constituency of disabled people;
- 2) disabled people and researchers work together to achieve a collective analysis of the research problem; and



3) alliances are formed between disabled people, researchers and other experts, although these alliances must be 'under the control and primarily in the interests' of disabled people.

While this thesis does adhere to many of the principles within the emancipatory research paradigm, certainly the first three in Chappell's summative list, realistically, the tenets of the participatory research approach are more achievable. Chappell (2000, p.40) argues that participatory research is better understood as a 'pragmatic compromise between the conflicting pressures on researchers'. My approach to this research involves a commitment 'both to a social analysis of disablement and to the development of the disabled people's movement' (Stone and Priestley, 1996, p.702), although the issues being tackled within this project (and the research questions) have not been initiated by the research participants – I have brought the research problem to their attention in order to produce an analysis of representations of Down's syndrome in documentaries. Rather than researching this issue on their behalf, I have undertaken this project in partnership with the co-researchers, which is more feasible than if the work was based solely on emancipatory methodology. In line with the principles of inclusive research, I accept my expertise as a researcher while privileging the expertise of my co-researchers as 'knowers' (Stone and Priestley, 1996, p.715).

Throughout the research, I have taken my responsibilities as a non-disabled researcher seriously and have been committed to conveying the experiences of my co-researchers as accurately and truthfully as possible. Any participatory research with people with learning disabilities poses the 'obvious danger' of the non-disabled researcher 'assuming a dominant role in the research process' (Chappell, 2000, p.41). I am aware that hierarchies cannot be reversed simply by stating they are. As Stone and Priestley (p.704) state, it is crucial to acknowledge that:

disabled people as a group are in an oppressed position and that research is conducted within a wider context of oppressive social relations built upon the privilege and power of non-disabled people. It is thus inappropriate to consider disability research production as an activity discrete from its social context.

Chappell (2000, p.42) argues that historically, people with learning disabilities have been excluded from academia and research. I have tried to use my position to 'articulate the experience of people with learning difficulties to the outside world'. This thesis utilises a participatory approach so that co-researchers, in partnership with myself, can achieve elevated influence over the research process and highlight some of the issues they face regarding representation.

In the UK, in particular, the distinction between emancipatory and participatory research approaches is hotly debated (Porter and Lacey, 2005, p.86). However, this

thesis works from an understanding that any research based on the fundamental principles of inclusive research need not get embroiled in theoretical definitions. As this thesis shows, research that aims to empower disabled people should be based on political (emancipatory) and activist (participatory) ideologies, and a combination of both approaches can be beneficial.

### **Arts-based research**

As the sections that follow will demonstrate, I adopted an art-based approach to inquiry throughout the research analysis. The decision to use an arts-based approach to the research was twofold. While employed at a self-advocacy organisation, I learned that members preferred working on projects involving more creative research methods, as they found this research method more exciting and accessible. Secondly, my goal with this thesis was to delve into and disrupt normative representations of Down's syndrome and offer alternative imaginations of Down's syndrome representation in documentaries. Creative research methods would enable me to accomplish this. Arts-based methodological approaches are often relied upon instead of more conventional methodologies when research objectives are to 'explore, describe, evoke, provoke, or unsettle' (Leavy, 2017, p.191).

Arts-based research (ABR) emerged as a way of crossing the boundaries between science and art and working towards revolutionising 'institutionalized classist, racist, and colonizing ways of experiencing and discoursing about human experience' (Finley, 2008, p.73). Although Finley does not explicitly reference ableism within this statement, I take this to be implicit. ABR practices often draw on visual art, music, dance, performance and film (as well as many other art forms) in order to generate, analyse, interpret and represent data across the different stages of a research project (Leavy, 2020, p.ix). Not only does this thesis work from an ABR research approach in that the texts being analysed are documentary films and series, but the methodology being used to elicit data is creative. In order to explore documentaries and imagine alternative ways of producing documentaries about Down's syndrome, we created a mock documentary trailer based explicitly on the vision and imaginativeness of the co-researchers.

Art-based enquiry is said to have been used in the field of psychology since the 1860s (Kossak, 2013, p.19). ABR has developed from art-based enquiry and allows researchers to immerse themselves in creative processes and academic reflection whereby 'the phenomenological experience is represented through the creative act itself' (Kossak, 2013, p.20). An arts-based approach was chosen for this project not only so that the invisible can be made visible (an important element in any disability-related

project) but also because, as Kossak (2013, p.25) argues, in line with Aristotelian philosophy, 'art is a way of knowing'. I intend for the data (art) generated within this research to serve as a legitimised, valid and valued body of knowledge produced by people living with Down's syndrome. Within the group sessions, I created a space for co-researchers to explore, reflect on and share their self-knowledge, which in turn conveyed relatively unheard 'truths' about Down's syndrome from the perspectives of the co-researchers. The meanings that the co-researchers give to their reality were navigated through ABR, meaning that their own understandings could be processed in fluid and diverse ways (Burch, 2021).

In line with disability studies scholars Ignagni and Church (2008, p.627), this project considered past and possible representations of disability through arts-based inquiry but, more importantly, used an arts-based approach to investigate Down's syndrome *through* the arts. Several disability studies scholars with an interest in disability research have written about the ambivalent relationship between ABR and disabled people (Davis, 2002; Titchkosky, 2003; Snyder and Mitchell, 2006; Ignagni and Church, 2008; Garland-Thomson, 2009). Historically, artistic endeavours involving disabled people have led to either social exclusion or normalisation. Through the lens of artistic inquiry, disabled people can be looked at as objects of curiosity, inspiration or exploration with an emphasis on 'fixing' disabled bodies (for example, art that is used for therapeutic purposes, such as music therapy to teach children with autism listening skills). Alternatively, disabled people can be met with an artistic 'inquiring gaze' that is 'motivated by aesthetics or a desire for knowledge' (Ignagni and Church, 2008, p.626). That is, *through* art, research can result in greater participation in the processes of knowledge production (Ignagni and Church, 2008, p.626). In relation to medicine-based documentary films in particular, Snyder and Mitchell (2006, p.3, original italics) characterise this specific medium as an example of what they term 'cultural locations of disability'. They argue that disabled people often find themselves being 'deposited' within cultural locations of disability, often without their consent (Snyder and Mitchell, 2006, p.3). The aim of this project was to reverse this dominant tradition. Instead, an arts-based approach that analyses and utilises documentary *empowered* co-researchers, turning the tables, so to speak, by providing a 'meaningful participation in the invention of culture itself', rather than inhibiting it (Snyder and Mitchell, 2006, p.3).

By reimagining artistic representations of disability, or more specifically – Down's syndrome, this project contributes to disability culture, blurring the boundaries between "them and us" and disrupting the taken-for-granted assumptions about disability and a life with Down's syndrome (Ignagni and Church, 2008). As Finley (2008, p.72) suggests,

ABR can be thought of as a 'radical, politically grounded statement about social justice'. The data generated as part of this project hands over control to the co-researchers in terms of what knowledge is being produced and how this is disseminated. The group controlled and directed the blueprint for a documentary and the short trailer that was produced. They incorporated their reactions to dominant disability documentary depictions and provided an alternative way of representing life with Down's syndrome, through the medium of film.

### **Positionality and reflexivity**

As the previous section touched upon, traditional social research relations often place disabled research participants as the objects of research. This places participants in an inferior position to researchers, often alienating them from the research process on a collective and individual level (Sullivan, 2009, p.73). By overtly stating my positionality as a non-disabled, white, female, disability rights advocate and academic, as well as making clear to participants that this project is collaborative and that they would have the space and agency to shape the direction of the analysis, this works towards avoiding the power imbalance that often transpires in disability research. From the outset, I have acknowledged that my perspectives are very much based on my positionality, which has inevitably affected every research phase (Rowe, 2014). As Charon (2010, p.11) states, rationally evaluating one's own perspective (or 'conceptual framework') is a complicated undertaking. Our perspectives amount to a 'set of assumptions, values and beliefs' that we use to shape our perceptions and control our behaviour (Charon, 2010, p.11). My position as a researcher is not to strive for total objectivity, and I do not believe that identifying the subjective nature of this research invalidates the outcomes or makes it any less scholastically relevant. An individual has many perspectives and these act as 'filters' which prevent an individual from seeing 'all of reality' (Charon, 2010, p.11). Furthermore, no object, phenomenon or person can be understood from just one perspective – multiple perspectives may be used and each one might tell us something important or relevant (Charon, 2010).

My sociological position does not exist in a vacuum. I cannot claim neutrality in my research, as it is unreasonable to claim objectivity from the social world I am researching (Hammersley and Atkinson, 2007). My positionality fluctuated between my perspective as a woman, a student, a social activist (and many more). How I understand disability is reflected by my social position, my gender and my status. It is important that I acknowledge my position as a white female who has never received a disability diagnosis and whose only family member with Down's syndrome is a deceased distant cousin. I could be described as 'occupying a position of white-able-

bodied-and-minded privilege' (Goodley, 2020, p.6), a description that I would accept. Indeed, my position in the field of disability studies is something I continually reflect upon and frequently grapple with. The place of non-disabled researchers in disability studies is widely debated (Stone and Priestley, 1996; Barnes and Mercer, 1997), and while I do not currently identify as disabled, I understand that, during the course of my academic career, my identity is subject to change. My mental health condition, autoimmune disease and tinnitus do not currently disable me in terms of how I interact with attitudinal and environmental barriers, but I am aware of the provisionality of my health status. Nonetheless, my position will impact upon how I understand disability (and Down's syndrome) and conduct research in this field. I do not have Down's syndrome, and I have made clear to co-researchers throughout our time working on the project that I do not wish to remove the voices of people with Down's syndrome or speak on their behalf. Rather, my role is to place their voices and experiences at the forefront (Schubotz, 2020). Through continuous reflection on my positionality throughout the research process,<sup>18</sup> I strove to make methodological decisions that would allow the co-researchers to steer the co-analysis and trailer-making collaboration, meaning that I could participate as a member of the research group rather than as an instructor or advisor.

The degree of commonality between the research participants and myself continuously shifted. For instance, we had similar passions and hobbies (such as music and crafting) outside of our working lives, but our working days and levels of autonomy were very different. Whereas I work within a university setting and make the majority of any personal decisions myself, the co-researchers worked within the charity sector and, on a personal level, had family members and professionals making many decisions for them. Recognising these shifts and acknowledging that they influenced my values and thoughts, and ultimately what I understand as knowledge, has been crucial in this research (Charon, 2010; Rowe, 2014). As this research has been conducted with a marginalised group, it has been essential for me to be critical of my positionality and reflexivity and recognise my 'power' within this social dynamic. I have been explicit in my intentions throughout each phase of the research process and highlighted that, although I am the 'outsider' within this 'non-equivalent relationship', my goal is to collaborate with experts/'insiders' (Rowe, 2014, p.627). In doing so, we are

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<sup>18</sup> In order to ensure continual reflection, I kept a reflexive fieldwork journal. This allowed me to self-critique my positionality during each stage of the research and document any ethical and practical issues that emerged during the research (Begoray and Banister, 2010, p.788).

collectively conducting research that challenges their oppression and aims to have a meaningful impact on their empowerment.

### **Sampling and data collection**

The research population were adults aged 18 or over who have Down's syndrome. During recruitment, I specified that this could be any form of Down's syndrome (Trisomy 21, Mosaic or Translocation Down's syndrome), and I welcomed participants of any gender, culture, or religion. I also welcomed a range of generational perspectives, and participants did not need to have watched the documentaries beforehand or have any knowledge of the themes discussed in them.

Before commencing the fieldwork, I had been in contact with a local self-advocacy group (SAG) for people with learning disabilities.<sup>19</sup> I informed the gatekeeper of this organisation of my proposed research and my requirement for members of the SAG with Down's syndrome. Once ethical approval had been granted, I arranged a meeting with the gatekeeper and potential participants to explain more about the research. I produced an easy-read information sheet for members interested in the project. Two weeks after this meeting, the gatekeeper confirmed that six members with Down's syndrome were interested in joining the project; however, by the time the fieldwork commenced, this number had reduced to four (due to miscommunication between new and previous gatekeepers). Of the four participants, one dropped out after the first Film Club but was happy for her views expressed in the first session to be included in the thesis.

Given the parameters of this research and the qualitative nature, the sample size was deliberately intended to be smaller in size, as I anticipated that the data collection was likely to be substantial. However, due to the reduced number of co-researchers, I attempted to recruit a second round of participants. In order to do this, I shared details of the project through my own social media channels and University of Leeds accounts, such as The Centre for Disability Studies and Faculty of Social Sciences. I produced all project information in easy-read format and a short animated video explaining what the project entailed. Additionally, I held pop-up sessions in a local café run by and for people with Down's syndrome, where I was available to meet with potential participants and discuss the project over coffee and cake. Unfortunately, I was unsuccessful in recruiting a further group of co-researchers and, therefore, ended up working with a smaller sample size than initially anticipated. As a way of addressing this, and in order to gather more data, I received permission from the co-researchers to visit other

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<sup>19</sup> I refer to the self-advocacy group using the acronym SAG rather than using the name of the organisation. This is to ensure the anonymity of the co-researchers.

learning disability organisations, where I screened the mock documentary trailer and gathered audience responses via 'vox pop' style on-camera interviews. These sessions proved very successful, and I gathered valuable data from audiences with lived experiences of learning disabilities. Before meeting with these organisations, I revisited the ethical implications and obtained updated ethical approval from the Ethics Committee (see Appendix I).

The co-researchers were a 27-year-old female and two males aged 54 and 56. They all attended the same SAG and had been friends and colleagues for many years. Other than their shared condition (Down's syndrome) and the fact that they lived with their parents, other characteristics and demographic information were unasked and unknown as this was not relevant to the project. The only sampling criteria the co-researchers needed to meet was that they were over 18 years of age and had Down's syndrome.

Recruitment for the fieldwork was directly negotiated with the gatekeepers at the SAG. Informed consent was obtained from each co-researcher and provided in an accessible, easy-read format. Before the first Film Club had taken place, I enquired via the gatekeeper whether any participants had specific access requirements. At this point, it was agreed that it would be best to spread each Film Club out over the course of a working day (10 am to 3 pm for members of the SAG). I also arranged regular rest breaks and one-hour lunches. Other than certain dietary requirements, these were the only reasonable adjustments that needed to be made.

The Film Clubs took place at the University of Leeds campus, and I arranged travel to and from campus for each session. The third phase of the research involved storyboarding and filming a mock documentary trailer, and this took place in several locations, including the office space and training café used by the SAG.<sup>20</sup>

During stages two and three of the data collection (outlined below), I gave co-researchers various options for expressing their thoughts. They could do this verbally or write down or draw their thoughts and feelings, with or without my support and the aid of the SAG support worker. Creative methods were optional, and typically, the co-researchers used verbal communication to express their opinions, with very little support from myself or the support worker. With any research being conducted with people with a learning disability and their service provider or support worker present,

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<sup>20</sup> A storyboard is a visual representation of a film sequence, breaking down the action into individual panels. Within these panels can be images, drawings, dialogue, or any information relevant to the mapping out of the film (or in this case, film trailer).

there is a concern that gatekeepers/professional staff may attempt to interfere with the research or speak on behalf of participants. Before the Film Clubs took place, I discussed the objectives of the project with the support worker. I clarified that my role involved facilitation of the session and support where required, and all the support worker would need to contribute was guidance or support if or when the co-researchers asked for it and possibly help with written or verbal communication if required. For ethical reasons, a support worker was required to be present during the research, and I acknowledge that this may impact how the co-researchers answered questions or expressed themselves.

### **Methods of data analysis and generation**

In the spirit of co-production of knowledge, I conducted the Stage One analysis myself and Stages Two and Three of the analysis collaboratively with the co-researchers. Therefore, there is no usual division between stages of data collection and analysis of the data. There is a merging of these stages, as the remainder of this section will outline.

#### **Stage One – Multimodal textual analysis**

The first phase of the research involved a critical analysis of three documentaries broadcast in the UK between 2012 and 2017: *The Specials*, *The Undateables*, and *A World Without Down's Syndrome?*. This phase of the analysis employed multimodal critical discourse analysis (Kress and Van Leeuwen, 2001; Machin and Mayr, 2012) and textual analysis. The study of multimodality stems from the field of visual semiotics in which 'common semiotic principles operate in and across different modes' (Kress and Van Leeuwen, 2001, p.2). Pioneered by the linguists Gunther Kress and Theo van Leeuwen, multimodal analysis is a 'social semiotic approach to visual communications' and representations which provides tools for the analysis of visual texts (Machin, 2007, p.viii).

Where the study of semiotics focuses on systematically identifying individual signs and what they might signify (for example, the colour red might connote danger), a multimodal approach studies the way that signs are used in multiple modes, as well as how the interpreter might recognise and make meaning from these multiple signs (Kress and Van Leeuwen, 2001; Machin, 2007; Machin and Mayr, 2012). The most straightforward characterisation of multimodal analysis is that it is 'an analysis of the rules and principles that allows viewers to understand the meaning potential' of certain visual elements, such as framing, colour, sound and typeface (Machin, 2007, pp.ix-x). In order to explain the relevance of multimodal analysis and to contextualise this analytic method within the parameters of this thesis, I will borrow an example outlined by Machin (2007, p.20):



When we switch on the television to watch a news broadcast we can see the way that words and graphics have invaded the visual as captions flow beneath the presenter as they speak, as graphics may appear behind them. Of course, digital technologies can explain how this has become much easier to do. But they cannot allow us to explain how we should decide to merge, to change the traditional roles that they formerly played. They cannot explain why there should now be such attention to these details as never before, as in the case of the developments in newspapers and magazine.

Like news broadcasts, documentaries include many recognisable visual elements that each play a specific role in how audiences make meaning. By approaching the medium of documentary film and television using the toolkit available through multimodal analysis, we should be able to recognise the visual elements, sounds, language, icons and images that, when combined, communicate specific ideas and concepts to audiences who then interpret these signs to make meaning of the scenes they watch and characters they might encounter.

A multimodal text is one that creates meaning by using more than one semiotic system or mode of communication, such as linguistic (written or spoken), visual and sound. Film is the most obvious example of a multimodal text, but computer games, advertisements and websites are also examples. My analytical approach to the documentaries also involved textual film analysis. Textual analysis, in literary and film studies, involves deconstructing a text 'into its constituent formal elements', tracing the different modes and how they interweave throughout the course of a film (Kuhn and Westwell, 2020, no pagination). Both multimodal and textual analysis approaches involve the reader drawing on their own knowledge of a specific culture within the text in an attempt to form an interpretation of said text, essentially trying to identify the meaning-making elements within the text (McKee, 2003). By deconstructing the documentaries, I have been able to identify which modes, genre conventions and signifiers create meaning and how audiences might interpret this.

I analysed the documentaries during the first stage of the fieldwork. I watched the documentary film (*A World Without Down's Syndrome?*) in full, as well as all episodes from both seasons of *The Specials*. Out of the 11 seasons of *The Undateables*, six episodes featured cast members with Down's syndrome. I selected three of these episodes based on the amount of airtime the cast members had in the episode (and, therefore, with more potentiality for textual analysis). I watched these episodes in their entirety and took detailed notes during this initial viewing of the documentaries. The second step involved accessing transcripts for the documentaries (using the subtitles available on Box of Broadcast), which I then annotated during a second viewing of the texts. By conducting several readings of the texts, I was able to identify visual

elements, sounds and scenes that I deemed useful for further examination in the co-analysis stage.

### **Stage Two – Group analysis**

The second research phase involved collecting empirical data through group discussions with participants. I hosted three film clubs whereby I met with my co-researchers to view excerpts from *The Specials*, *The Undateables*, and *A World Without Down's Syndrome?* I used a focus group technique to facilitate group discussions, as this enabled less formality and more flexibility. One of the specific features of the focus group is that this technique uses 'non-standard' procedures for collecting information (data), meaning that the discussion outline and questions being asked do not follow a predetermined or rigid order (Acocella and Cataldi, 2021, p.5). Acocella and Cataldi (2021, p.6) suggest that the term *information* is preferable to *data* as the latter etymologically refers to something that is given, something that already exists and is merely waiting to be collected by the researcher. The reality is that research data is always influenced by the social context in which it is collected; therefore, in the focus group, the data (or information) are the discussions produced by the verbal and non-verbal interactions between researchers and participants. It was important that co-researchers felt comfortable and relaxed during the sessions. The versatility of a focus group technique allowed for communication to feel more like everyday interactions than formal or imposing discussions. One of the main objectives of this research was to hear how people with Down's syndrome experience documentaries about relationships, independence and PNS screening debates. Therefore, the phenomenological basis of focus groups was ideal and created a synergy within the group that meant they could fully express themselves.

I organised three focus group sessions, which I named 'Film Clubs' so as to add to the informality and reflect the sense of fun I wanted to create within the sessions. My previous experience working at a People First organisation meant I was aware that members of these organisations are regularly asked to participate in research. Many of the people I worked with found this tedious, especially if the research did not involve creative methods.<sup>21</sup> For that reason, I intended to create a research project that was not only of academic and social relevance but one that the participants would enjoy, where they could be creative, and the arts-based activities were guided by their

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<sup>21</sup> People First membership organisations run throughout various towns and cities in the UK. These organisations are run by and for people with learning disabilities and involve self-advocacy practices that enable people to 'speak out, be respected and live active, healthy and happy lives' (People First Merseyside, 2020).

concerns and preferences. During the Film Clubs, I was responsible for selecting discussion points, but these were not fixed, and conversations could flow freely. Stage Three of the fieldwork also allowed for creativity, and co-researchers were responsible for the direction of the documentary trailer activity. I will cover this in greater detail in the next section.

Another important aspect I considered during the fieldwork's earlier stages was the location of the Film Clubs. I informed the gatekeeper and participants that location options were: a) on the University campus; b) at the SAG premises (they had several spaces in which they worked within an office unit); c) or a neutral building that was accessible and within my research budget. The co-researchers decided to conduct the Film Clubs on campus, as they had previously visited the university for another project and enjoyed working from this location. We carried out the storyboarding and film-making activities within their offices, where there was more space to film.

Film Club One involved an analysis of *The Specials*, and the theme we were exploring was Down's syndrome and in(ter)dependence. Film Club Two screened excerpts from *The Undateables*, and the theme was relationships and sexuality. The final Film Club explored issues around PNS for Down's syndrome and selective abortion, and together, we watched scenes from the documentary film *A World Without Down's Syndrome?*

The group discussions that took place in the three film clubs were an opportunity to find out how the co-researchers felt about the documentaries, identify whether the documentaries sparked any particular emotions, enquire as to whether the themes covered in the documentaries made them think about their own reality and whether there were any similarities or differences. As the co-analysis took place, I attempted to find out from co-researchers what they might do differently (or similarly) if they had an opportunity to produce their own documentary (see Appendix F). I intended for the group discussions to be as flexible as possible; therefore, the questions in Appendix F were not rigorously followed but acted as discussion prompts rather than a script. Participants needed to feel free to explore the idea of making their own documentary without me inadvertently guiding their ideas. The film clubs and analytical work carried out within them were audio and video-recorded, and I transcribed any relevant data/information after the event. This meant that I could fully engage in the group discussions without needing to focus on recording important aspects of each conversation, as I would have footage I could later rely on during the transcription stage. The video recording used a wide-angled lens so that all co-researchers would fit in the frame, and I could observe body language and facial expressions throughout the sessions. This was particularly useful as oftentimes,

the co-researchers would use hand gestures rather than spoken discourse to explain what they meant.

### **Stage Three – Co-producing the documentary trailer**

The final phase of the analysis involved storyboarding the co-researchers' thoughts and ideas in terms of how they would like a life with Down's syndrome to be represented within the documentary genre. During the Film Clubs, I prompted co-researchers to imagine how they would like their own hypothetical documentary film to be produced. I collected any ideas that emerged from the Stage 2 co-analysis and used these as prompts during the storyboarding sessions in Stage 3. For example, Albert had suggested he could be filmed travelling independently in Film Club One, so I reminded him of his idea during our storyboarding work.

We met on three separate occasions to storyboard and film the mock documentary trailer. In the first storyboarding session, we created mind maps of how the co-researchers envisioned their documentary trailer (see Appendix H). We used pens, flipchart paper and whiteboards to record our ideas. We revisited the list of questions above that were used in the Film Clubs, and over the course of the session, the co-researchers decided what they wanted me to film, how it would be filmed, the locations of each scene and the logistics of the production, such as narrating the trailer themselves and including accessible captioning. I will discuss the process of co-producing the trailer in more detail in Chapter Eight.

We spent the second and third sessions filming content for the trailer. This involved travelling to different locations, filming, and interviewing co-researchers 'on-the-go'. As one of the co-researchers (Dawn) had requested to be filmed at work, I travelled to the local café she works at (with their full permission) and filmed her Saturday shift shortly after the final group session. During the final session, we also recorded voiceover material to be used in the trailer.

The co-researchers entirely steered this phase of the research, and they shaped how the trailer was produced. Following the storyboarding and filming sessions, I used editing software to create the mock trailer. I edited the previously recorded audio and video footage and produced a short trailer. Once I had finished editing the trailer, I met with the group and asked them to watch the trailer separately, after which I received feedback on what they liked and did not like. I was mindful of potential peer effects that can occur during group discussions; therefore, I felt it was important for the co-researchers to watch the trailer independently so as to receive their authentic feedback. All three co-researchers were happy with the edit and decided they would

like to hold a premiere for the trailer with their fellow colleagues at the self-advocacy group. This was arranged, and after members had watched the trailer, I filmed audience responses and conducted 'vox pop'-style interviews for feedback.

### **Audience responses**

Due to the success of the film premiere and audience reviews, as well as concerns over a reduced amount of data due to participant drop-outs, I decided to screen the trailer with another local SAG and gather their reactions to it. With the permission of the co-researchers, I visited a local organisation that works with people with learning disabilities and screened the mock documentary trailer. Post-screening, I conducted 'vox pop' style interviews with audience members to gauge their responses to the trailer and ask how they would choose to be represented on screen if given the opportunity. These short interviews were collated and edited into one video for the purpose of analysis and were not shared with anyone else. Each audience member taking part in the short interviews was asked to sign a consent form and assured that their responses would be anonymised in the thesis (see Appendix C for a copy of the easy-read consent form used).

Once all stages of data generation were complete, I transcribed the six group sessions and audience responses and used thematic analysis in order to complete analytical readings of the data. I read the transcribed data several times, and I was able to extract interesting and relevant areas, which I then organised into thematic categories. This loose coding framework was revised and reinterpreted during the course of the coding process until themes and discussion points to be expanded on in the thesis were finalised.

I then revisited my analysis following the analysis conducted with the co-researchers. Both analyses and interpretations of the documentaries were compared, and the differences and similarities between how I understood the texts and how the co-researchers interpreted them revealed interesting findings, which I will discuss in depth in chapters 5-7. One of the most important aspects of my research is that I am relying equally on my own analysis and interpretation of the documentaries and the experiential knowledge produced through the participants' analysis of the same documentaries, which the next section will elaborate on further.

### **Ethical considerations**

#### **Confidentiality and anonymity**

All participants were asked to select a pseudonym in order to protect their confidentiality and anonymity. The participant information sheet included a research

participant Privacy Notice in line with the Data Protection Act and The University of Leeds Data Protection Code of Practice. All personal data collected was classified as confidential, securely stored, and managed carefully. Any personal or descriptive data has been de-identified and presented in ways which limit attribution to specific individuals. For example, I use the acronym SAG to refer to the self advocacy group the co-researchers are a part of. When referring to them specifically in transcripts, I anonymise the name with stars (\*\*\*\*\*). Similarly, when the co-researchers mention the names of other people outside of this research, I use stars to anonymise their names. The nature of the research (video-recorded group sessions and co-production of the documentary trailer) meant I could not promise 100% confidentiality to participants. For example, I could not guarantee that all participants would respect confidentiality, although best efforts have been made to maintain this, and I discussed the importance of confidentiality with the group.

Any recorded footage was only shared subject to the permission of the co-researchers. For example, one co-researcher thought it would be useful to upload the mock trailer on YouTube to share it with other members of their organisation and family and friends. Therefore, this was uploaded with the permission of other co-researchers, and once I had explained that I would copyright the material (see Appendix G). I explained to the co-researchers that there are limits to their confidentiality due to inadvertent breaches, and the informed consent document outlined that confidentiality cannot be 100% assured. For example, if a participant disclosed information I believed to be a safeguarding issue, I would have first worked with the participant to encourage and support them to report this to the relevant authorities. If they were unable or unwilling to do this and I judged that the individual was at significant risk of harm, I would have been responsible for reporting this safeguarding issue directly to a relevant body.

### **Informed consent**

In line with the ESRC Framework for Research Ethics core principles, participants were fully informed about the purpose, nature, and possible uses of the research and their data. From the outset, I informed participants about what their involvement in the research entails (including potential risks). Full and informed consent was sought, and consent was re-visited regularly as the project developed. I made the co-researchers aware that participation (including group work and answering questions) was completely voluntary, and they could withdraw consent at any point without negative consequences. I informed participants that video and audio recordings of group work and interviews could be stopped at any time, and they were also given sufficient time to consider their participation fully. I explained this information verbally and through an

easy-read participant information sheet sent prior to the commencement of the first Film Club.

At no point did I assume that because the co-researchers had a learning disability, they would be unable to give informed consent. All members of the SAG have previously demonstrated that they can give informed consent as they have completed membership forms covering all research projects and activities. I am confident that informed consent was obtained, as all of the project information was relayed in an accessible manner. Co-researchers also had access to a member of staff from the SAG throughout the entirety of the research, who assisted in communicating the meaning of informed consent when necessary.

### **Avoiding 'gazing', navigating sensitive subjects and addressing 'vulnerability'**

It has been widely reported that traditional research within social and medical disciplines has a somewhat problematic history with disabled people (Oliver, 1990; Morris, 1992; Zarb, 1992; Barnes and Mercer, 1997; Barnes, 2003; Tregaskis and Goodley, 2005). Advocates within the inclusive research paradigm have described how, historically, research pursuits have treated disabled people as research subjects and how social research relations often reproduce systems of oppression, serving only the researcher and not the 'researched' (Ramcharan et al., 2004, p.85). Perhaps one of the most important ethical considerations to be made in this research relates to the 'inquiring gaze' (Ignagni and Church, 2008, p.626). Traditional research involving disabled people is often based on observation, or what Garland-Thomson (2009, p.48) refers to as 'staring for the sake of knowing', with the primary aim being to produce knowledge about a particular impairment or medical condition. Disabled people have had to endure 'curious staring' (Garland-Thomson, 2009, p.47) and the 'medical gaze' (Foucault, 2003, p.9) since the birth of medical-scientific inquiry. This 'human curiosity' as a means of knowledge-gathering has often resulted in disabled people, or any human variation that differs from the so-called 'norm', being scrutinised, categorised, and frequently converted 'into the monstrous, sick, polluted, contagious, mad, queer, and deviant' (Garland-Thomson, 2009, p.49). This thesis does not regard individuals with Down's syndrome as an 'object of curiosity' (Ignagni and Church, 2008, p.632) and does not seek to feed curious appetites surrounding the medical condition. Instead, this research seeks to draw on ABR in order to provide alternative ways to 'language' the experience of Down's syndrome and potentially unlock new relationships between audiences, researchers and participants (Ignagni and Church, 2008, p.633).

As this research involved human participants, a further ethical issue to be considered involves the relational concept of 'vulnerability'. This concept was discussed at length in Chapter Two; however, in terms of ethical procedures, the term *vulnerability* refers to any participants who might be at an increased risk of harm or wrongdoing as a result of the research process (Bracken-Roche et al., 2017). According to the University of Leeds ethics guidelines, examples of those belonging to vulnerable groups include children, those with 'mental disabilities' and individuals who can only give informed consent through a parent, carer or guardian (Nadin, 2021, p.3). As Down's syndrome is a congenital condition and also involves some degree of learning disability, an individual with this condition would fall under the classification of 'vulnerable'. It is unknown whether the co-researchers did indeed consider themselves to be 'vulnerable', and the concept of vulnerability does not necessarily match the lived experience of the co-researchers (van den Hoonaard, 2018, p.305). Nonetheless, for the purposes of this research and in accordance with ethics committee guidelines, participants were treated as belonging to a vulnerable social group. Therefore, I paid special attention to ensuring that the rights and dignity of such participants were safeguarded.

Finally, as many of the themes and topics that were explored in this research pertained to sensitive and potentially distressing issues, careful consideration was paid to how I would broach these issues with co-researchers. Hollomotz (2018) states that many researchers avoid sensitive discussions with 'vulnerable' populations, often due to concerns about daunting ethical application processes. In order to ensure the safety and well-being of my co-researchers (and to gain ethical approval), I reviewed the documentary footage prior to the fieldwork. I only screened excerpts that were sensitively portrayed and did not include overly graphic or distressing scenes. This was especially important when screening *A World Without Down's Syndrome?* as some of the discussions around selective abortion and the eradication of Down's syndrome could potentially be upsetting for some participants. I am mindful, however, that this may appear in some way paternalistic and that I, as a gatekeeper, was deciding what co-researchers can and cannot handle in terms of distress levels. To resolve this, I ensured that co-researchers knew that I would provide access to these if they wish to view the full film or series in their own time. Co-researchers were reminded at every stage of the research process that if any discussions were too upsetting and they wished to leave the conversation or no longer wanted to participate, these options were available to them at any point. I also provided co-researchers with a communication tool that they could use to let me know (non-verbally) that they were 'okay' or 'not okay' (see Appendix J). I also provided co-researchers with an easy-read handout detailing organisations they could contact 'out of hours' for support if they felt distressed by any of the topics (see Appendix



l). In addition, as the Film Clubs followed a focus group methodology, I anticipated that participants would benefit from this kind of environment as it allows peer group support and reassurance (Liamputtong, 2011, p.107). This became evident in all of the group sessions, as co-researchers frequently offered one another support and reassurance.

One staff member from the SAG accompanied participants to the Film Clubs and was present during some of the storyboarding activities. Co-researchers also had the option to bring along family members or friends for support. While conducting research with people with learning disabilities can present certain challenges, these difficulties must be navigated willingly and appropriately so that people with Down's syndrome are given an opportunity to voice their thoughts on sensitive issues such as right-to-life debates, selective abortion, right to intimate relationships and living independently.

### **Limitations of research methods**

This research sought to explore discourses of Down's syndrome within documentaries and to deepen understanding of the experience of cultural representations from the expertise of people with Down's syndrome. Creatively and collaboratively, co-researchers have formed epistemologies (knowledge based on their lived experiences) surrounding life with Down's syndrome and how they navigate issues around interdependence, relationships and PNS. The methodological aims and objectives have been accomplished in many ways; however, it is important to acknowledge the limitations of the research methods and consider the possibility that they may have impacted the overall thesis. The remainder of this section will comment on how power dynamics and acquiescence may have limited the findings and discuss some of the practical challenges I faced during the fieldwork.

### **Power dynamics and acquiescence**

As with any research involving disabled people, issues around uneven power dynamics exist and need to be acknowledged and addressed throughout the life of the research project (Porter and Lacey, 2005). I did my utmost to assure co-researchers that my role as the researcher did not assume power or control – I was not there to educate or instruct but to facilitate group discussions and provide support where needed. Even with such assurances, it is possible that the co-researchers were impacted by the power dynamic within our group, although this was not suggested in any conversations I had with them or the gatekeepers. For instance, there is no way of knowing if acquiescence took place within our discussions or whether the co-researchers' answers were based on what they thought I wanted to hear.

Much of the literature on research involving people with a learning disability suggests that there is a greater tendency for respondents to acquiesce – agree with anything the researcher is saying – a paradox that is often referred to as ‘yea-saying’ (Finlay and Lyons, 2002, p.14). This is usually explained by suggestions that learning disabled people are more susceptible to suggestibility and generally are more submissive, with few researchers considering other potential reasons for acquiescence, such as interview style or research setting (Finlay and Lyons, 2002; Porter and Lacey, 2005). The challenges that come with interviewing people with learning disabilities are predominantly attributed to some sort of failure on the part of the respondent – they are often described as ‘lacking’ the skills required for a successful interview (Hollomotz, 2018, p.161).

Discussing acquiescence in the context of children, Porter and Lacey (2005) suggest that children only appear to acquiesce in situations where either the interview questions are too complex, they feel interrogated, or when abstract concepts are not explained in sufficient detail. It is imperative when working with people with learning disabilities that the depth of questioning is altered to suit individual respondents, dependent on their communication methods and personal objectives for the research project (Hollomotz, 2018, p.153). For example, when I asked a question that was met with silence or unsure expressions during one of our group discussions, I rephrased the question to make it easier to understand. Similarly, the co-researchers were comfortable enough to tell me when they were unsure of something. I would always confirm understanding before moving on with the discussion. This can be seen in the following transcription from a discussion we had during Film Club Three:

Researcher: Yes so basically if she finds out that the baby has got Down's syndrome she's got a choice. She can either keep the baby or she can have what's called a termination

Albert: Termination

Kevin: I was gonna say that!

Researcher: Yeah, termination

Dawn: Yeah

Researcher: So have any of you heard that word before?

Albert: Yeah, termination yeah I've heard of it

Researcher: Do you know what it means?

Albert: No

Researcher: No, ((looking at Kevin)) what about you?

Albert: Have you Kevin?

Kevin: I've heard of it

Researcher: Yeah so it basically-when a pregnant woman has a termination, it means that she's having a medical procedure to end the pregnancy.

Albert: Yeah

Researcher: And sometimes people call it an abortion.

Kevin: Oh I was gonna say that.

Through the use of plain, straightforward language and concrete reference tools (presentations with visual corresponding images), these discussions were not only made more accessible, but they improved the quality of the data being collected (Hollomotz, 2018, p.153).

### **Practical challenges**

I faced some technical challenges during the first Film Club, which were unavoidable. For example, the HDMI cable to connect my laptop to the large monitor was defective. Fortunately, this did not cause too much disruption – as the group was small, we were able to comfortably sit together and watch the documentaries and view slides from my laptop. Had there been more than three participants, this would not have been possible.

Another practical challenge transpired during the transcription phase. Two of the three co-researchers had significant speech impairments, which meant that whilst transcribing the sessions, I faced some difficulties. I often had to listen to audio from the sessions several times to make out certain words or phrases. When this was not possible, I would try to lip-read utterances using the video recordings. However, there were some instances where this was not possible; therefore, a small number of utterances were left blank in the transcription. Rather than perceiving this as a methodological challenge borne of differing communication styles, the fault, I believe, lies with the technology used. In future research, I would invest in better-quality audio equipment to enhance speakers' voices and remove background noise.

### **Dissemination of research**

One of the conditions of my funding body is to make my thesis available on their repository of theses. Once I have completed my viva, I intend to disseminate the findings of this research in several ways. I intend to publish several academic publications relating to this research project and my consequent findings. I also intend to apply for a post-doctoral fellowship in the hopes that a documentary film can be co-produced as part of an ongoing collaboration with people with learning disabilities. I situate myself within disability studies, and I understand this field as a site where academic knowledge should be made accessible beyond academia in keeping with the spirit of emancipatory

research. Therefore, I intend for my findings to be accessible to people with Down's syndrome and people with learning disabilities, as well as the general public. I intend to share the easy read Executive Summary in the opening pages of this thesis with People First organisations as well as distribute this through my own social media platforms. In doing so, this disseminates the project's findings to a broader audience in an accessible manner. However, most importantly, it means the research is working towards the greater goal of a fairer, less disabling society. It is difficult for a doctoral thesis to make immediate, radical change; however, this research certainly works towards social change, bringing us that bit closer to the horizon.

## ~ Chapter Five ~

### Representing Down's Syndrome and In(ter)dependence

#### Introduction

In Chapter Three, I briefly discussed some of the critical literature surrounding in(ter)dependence and Down's syndrome and how the issue of dependence/independence is often presented within different genres. This chapter will examine how in(ter)dependence frames the representation of people with Down's syndrome in the documentary series, *The Specials*. This chapter combines my research on the making of the series with my own analysis, and the co-analysis conducted with co-researchers, in order to explore the discursive practices evident in *The Specials*. The following sub-sections will focus on specific scenes within *The Specials* that represent in(ter)dependence, including the housemates' weekly food shop, a trip to Malta and various scenes demonstrating peer support. The aim of this chapter is to demonstrate how dependency and in(ter)dependency can be embraced while dualistically offering alternatives to dangerous, dehumanising narratives of dependency, as described by Goodley (2020). I will explore the oppositional work (or rehumanising) being conducted in *The Specials*, drawing attention to examples of dependency being embraced in the framing of the docuseries. Before introducing the analysis, I will provide an outline of the docuseries and comment on the background of the production. I will also outline some of the key terms defined to co-researchers prior to the screening of *The Specials*, discuss the co-researchers' initial impressions of the show having watched the introductory scenes, as well as considering the co-researchers' reactions to the title of the docuseries.

#### Background of *The Specials*

The two-season docuseries, *The Specials*, follows a group of five housemates living together in Brighton, UK. Hilly, Sam, Megan, Lewis and Lucy were in their late teens/early twenties at the time of filming. All but one of the housemates have Down's syndrome (Lewis has William's syndrome).<sup>22</sup> The house they share was sourced by Hilly's parents – Carol and Dafydd – and they had been living together for two years before filming for the show began. The process of securing funding for the shared house was complicated. An interview with Carol and Dafydd on *The Specials*' website

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<sup>22</sup> William's syndrome is a rare genetic condition that approximately one in 18,000 people in the UK live with. Much like Down's syndrome, people with William's syndrome often have distinctive facial characteristics and some form of learning disability (Williams Syndrome Foundation, 2022).

outlined Hilly's accommodation options following her nineteenth birthday. These options, given to Hilly by social services, were staying at home with her parents, applying for the waiting list for a council home, where she would live alone, or living in a residential care home or supported living facility (*The Specials*, [no date]-a). None of these options appealed to Hilly, who had conveyed that she wanted to live with her friends in shared accommodation. Carol and Dafydd went about setting this up, but it was an arduous task. Potential housemates, support staff, and a property were easily found; however, obtaining the government funding required for this residential living was difficult. Each potential housemate was entitled to disability-related welfare payments (direct payments); however, this would cover only the living costs of each applicant, not the cost of the rent and support staff. Carol and Dafydd persevered after having seven funding applications rejected by public organisations controlling the funding. Once they had enlisted their local MP to become involved in the process, the funding application was finally accepted, and a rental agreement could be taken out on the house. After two years of fighting and advocating, Hilly was able to move into a house in Brighton with friends she had known since childhood.<sup>23</sup>

*The Specials* followed the everyday lives of the housemates – their relationships (with partners, family and friends), their education or work lives, holidays and social activities. The docuseries was observational and unscripted, depicting the everyday lives of young adults living away from home for the first time and the trials and tribulations that come with this transitional time of life.

### **Context of production**

*The Specials* was conceived by a production company called Objective Productions, which worked on behalf of Channel Four, one of the UK's major broadcast television networks. Channel Four has a reputation for the production of 'real-life' documentaries and reality shows and prides itself on having produced 'ground-breaking representation of disabled people throughout [its] 40 year history' (Channel Four Television Corporation, 2022, no pagination). As the home of the *Paralympics*, as well as shows such as *Born to be Different* and *The Undateables* (one of the other documentaries we analysed as part of this research), Channel Four's inclusion policy aims to bring disabled people to television screens and to have a positive impact on both disabled people and non-disabled people alike. According to a creative brief written by the 'C4 Disability Disruption Commission' in 2022, the commission states that its aims are to

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<sup>23</sup> Carol and Dafydd have since opened similar shared houses for people with learning disabilities in their local community and continue to offer advice to anyone looking to do the same (Small Opportunities, no date).

'radically change the national conversation around disability' (Channel Four Television Corporation, 2022, no pagination). Objective Productions was asked by Channel 4 to produce a non-transmissible pilot, filming material for a documentary about people with learning disabilities. Objective Productions then hired television producer Katy Lock to help film the pilot. At the point in which Lock acquired this role, *The Specials* housemates had already been cast. It is unclear how Objective Productions cast the housemates; however, Lock recalls being told that, during Objective Productions' search for potential cast members (via several learning disability organisations), they had been informed of a new house that Hilly's parents had set up, and enquiries were made from there (Lock, 2022).

Together with housemates Sam, Lucy, Hilly and Lewis (Megan had not moved into the house at this point), Lock produced a short taster film, and the pilot was pitched to C4 commissioners. Although Lock considered the pilot episode a real success, the commissioners disagreed and rejected the pilot (for reasons unknown). Lock described in an interview how excited she had been to produce *The Specials*, as it was very different to projects she had worked on previously in terms of there being no steered conversations and the cast's dialogue being completely genuine and authentic (Mize, [no date]). Whereas many documentary reality television shows involve an element of artifice, with many contrived scenarios playing out in order to meet the expectations of networks and command the attention of viewers, Lock felt that *The Specials* was unique in the sense that the documentary footage and dialogue within it was completely spontaneous – the crew simply filmed what the housemates were doing and talking about (Mize, [no date]). For this reason, Lock decided to film and fund the production of *The Specials* herself, with the help of her partner (Daniel May). The decision was made to broadcast *The Specials* as a web series, and production of the show began (Lock, [no date]-b).

Filming took place between 2008 and 2009, and Lock and May produced ten 10-minute episodes, which were released via *The Specials* website every two weeks between September and December 2009. The web series was well received, and press releases were strategically used to generate commissioning interest. As a result, media coverage of the show was extensive, including reviews from broadsheet newspapers (Raeside, 2017). Four months after releasing the first 'webisode', the show was nominated for a Webby Award,<sup>24</sup> eventually winning in two separate categories – 'The

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<sup>24</sup> The Webby Award, established in 1996 and presented by the International Academy of Digital Arts and Sciences (IADAS), is the 'leading international award honoring excellence on the Internet' (The Webby Awards, 2022, no pagination).

Webby' and 'People's Choice' in the reality category. According to the official website, this category refers to 'original online programming of a generally unscripted nature, documenting actual events over fiction, and featuring "ordinary" people over professional actors' (The Webby Awards, 2010, no pagination).

Despite the success of *The Specials* and its accomplishments, Lock and May were forced to return to their 'day jobs' for financial reasons. The show had not been commissioned by any television networks, and although they wanted to produce a second season, they had to work on other projects until they had gathered more funds. It was not until 2011 that they received an unanticipated email from the office of Carolyn Strauss, who was the former head of HBO (a major US television network). A meeting was arranged, and Strauss, who at the time was co-producing the popular television series *Game of Thrones* with D.B. Weiss, told the producers that they both loved the show and saw the value in this kind of docuseries being broadcast to a mainstream audience (Lock, [no date]-a). Renowned American actress and comedian Rosie O'Donnell also praised the docuseries and, together with Strauss, put forward the show to Oprah Winfrey, who agreed to commission the series through her television network OWN (Oprah Winfrey Network).

The producers sold a licence for *The Specials* to OWN, rather than a full commission, as they felt it was important to protect the housemates and the integrity of the show and worried that selling the full commission would mean less control and limitations to broadcasting rights in other countries. The original format of the web docuseries was ten 10-minute episodes. However, OWN requested that the producers re-edit the season and instead have six 21-minute episodes. Lock and May re-edited Season One whilst filming for Season Two was underway, and both seasons were broadcast in the US as a back-to-back marathon on 7<sup>th</sup> September 2014. The show had an even bigger audience in the US, and anyone outside of the US could still watch it through *The Specials* website, provided they paid the £16.00 subscription fee.

### **Why *The Specials*?**

One of the key themes I am exploring throughout this thesis is in(ter)dependence. More specifically, I address the assumed *dependence* of people with Down's syndrome and disabled people generally. I selected *The Specials* as a documentary that might fit into this theme of in(ter)dependence based on its synopsis: 'Multi-award winning series following the lives of Sam, Hilly, Lucy, Lewis and Megan, 5 friends with intellectual disabilities who share a house in Brighton' (*The Specials*, no date-b).



*The Specials* and the context in which it was produced illustrate how normative and ableist representations of Down's syndrome can be countered using documentary as a form. As previously discussed in Chapter Three, documentary can be utilised as a valuable tool to represent the diverse lived realities of disabled people, especially when disabled subjects are collaborators as opposed to observable subjects. This thesis seeks to disrupt the assumed vulnerability and dependence of people with Down's syndrome, as well as 'rehumanise' dependency by embracing it as a core aspect of being human (Goodley, 2020, p.67). As the following analysis will show, *The Specials* has the potential to offer an alternative re-imagination of what it means to live with Down's syndrome. The remainder of this chapter will establish how *The Specials* represented the theme of in(ter)dependence and what techniques were used in the production process in order to do so, as well as questioning whether this docuseries works towards transforming assumptions often made by non-disabled people about vulnerability and dependence in terms of able-ness.

## **Initial impressions**

### **Opening credits**

The opening credits for the first episode of *The Specials* serves as a brief introduction to the series, and the voiceover uses one of the housemates (Sam) as the narrator. This scene introduces each of the housemates and gives a brief snapshot of their personalities, with Sam declaring himself a 'ladies' man', Lucy excitedly exclaiming she 'might have a pint of shandy tonight!', Lewis killing zombies on a computer game, and Hilly showing off her new shopping purchase, a lacy lilac bra. Next, Sam provides the setup narrative that informs the audience of certain key points: that Hilly's parents helped the housemates arrange the house share and that Lucy has a job in a charity shop while the rest of the housemates are still attending college. Sam's setup narrative concludes by telling the audience that they have good times and bad times (already debunking the myth that people with Down's syndrome are always happy), with transitioning shots of housemates in scenes depicting these good and bad times, asserting that whatever the circumstances, they 'stick together' (*The Specials*, 2014a).

The opening scene finishes with the tagline: 'This is our world, and we want to share it with you'. From the outset, it is clear that ownership is an important aspect of the docuseries. Rather than using a voice actor or celebrity to provide voiceover narration (as we will see in Chapter Six is the case with *The Undateables*), *The Specials* uses the documentary subjects, the housemates, as narrators of every episode.

Documentaries often 'use a participant's voice-over as narration because they have insider knowledge and a right to an opinion' (Rabiger and Hermann, 2020, p.486), and

the explicit presence of the housemates as narrators in *The Specials* projects a clear message – that only they can accurately tell their own stories. Each episode is narrated by Megan, Sam, Lucy, or Lewis.<sup>25</sup> During Film Club One, I asked co-researchers about the voiceover narration, and they all agreed that it was a good thing to have people with learning disabilities telling their own stories, suggesting that it shows intellect and understanding:

Researcher: So it's good to #use# the people with Down's syndrome, and why do you think it's good?

Dawn: #Yeah#

Albert: Using brains.

Researcher: Cos they're using their brains?

Albert: Brain

Researcher: Yeah

Albert: To get, erm, if you don't have a brain, you're stuck

Researcher: Yeah

What I understood Albert to mean here is that using the housemates as narrators shows that people with learning disabilities possess intelligence and can tell their own stories reliably. The narration in *The Specials* is an example of cripistemology, as defined in Chapter Three, whereby the housemates are presenting their own knowledges (or cripistemologies) about Down's syndrome and in(ter)dependence. The embodied narratives of the housemates counter the normative epistemologies of Down's syndrome. In doing so, *The Specials* provides a template for good practice and shows that when the cast is given the time and relevant support, disability documentaries do not need to rely on the voices of non-disabled people to provide and articulate the narrative. This not only allows for a representation that is much more grounded in the housemates' interests and priorities but also strengthens the housemates' sense of ownership.

### ***The Specials*: problematic title?**

Before playing the opening scene, a co-researcher noticed the title 'The Specials' on the projection whiteboard and expressed her disapproval of the term 'special', stating that the title made her feel like she was not 'real'. Clearly, the stigma attached to the label 'special needs' triggered an emotional response from this co-researcher. This is unsurprising given the problematic history of this term and the age of the participant (early 50s). Most of the co-researchers were educated at a time when people with Down's syndrome were placed in segregated schools for children labelled as having 'special needs'. It would seem the long-term scarring of being ascribed the label of

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<sup>25</sup> Hilly was the only housemate that did not narrate any episodes. It is unclear whether this is Hilly's decision or the producer's. This will be commented on further in Chapter Eight.

'special needs' is present for at least one of the co-researchers and that the 'special needs straightjacket' that Roger Slee talks of can feel just as constrictive, even decades after leaving the education system (Slee and Allan, 2001, p.177).

Although I explained that the subjects of the documentary worked closely with the producers and that they would likely have decided on the title *The Specials* themselves, perhaps as a way of reclaiming the negative term and making it something more positive, I got the impression that this did little to comfort this particular co-researcher, as her response to my explanation was: 'That's what I feel, it's being equal'. Clearly, the term 'special' evokes negative feelings around oppression and inequality for this co-researcher, and perhaps some sort of clarification from the housemates themselves at the beginning of the first episode may have alleviated her concerns.

A post on *The Specials'* Facebook account explained how the title came about and how each housemate feels about being referred to as 'The Specials'. Their post revealed there were several reasons for choosing the title:

We wanted a cool, dynamic title – one that captures the fact the housemates are close friends, who share a common bond and are a force to be reckoned with. The guys' bond comes from their friendship, their shared past, their youthful joy for life but also the fact they have an intellectual disability. The term 'The Specials' has a positive resonance in the UK – it's the name of a famous British ska band from the 70s. 'The Specials' were cool, had real attitude and are still going strong today! So for us, the title captured all of these elements brilliantly ... This show isn't about difference. There is not a single scene in Season 1 in which the guys discuss their disability. This isn't because it's a subject we avoided, but because this reality isn't something the guys talk about in their day-to-day lives ... They are just like any other young adult living at the heart of mainstream society and yet they do all this while still having an intellectual disability. We wanted the title, at least, to acknowledge this reality in a positive way ... The word 'special' is commonly used within the intellectual disability community as a factual or positive word: from 'special needs', to 'special education' to the Special Olympics. No doubt 'special' can also be used cruelly, but I think this all comes down to context. In our show we want to make sure the word is entirely positive. Special is a good word! The guys ARE special – but not because of their disability but because they're incredible individuals! (*The Specials*, 2014).

This Facebook post suggests that, for some people with a learning disability (including the housemates from the show), reclaiming the term 'special' is a way of affirming that they see their learning disability in a positive light and are proud to identify as 'special'. However, the term 'special', for many disabled activists and scholars, is generally avoided (Linton, 1998). As Linton (1998) suggests, dictionary definitions of 'special' refer to exceptionalism and extraordinariness – which does not translate to the usage of the term within special education. Within an educational context, 'special' often denotes

segregation – discourses of ‘special needs’ education disable many students ‘through the exclusionary practices of segregated schooling’ or by being labelled as ‘special needs’ (Runswick-Cole and Hodge, 2009, p.199). Although the term is not used in an educational context in the docuseries and is certainly not intentionally derogatory, it still carries with it a negative subtext for many people within the learning disability community and does not overtly serve as an affirmative descriptor of people with learning disabilities. In hindsight, I would have researched the origin of *The Specials*’ title before Film Club One. That way, I would have been able to show the co-researchers the explanation posted on Facebook and better explain (or even justify) a reason for analysing a documentary with this title.

### Defining key terms

It was important for co-researchers to understand the themes we were going to explore before our analysis of *The Specials* took place. Before the selected scenes depicting in(ter)dependence were played for co-researchers, I provided a definition of what I thought best described the term ‘independence’:

Researcher: I have a feeling you will all know about this word. So-

Lisa: ( ) independent living

Albert: Independent traveller!

Support Worker: It’s what [our organisation’s] all about isn’t it?

All: Yeah

Support Worker: And self-advocacy

Researcher: Yeah, it’s so important isn’t it?

Albert: Yeah it is.

Researcher: So I’ve just put a little definition which #says#

Lisa: #( )# I see a house  
there

Researcher: Yes. So it’s got the house ((gesturing to different images on whiteboard)) it’s got someone at work, it’s got someone else at work and then it’s got someone doing what we’re doing now, all sat around a table talking about things.

Albert: Discussed.

Researcher: Discussing, yeah. So to live independently means that people can live with dignity, which is something that you’ll all know about, and it means they can make their own choices and they can all be part of society. So does that make sense?

All: Yeah

Interestingly, co-researchers were quick to point out that, to them, independence prompted ideas around independent living and independent travelling. As the co-researchers are all members of a local self-advocacy organisation, independence is a topic that I presumed had already been discussed at length. Being an independent traveller is clearly important to Albert, as is the idea of living independently for Lisa. In fact, during the latter stages of the fieldwork, when we came to storyboard a

documentary trailer, Albert chose to be filmed travelling on the bus and talking about his role as a volunteer travel ambassador, which I will return to in Chapter Eight.

Another term that was defined at the start of the first Film Club was 'representation'. I presented all definitions and important information to co-researchers using concise and clear language alongside an explanatory image. In the case of representation, I defined this as 'the way a person or thing is shown' alongside an animated image of the back of a woman's head staring into a television and seeing herself reflected in the television monitor. When we were discussing this slide, Kevin suggested that representation is 'like a mirror', which I consider to be a useful metaphor to describe how vital disability representation is – when we see a person like ourselves on the television, it can often feel like a mirrored version of oneself is being represented. For Kevin, representation means seeing someone like him, and although this will not be the first time Kevin has seen someone with Down's syndrome on television, it may well be the first time he has seen someone with Down's syndrome in a documentary film or series. Indeed, when I first played the trailer for *The Specials* to my co-researchers, Albert immediately suggested that they should 'have a go' and was interested in how they, as a group, could represent themselves through documentary.

The idea of representation functioning as almost mirror-like also transpired during the audience review interviews.<sup>26</sup> One respondent, when asked about the importance of people with learning disabilities being represented in documentaries, quite fittingly stated, 'If we can see it, we can be it'. This statement, I believe, encapsulates one of the key messages in this thesis: that the significance of representation cannot be underestimated. The respondents' comments correspond with Hall's reflective approach to representation, as discussed in Chapter Three. For the respondent who believes that representation is mirror-like, it is enough that someone with learning disabilities is shown on screen, helping them to *feel* represented, regardless of the form this representation takes. From a constructionist point of view, the images and language within the scenes are what create meaning. Reality is not so much being reflected as it is *produced*; a version of reality is being represented. This is not to take away from the respondent's powerful statement that 'if we see it, we can be it'; rather, it merely highlights the constructed nature of disability representations and the potentiality they hold for misrepresentation and subjectivity.

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<sup>26</sup> The mock documentary trailer that was co-produced with participants was screened for different learning disability organisations. After the screening, members were interviewed for audience reviews (see Chapter Four for more details).

## Analysis

### The 'Big Shop'

One of the scenes we analysed from Episode 3 in Season 1 of *The Specials* depicts the housemates undergoing their weekly food shop, introduced to viewers by a voice overlay from Sam stating, 'Meanwhile, we need to do our big shop' (*The Specials*, 2014a). Lewis, Sam, Hilly and Lucy are food shopping (Megan is not present as she is away practising for the Special Olympics). The scene opens with a low shot of four sets of feet around a trolley, with fast-paced transitioning shots showing the housemates inspecting fresh produce. Quirky, upbeat music plays in the background as Sam (narrating) states it can take them quite a long time to complete the food shop. The shot then transitions to Sam suggesting they add beers to the trolley, with Lewis telling him they do not need beers.

Hilly appears to have assigned herself as group leader, as she is the housemate seen pushing the trolley, holding a purse and instructing the other housemates on what to pick from the shelves. Hilly seems to be the most outspoken of the group and clashes with several housemates during the food shop. For instance, Lucy suggests they need to buy cat food (for the resident house cat), to which Hilly exasperatedly replies: 'We got some at home Luce'. Lucy replies, 'Well, we need some more', and when Sam then picks up cat food from the shelf, Hilly pushes past him with the trolley and tells him they are not getting it. Between them, the housemates have to decide which items are necessities and which are not. Although support workers can briefly be seen in the background of certain shots, they do not intervene, and the housemates are left to make these decisions on their own. While this may seem like a trivial point, for many people with learning disabilities living in group residential settings, choice and autonomy are limited and often non-existent. Hingsburger (1995, p.13) argues that people with learning disabilities are not taught to develop their decision-making skills, and the 'prison of protection' so many disabled people can find themselves within means that they are *never* given the opportunity to learn how to make decisions. Hingsburger perfectly illustrates the discriminatory nature of protection from decision-making by suggesting:

The very first time you looked up at your parents and howled something like, "WHEN I GROW UP I'M NEVER, EVER, EVER GOING TO EAT PEAS AGAIN", you were saying, even as a child, you could envision a future where you would make decisions about your life. Unfortunately, many people with disabilities are still "eating peas" because they never grew into a state of independence that would allow them such freedom[.] (Hingsburger, 1995, p.22, original emphasis)

Semi-independent or supported living arrangements, such as the arrangement in place for the housemates, make it possible for people with learning disabilities to apply their decision-making skills – they can never ‘eat peas’ again if that is their choice.

Supported living accommodation also contributes to the increase of social networks of disabled people and can empower them to participate more in community life (Cumella and Lyons, 2018). For the housemates to be shown controlling their weekly food shop and paying for the items themselves is significant – it presents to the audience a level of independence and autonomy that contrasts with documentaries that present children and adults with Down's syndrome as dependent and burdensome.<sup>27</sup>

Sam pays for the shopping using his card (or perhaps a bank card for an account shared between housemates) and reads out the bill's total cost from the till display (£167). As the group leaves the supermarket, Lewis can be heard saying, ‘How much? You’re joking!’. Closing the scene with Lewis’s humorous remark adds entertainment value and, more importantly, reiterates the humanity of people with a learning disability. Almost every adult at some point in their lives (or perhaps even after every shopping trip) has voiced their shock at the cost of a weekly shop. It also shows that Lewis understands the relative cost of things; his shock implies that he is cognisant of how much their usual ‘big shops’ costs, which, again, counters narratives of dependency.

Financial autonomy is shown in the ‘big shop’ scene and in a scene from Season 1, Episode 2, where Hilly is shown shopping for a dress and using her bank card to pay for it. In framing the shopping scenes in this way, *The Specials* represents its subjects as adults doing everyday, ordinary things, with autonomy over what to buy and how much to spend. For many people with learning disabilities viewing the show, this could be reassuring or encouraging. Furthermore, for those with preconceived ideas of Down’s syndrome or learning disabilities, seeing the housemates being presented as independent in terms of paying for their own things might be informative and could perhaps lead them to question any assumptions they may have held concerning Down’s syndrome and dependency.

Throughout the ‘big shop’ scene, the musical overlay consists of a playful melody of trumpets, which appears to create a sense of frenzy in the scene. The filmmakers have

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<sup>27</sup> Examples of such documentaries are the films *Educating Peter* (1992) and *Graduating Peter* (2001) or the series *The Special Needs Hotel* (2015). Previous research I have conducted analysing these documentaries argues that they represent children and adults with Down’s syndrome as burdensome and either depict scenes whereby the characters with Down’s syndrome are criticised for depending on support from their families or they are forced to move out of the family home to stay in residential communities where they can learn to be ‘properly’ independent.

used camera angles, transitional techniques, and music to create an impression of a functional, albeit chaotic, food shop, perhaps for entertainment purposes or perhaps because the weekly shop was actually somewhat frantic. The fast-paced shots transition from one housemate to another as they select items from the shelves, negotiating what products they ought to purchase. As Sam pointed out at the beginning of the scene, completing the big shop can take the housemates some time. Rather than reflecting this, the producers have kept this scene relatively short by using an ellipsis technique and editing it as a lively montage that switches between dialogue and music. It is impossible to know how authentic this scene really is, as with any documentary scene. What is important in this co-analysis is that the housemates' autonomy and decision-making skills are being foregrounded.

Upon watching this scene, co-researchers quickly started thinking of ways they could represent themselves in a documentary, and before the first Film Club had finished, Lisa was adamant that they would not be 'copycat[s]' by making their documentary look like *The Specials*. Instead, they would represent independence on their own terms. While the co-researchers agreed that this scene was an excellent way to highlight the in(ter)dependence of the housemates, as they can be seen selecting which items to buy and paying for these items with their own bank card, they were considering ways of better presenting Down's syndrome and independence:

Lisa: I'm thinking as well before I do forget like if you're someone what can answer the phone or owt like that and you picked it up and you said "hello? This is Lisa speaking" as an example, you can film that.

Researcher: Yes. So that's the kind of thing that you think would show independence more?

Lisa: Yeah

Researcher: You at work?

Albert: Mmmmmm

Lisa: And also as well ( ) more independent showing you typing on your laptop or summat like #that# or a computer.

Albert: #Yeah#

Researcher: So you think that kind of a scene would be to show your independence rather than just following you around at the shops?

Lisa: It's alright doing that when you can do it you see. Walking around the different shops. But that's different. It's like window shopping...It's like going out to work you can record somebody doing that or going t'bank and that's real life.

Lisa believed that an emphasis on filming 'real life' is crucial. Just like *The Specials* included 'real life' scenarios such as the food shop, co-researchers were interested in different ways they could show their everyday lives within the form of a documentary. For them, being filmed at work and using different technologies would effectively



demonstrate their independence on screen.<sup>28</sup> Lisa's suggestion that they could be filmed using phones and computers is significant. For many disabled people, independence can be jeopardised by a lack of access to technology. Research into the marginalisation of people with learning disabilities in terms of being unable to access technology confirms that all disabled people, especially people with cognitive impairments, can benefit from technology (including mobile phones and social media apps) and that innovative technologies can have a positive impact on how people with a learning disability function in their communities and workplaces (Bodine and Lewis, 2004; Lewis, 2006; Martin et al., 2021; The World Wide Web Consortium (W3C), 2021). Peter Blanck's (2017, p.41) work on access to the World Wide Web for people with cognitive impairments (including learning disabilities) argues that being able to access the Web 'is an enabler of basic human and civil rights'.

Nevertheless, access to technology and web content is not the only requirement – *accessibility* also needs to be considered. Web-content equality is based on being able to make *use* of technology and the internet (accessibility), something that 'overly complex interfaces, lack of information alternatives ... and the inability to transform content presentation' make very difficult for those with a cognitive impairment (Blanck, 2017, p.41). Lisa's suggestion that the co-researchers film themselves accessing and using technological devices positions them as integral to the workings of the self-advocacy organisation (after all, it cannot function and lacks any purpose without the presence of people with learning disabilities). It simultaneously demonstrates independence in the context of an office environment. Lisa raises an important point that supports Blanck's assertion that access to, and accessibility of, technology and the web can support the independence of people with a learning disability.

Furthermore, the suggestion that the co-researchers use technology on camera also has semiotic significance. Evidencing their use of technology could be an attempt to signify independence. Rather than overtly and verbally explaining her independence, perhaps Lisa understands the laptop and phone as visual signifiers of 'work' and independence. Including these signifiers within a scene would subtly suggest to viewers that the co-researchers can complete work-related tasks using technology and, indeed, possess the skills, confidence and level of independence required within a work environment.

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<sup>28</sup> Some of the participants referred to the work they do within the self-advocacy organisation as 'work'. Although they are not being paid for their roles within the organisation, for them this is their job, somewhere they go to most weekdays to work on various projects.

## **Conflict resolution**

The shopping scene depicts the housemates making financial decisions for themselves as well as what to buy (and ultimately consume). Several other scenes in *The Specials* also demonstrate the autonomy of the housemates. For example, in an episode that shows the housemates going on holiday to Malta (*The Specials*, 2014c), there are several scenes involving group discussions and, at times, conflict whereby the housemates are seen to be expressing their choices and resolving disputes. Six minutes into this episode, the group are sitting on the beach discussing how they should spend their evening. A disagreement ensues when Hilly, who wants to go for dinner and karaoke, is outvoted by the remaining four housemates, who all want to go nightclubbing. The camera angle is at eye level with the housemates sitting inside a windbreaker on the sand, and as the discussion begins, the background music fades, leaving just the noise of the housemates talking and the sound of the waves. When Lucy tells Hilly she has been outvoted and needs to consider what the other housemates want to do, Hilly tries to get Lewis (who is listening to music through his headphones) on-side, to no avail. Megan, the quietest of the group, confirms that she wants to go nightclubbing. After Sam sternly tells Hilly, 'It is OUR decision,' Hilly says she does not want to hear another word from Sam, and the shot fades to black.

The following scene transitions with the sound of pulsating dance music and the local nightlife fading in, with Sam's narration confirming that the group still had not decided how they would spend their evening. It would appear that Hilly's parents and the support workers, who were accompanying the housemates on the trip, have not intervened and have left the housemates to decide between themselves. From behind the camera, the producer asks Lewis and Lucy, who are outside the hotel dressed and ready for the evening, 'Where are we going tonight then?' to which they both reply that they do not know. The camera then captures Megan and Sam asking each other what the plans for the night are, and Sam says, 'Oh, I know', and then proceeds to dance while singing a lyric from a popular Ricky Martin song, 'She Bangs'. Hilly playfully bats Sam away while telling him to 'get a grip', and the group heads off to the nightlife strip.

As they are walking to a bar, Sam's voiceover states that he and Hilly are still arguing; the camera then follows Sam as he walks and talks directly to the camera, stating, 'I want you to tell Hilly she's annoying'. The shot then transitions to an 'on-the-run' interview with Hilly, who, walking towards the camera, states, 'Sam ought to behave, or be quiet, or zip it'. Sam's narration continues as the housemates sit in a bar, and it is confirmed that the group (or possibly just Sam and Hilly) compromised on cocktails. Tensions remain high, and Sam and Hilly, who are sitting next to each other, continue

to bicker until Hilly makes the entire group laugh when she exclaims, 'It's over you and me, okay? And I can't sit next to you, and not tonight!'. Sam responds by theatrically dropping his forehead to the table, and the housemates and support team break out in more laughter. A cheerful musical overlay fades in, with a montage of shots showing the housemates laughing and Sam and Hilly hugging play out until everyone around the table raise their glasses and shout 'cheers!'. The scene then fades to black.

As with the shopping scene, it is evident that, whilst on holiday, either support staff or parents accompany the housemates – but their on-screen presence is limited. The decision to have the housemates in the foreground and keep support staff and parents in the background (through lighting techniques and camera angles) is a testament to the ethos of the show – the commitment to following the lives of Hilly, Sam, Megan, Lucy and Lewis, not their families or support workers. In terms of framing in(ter)dependence, *The Specials* exemplifies how it is possible to keep the focal point on the subjects of the documentary without relying heavily on the narratives of family and friends, which is often common in the telling of stories of a life with Down's syndrome.

Our co-analysis of the scene depicting a dispute between the housemates initiated the following conversation between co-researchers:

Lisa: I think me and Albert does that quite a lot don't we Albert?

Researcher: You and Albert disagree a lot?

Albert: Mmmmm

((Laughter))

Kevin: I'm not surprised! I'm not surprised!

Lisa: We were going out on me birthday and he wanted summat else on and I said I thought it were my day? Being my birthday.

Researcher: So when you two disagree

Lisa: We didn't really disagree, he just went off in a mood.

Researcher: Stormed off in a mood Albert?

Albert: I can ( )

((Laughter))

Lisa: Only cos he didn't want to know

Researcher: But how do you normally deal with people who disagree with you?

Albert: I'm fine

Researcher: You're fine?

Albert: Yeah

Researcher: But how do you make sure that you-that your choices are heard?

Lisa: I think erm, I don't know myself actually.

Albert: Erm, respect

Researcher: And how do you make sure people respect you?

Albert: Talk to em and respect.

Researcher: You show respect when you talk to them?

Lisa: Well he didn't respect me cos he went off in a mood.

Albert: No

((Laughter))

Lisa: Yeah

Kevin: I'm saying nothing!

((Laughter))

Albert: I'm not!

Lisa: We've started already now haven't we?

Albert: I know we are

Viewing the housemates prompted Albert and Lisa to reflect on their own past disputes and how they dealt with them. Lisa recounted a disagreement that took place on her birthday over what to watch on television. They recalled how Albert 'went off in a mood' when he could not watch his choice of television programme, and although he was clearly upset at the time, Albert now seemed to see the humour in the situation. When I asked co-researchers how they would usually ensure that their voices and choices are heard, Albert believed that if he showed respect to the person he was dealing with, he would receive the same respect in return.

*The Specials* includes several scenes where housemates can be seen expressing choice and autonomy. The most significant example of this would be in the first episode, which shows Megan moving into the house. Megan's move from her family home to the house share is presented to the audience as being a move of her own accord; she has made the decision to move to Brighton and live with her friends and, despite her parents' concerns, she is happy about this decision and enthusiastic about starting this new chapter in her life.<sup>29</sup> The reality for many people with a learning disability is that they do not always have the option to move out of the family home, either because their parents do not want them to or because there is no suitable housing accommodation made available to them via the welfare system.

Other examples of choice and autonomy are presented in scenes such as Hilly in the beauty salon, deciding which colour to have her nails painted (Season 1, Episode 5) or picking out an evening gown for her dance performance with Sam (Season 1, Episode 2). Lewis can also be seen articulating his autonomy in relation to food. Season 1, Episode 3, shows the housemates at college learning about healthy foods. In the subsequent scene, where housemates meet up for lunch, Lewis chooses what to eat from the deli counter and, after some deliberation, opts for a chocolate bar. Knowing this is not a 'healthy' snack option, he pauses for thought and then decides, 'Ah, sod it!'

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<sup>29</sup> A stark contrast to Megan's move can be found in a scene in the docuseries mentioned in note 27 page 126, *The Special Needs Hotel* (2015), which shows an interview with a parent of a child being sent to live and train in the specialist hotel for people with learning disabilities. A parent admits that their child does not necessarily want to move out of the family home or train in the hotel but they are making them do it anyway as it is 'for their own good'.

(S1 E3). This scene is reminiscent of Hingsburger's 'peas' illustration discussed earlier and serves as a real-world example of disabled people both having and demonstrating autonomy.

The housemates' freedom to spend their time as they please is also highlighted in a scene in Season 1 Episode 3 where Sam's narration tells the audience that while Megan is away training for the Special Olympics, 'the rest of us are doing our own thing'. Lucy is getting ready for a date, Lewis is playing computer games, and Sam is reading and reciting Shakespeare. These short single shots work in tandem to represent the housemates as independent but also serve to debunk many of the myths surrounding Down's syndrome, such as that people with Down's syndrome cannot read or write or cannot enjoy romantic relationships.

Scenes that counter the dependent narrative can also be found, where housemates are applying makeup, brushing their hair, or shaving – depicting them as independent in terms of personal care. It is significant that daily tasks such as brushing teeth or applying deodorant are included in the documentary. The dominant discourse of dependency is disrupted by showing the housemates' personal care routines. Equally, if any of the housemates did require support with personal care and this happened to be included in the documentary, this would not compromise their independent status. Rather, it would provide further evidence of in(ter)dependence in practice and serve as an example of how people with learning disabilities can live dignified, independent lives, regardless of the level of support they require, provided that appropriate support systems are in place.

Housemates were also shown expressing independence and autonomy in terms of the production of the documentary. For example, Season 1, Episode 5, includes a scene where Lewis is filmed by the front door of the house, waiting for Sam to return from his dance class. Lewis is keen to find out whether Sam has asked his crush out on a date. When Sam walks through the front door, Lewis beckons him to divulge: 'Go on, have you...?'. Sam is visibly confused and looks to the producer behind the camera and asks, 'What's going on?'. Lewis asks Sam if he has a girlfriend yet, and Sam responds by rubbing his head in exasperation. He then looks at the producer and says, 'Katy, come here', motioning for the producer to follow him into the kitchen, where he wants to sit down and have a one-on-one interview about this topic. Sam is directing the producer and communicating his preference as to how and where this narrative plays out, which shows control and autonomy, not only in the context of production, but also in more general terms. Sam is clear in that he wants to tell his story and chooses to do this without the other housemates in earshot. The inclusion of this scene in the final cut

could be an artistic decision, a way to emphasise the observational documentary style. I would be inclined to argue, however, that the framing of this scene suggests that the producers see the value in representing the housemates as independent and capable of autonomy, not just as documentary subjects but as co-creators.

### **Peer support**

*The Specials* also displays in(ter)dependence in the form of peer support. Throughout both seasons, the housemates are seen to provide and receive support from one another. By including scenes that represent 'mundane moments of dependency' that often go uncommented on (such as relationship advice, chats around the dinner table or helping each other get ready for a night out), *The Specials* reiterates the universality of human dependence (Goodley, 2020, p.64). Although the housemates have 24-hour staff support as part of their care package, the informal peer support system they have forged seems equally beneficial. The scenes are set up in a way that suggests the housemates consider their peer friendships *more* valuable than the formal support they receive. For example, there are several scenes where housemates are visibly upset or seek advice, and within all of these, the housemates provide support, not the paid workers. Scenes depict scenarios in which support staff assist the housemates, but these are minimal. It is unclear whether this is because the housemates simply did not require support in the scenes being filmed or whether it was a conscious decision from the producer to film more scenes without support workers in-shot. Either way, the result is that, while support from staff is definitely important in the running of the house, housemates appear to thrive in their interdependent lives with the support of one another, whether this is in a group support situation or one-to-one.

### **Personal issues**

The housemates can be seen demonstrating their in(ter)dependence in various contexts, some serious and some less so. It is clear that, regardless of the gravity of the problem, the housemates turn to each other in moments of crisis. For example, Season 1 sees Lucy struggle with family issues and health problems. Lucy struggles to control her weight, and when she decides to start a diet, the housemates immediately offer advice and suggest healthy eating options. Lucy's efforts to control her weight continue into Season 2. She talks about her relationship with food and her feelings of guilt when eating something unhealthy. Megan's voiceover narration confirms that Lucy has 'decided to get motivated', with Lucy in frame using a laptop to sign up for a sponsored run for charity, a run which 'she's roped Lewis into helping her train [for]' (*The Specials*, 2016b).

During Season 1, in a scene where Lucy is very emotional about her over-eating, she tells the producer she thinks her over-eating might stem from being upset about her parents' impending divorce. In a scene later in the same episode, Lucy sits at the table with the rest of the housemates and informs them, 'Mum and Dad might go to court soon'. Sam immediately offers the group's support, telling Lucy: 'Me, Hilly and Lewis are here to try and help you ... we are getting involved'. Lucy seems comforted by this and tells him, 'You already are Sam', smiling softly. The melodious background music intensifies, and the frame switches to the group standing in the back garden having a group hug before heading off to the pub. This scene not only displays the strength of the bond between housemates but also indicates how important it is to have networks of in(ter)dependence. Although Lucy is clearly very close to her family, it might be difficult to talk about her parent's divorce with them, so having the support of her peers, who know her well and understand her, is crucial. Representing these 'everyday realities of dependency' can go a long way in educating viewers on the 'replenishing qualities of dependency' (Goodley, 2020, pp. 65-73).

### **Practical advice**

Housemates also offer each other more practical support, as seen in Season 2, Episode 5, when Hilly and Megan discuss future plans with Sam. Sam does not feel ready to leave college and seems reluctant to get a job. In her voiceover narration, Megan explains that 'the last time [Sam] tried working, he got the sack'. Sam explains in a later scene that working is not his 'cup of tea' and that he wants to stay in 'high school' forever. Hilly and Megan try to discuss different employment options with Sam, suggesting he work at a café or in a shop:

Megan: D'ya wanna work in a shop?

Sam: No thank you.

Megan: Café?

Sam: Er no thank you.

Megan: ((laughing)) He's going to say no to everything ((looking at Hilly))  
What else?

Hilly: PC World?

Sam: No! Not PC World!

Hilly: Tesco's?

Sam: No! That's boring.

Megan: Really?

Sam: Yeah, I can't do um ... doing tills. No way.

Megan: Well there's another way of working in a shop ... stacking. Putting stuff on the shelves, that's what it is.

Sam: Yeah you stick it on the shelf ...but what do you do next?

Megan: More stuff. You're not gonna spend your lifetime on your iPad, Sam. I mean when you finish college, you will get ... something else ... to do.

Sam: Yes ... mum.

Megan: Sam! Sam.

Sam: Sorry.

Megan: You will get a job one day. Believe me. Only if you start listening.

Sam: Ok.

Megan: That's the main thing. And do things right. Yeah?

Sam: Yeah.

Megan: I mean it!

Megan and Hilly both feel ready to leave college and seem excited at the prospect of getting a job, but this does not appeal to Sam. Like many people in their late teens, Sam might find the transition from college to employment daunting, especially if he had a negative experience in previous jobs. On the other hand, perhaps the kinds of jobs suggested to Sam make him reluctant to work. Clearly, the idea of working in retail or the hospitality sector is unappealing to Sam. While society has undoubtedly come some way in the employment of disabled people - in that it is now against the law for employers to discriminate on the basis of disability - the type of paid work available to disabled people, especially those with a learning disability, is often limited. A recent survey asked people with learning disabilities who are currently in paid employment what types of jobs they do, with office work, work in health and social care, retail work and work in hospitality ranking highest (Harflett et al., 2023, p.18).

Furthermore, the ongoing economic crisis in the UK also means finding meaningful paid work can be difficult, even more so for people with learning disabilities. Unemployment rates for disabled people remain high, with those with a 'severe or specific' learning disability, autism or mental health issue having the lowest employment rates of any disability or health condition (Office for National Statistics, 2022). In addition, a recent report by the NHS on adult social care outcomes found that only 5.1% of people with a learning disability in England were in paid employment (NHS Digital, 2021). This exclusion and rejection from paid employment within the community can negatively impact the lives of disabled people, increase financial hardship, and exacerbate social isolation. Sam wishes to remain within the college environment because it is there that he feels included; his previous work experience has failed to give him a sense of belonging, which would explain his claim that 'working is not suitable for me'. Significantly, none of the co-researchers were in paid employment. Dawn trained at a charity organisation (a coffee shop run by and for people with Down's syndrome), Albert did not comment on any previous paid employment, and Kevin recalled a job he used to have in a clothes shop, but it is unknown if he was paid to work there. The continuing employment gap for people with learning disabilities makes it very difficult to gain the independence they are so often criticised for not having. They cannot, therefore, learn new skills through employment in a meaningful role. Organisations such as WorkFit (a Down's Syndrome Association programme) strive to address the employment gap and match job seekers to



employers registered on the programme. While there is clearly work to be done in this area, progress is being made, and perceptions around the suitability of people with Down's syndrome in paid employment are beginning to be challenged.

### **Relationship advice**

Both seasons of *The Specials* follow the romantic relationships of each housemate, some of which are with each other. For example, a 'love triangle' between Megan, Lewis and Sam emerged throughout the two seasons. When Megan first moved into the house, she began a relationship with Lewis, which was soon ended as he did not pay her enough attention. Eventually, Megan and Sam began a relationship, resulting in some tense and often awkward interactions with Lewis. Despite this, they all remained friends. Before dating Megan, Sam often turned to Lewis for relationship advice. For example, in Season 1, Episode 5, a scene shows Sam asking Lewis to come to another room for a private conversation. Megan's narration informs viewers that Sam plans to ask out someone from his dance class—Lewis's advice: 'Go for it. D'you wanna be my girlfriend, you gotta say. Or you could do what I did to Megan and say, "Oi, do you wanna be my girlfriend? That'll do me"' (*The Specials*, 2014b). When Sam returns from dance class, having failed to ask out the girl he likes, one of his support workers tries to give him some advice, to which Sam responds, 'Alex, don't give up your day job'. Sam responds very differently to Lewis's relationship advice, indicating his preference when seeking out advice about romantic relationships.

Hilly and Lucy also have active dating lives, with Hilly facing more trials and tribulations in her romantic journey. Hilly's dramatic breakups and reconciliations are documented throughout both seasons, with her housemates providing emotional support each time. One of the first examples of the housemates' rallying support comes in the second episode of Season 1 when Hilly's short-lived relationship with Robert is ended (by him) over a phone call while the housemates walk along Brighton promenade. Hilly does not take the news well and leaves the group to sit alone on the beach. Sam joins Hilly and tries to provide some comfort, but, somewhat unsurprisingly, Sam accidentally passing wind and telling her 'don't be acting like it's Eastenders' fails to comfort Hilly.

Fortunately, Lucy takes over from Sam, saying, 'Hills, can I take care of you now?' Hilly hugs Lucy and continues to sob, and Lucy tells Sam, 'I'm taking over now'. Although Sam and Lucy have very different approaches, the framing of this scene shows the important role that peer support plays in the lives of the housemates and provides a further example of embracing or re-humanising dependency.

During the analysis of *The Specials* with co-researchers, they, too, agreed that peer support and friendships were important. Moreover, they displayed their own peer support network throughout our sessions. This was illustrated prior to watching the scene showing *The Specials* going on a group holiday. When Albert saw that the housemates were in an airport, he stated that he might find that upsetting, as airports remind him of a past holiday when his mother became ill. When I gave Albert the option to skip ahead of the airport scene, Kevin told Albert: 'It's a film, Albert. We'll support you, we'll help you'. Lisa reiterated this and told Albert 'We're here to support you. We're a team, we'll work as a team'. Later in the session, when I asked the group how they thought the housemates reacted to Lucy's announcement of her parents' divorce, they agreed that they were supportive. As the co-researchers were answering this question, Kevin whispered to Dawn, 'I can support you', and when I commented on the levels of peer support in the group session, I asked Kevin why he thought it was important to be supportive of his peers. He answered: 'Cos it's like a part of group'. I understood Kevin's comments to mean that the process of in(ter)dependence within a network of his peers enables him to establish a sense of community and belonging. As an informal peer support network, members understand and can better support one another. For many members of formal programs, such as self-advocacy organisations, the peer friendships they make in these groups are often their only friendships (Emerson and McVilly, 2004; Merrells et al., 2019). Peer advocacy groups, such as the organisation the co-researchers are a part of, are crucial to helping people with a learning disability feel more connected – to each other and to their communities (Power and Bartlett, 2018); the supportive behaviour of the co-researchers during our group sessions only serves to bolster this argument.

Similarly to the co-researchers' ability to forge peer friendships through their membership in a self-advocacy group, the housemates in *The Specials* have formed irreplaceable relationships based on their lives together, sharing a home. However, as discussed earlier, local authorities in the UK do not typically sanction this kind of living arrangement for people with learning disabilities. Social services tend to offer support towards living in a residential setting or living alone. In(ter)dependence can be achieved whether living alone or in a residential environment; however, our analysis of *The Specials* shows that the housemates have an enhanced experience of in(ter)dependence as they are able to support one another in almost every situation they face, whether it be family troubles, relationship problems or negotiating the weekly food shop.

## Further reflections

Throughout both seasons of *The Specials*, the housemates can be seen living interdependently, enjoying typical pursuits for young adults – clubbing, dating, playing football, going to the nail salon, surfing, exercising and partying. The only time a housemate is represented doing something different to any other typical young adult is when Megan is filmed at the Special Olympics competing in the equestrian competition. Coverage of Megan’s sporting events is somewhat brief and challenges the supercrip trope. Megan is not singled out as being ‘exceptional’ for taking part in the competition, and the scenes portraying Megan at the Special Olympics are juxtaposed with scenes about her break-up with Lewis, Sam and Lewis’s surfing holiday and Lucy’s issues with over-eating. *The Specials* does not, however, only focus on the social activities of the housemates – the cast are also shown living interdependently in their ordinary, everyday lives as well, performing tasks such as cooking, personal care, cleaning, shopping and gardening. These scenes portray the rhythms and patterns of the every day as described in Wolfensberger’s (1983) normalisation and social role valorisation theories as discussed in Chapter Two. *The Specials* displays normalisation theory in practice and I would argue that, in representing the housemates’ ‘normative’ rhythms, their social value is, indeed, being valorised.

Like any young adult transitioning from living with family to living independently, household chores and the mundane aspects of taking care of their home become a part of the housemates’ everyday reality. Similarly, in line with the norms of this transition, it is not always smooth. *The Specials* does not steer away from the less joyful moments: there are scenes in which housemates are unhappy or unwilling to perform household chores. For example, one episode shows a scene where housemates toss a coin to decide who has to mop the kitchen floor that night. Hilly loses the coin toss and reacts by retreating to her room. Halfway up the stairs, Hilly (who recently experienced another relationship breakdown) shouts: ‘I’ve lost my boyfriend and now I’ve got to do the floor!’ (*The Specials*, 2016a). Scenes such as this not only add to the entertainment value of the series but also highlight the humanity of the housemates. Many viewers will identify with such scenarios. In a study investigating the (mis)representation of Down’s syndrome in UK media, Thomas (2020, p.693) worked with parents of children with Down’s syndrome and found that parents largely applaud recent ‘positive’ portrayals of people with Down’s syndrome yet have reservations in the sense that these representations often ‘fuel sanitized accounts which deny, or at least obscure, the harsh lived realities for many parents of disabled children’. *The Specials* refrains from only including sanitised narratives and there are several scenes that depict the housemates’ struggles. Significantly, these struggles are

not framed as a consequence of having Down's syndrome, they are simply realistic obstacles that most young adults face.

That being said, the show does not explore any sociopolitical issues that often come with living with Down's syndrome. For instance, in the scenes that discuss Sam's not wanting to gain employment, there was no acknowledgement of the low unemployment rates of people with Down's syndrome in the UK, as discussed earlier, and there are no episodes that address the issue of social isolation that many people with Down's syndrome face. For some, this might be a point of contention. This resonates with concerns that representing only the 'positive' aspects of living Down's syndrome or parenting a child with Down's syndrome is *misrepresentation* and could result in less societal impetus to address discriminatory social policies or unequal rights (Thomas, 2020). Both seasons of the show focus heavily on transitional moments in the life cycle and independence. Therefore, to incorporate dialogue about some of the many barriers that people with Down's syndrome face would have taken away from the objectives of the show – to tell the stories of these specific housemates during their transition into adulthood. The theme of transitional in(ter)dependence is important in *The Specials*, and a clear attempt to shift dominant understandings of Down's syndrome and dependency and to revalue people with learning disabilities.

The lack of commentary on the politics of Down's syndrome was not identified by the co-researchers. Rather, the significance of seeing people with Down's syndrome on television was evident in the early stages of the first group session. Before we screened any excerpts from *The Specials*, we discussed some television programmes featuring people with Down's syndrome. This sparked a discussion about the successes of several fashion models with Down's syndrome and how one young woman had progressed from a modelling career to building her own clothing brand, prompting the following response from Lisa: 'That's what I'm trying to be ... cos I like making things and I do dress-making'. Clearly, seeing other people with Down's syndrome on television is affirmative and aspirational for many other people living with the condition. Therefore, analysing and examining the different ways people with Down's syndrome are represented felt like a productive activity for the co-researchers, enabling them to consider how they might like to be represented on screen.

The responses to scenes depicting in(ter)dependence from the co-researchers ranged from recognition to reassurance. For Lisa, watching the 'big shop' scene and seeing the housemates pay for their own shopping was somewhat reassuring: 'I enjoyed it cos ... it felt like they were in control of their own money'. Housemates display their autonomy throughout the series, from paying for their own shopping, to each having

their own house key. These subtle demonstrations of autonomy and in(ter)dependence did not go unnoticed by the co-researchers. As Lisa stated, she derived genuine pleasure from watching documentaries about people she could relate to: 'I just like to watch it, watching people have a real life'. All of the co-researchers lived with family members or in supported living units; however, seeing the housemates living together in a house share prompted them to think about how showing this on television could educate viewers. There was also an appreciation of the way *The Specials* portrayed in(ter)dependence, and the nuanced meaning of in(ter)dependence, as shown in the following conversation:

Lisa: It's showing Down's syndrome can do stuff  
A: Yeah  
Researcher: Mm-hmmm  
Lisa: And also it's saying that Down's syndrome can have their own place if they wanted, and going out-everyday life, they go out shopping  
Researcher: Mm-hmmm  
Lisa: Keep that house and they keep going.  
Researcher: Mm-hmmm  
Lisa: And that's what it's all about  
Researcher: Yeah, absolutely. What do you think Kevin? Do you agree with that?  
Kevin: I do agree with that.  
Researcher: Mmm. So you think it shows a good level of independence?  
Lisa: Yeah  
Dawn: Yeah  
Kevin: Yeah I was gonna say that.  
Researcher: Cos although they're not doing it on their own, they're doing it as a group  
Kevin: We can all do it.  
Lisa: Yeah that's it!  
Dawn: Yeah  
Lisa: You're not doing it on your own, you're doing it as a group.  
Dawn: Yeah  
Researcher: Exactly, because independence doesn't mean having to do things by yourself, does it?  
Lisa: No  
((Dawn making happy humming noise))  
Researcher: It just means making your own choices...  
Albert: Yeah  
Researcher: ... having some dignity, you know, you can support each other as a group and still be very, very independent.  
All: Yeah

At the start of the first Film Club, when important words were defined to the group and in(ter)dependence was explained, the co-researchers seemed to understand and agree with the definition I used. I would argue that the above excerpt demonstrates this understanding and shows that the co-researchers have recognised the ways in which *The Specials* portrays a similar view of in(ter)dependence. While some of the co-researchers in the above discussion expressed their opinion verbally, non-verbal

expressions such as Dawn's happy humming make it clear how she feels about in(ter)dependence and that she does not view needing support in certain areas in life as a failure.

In this chapter, I have discussed the epistemological standpoint from which this thesis emerges, outlining my approach to knowledge production in the realms of disability research. Within the framework of a participatory research approach, this thesis presents rich data based on the lived experiences of people with Down's syndrome. It offers alternative imaginations of what a life with Down's syndrome might look like when film subjects are involved in the production process.

Overall, this chapter has demonstrated that *The Specials* and the work done with co-researchers counter the dominant narratives about Down's syndrome around dependence and vulnerability. The discussion with co-researchers affirms what was previously discussed in Chapter Two: that vulnerability and dependence are human traits, conditions that are not just attributable to disability. *The Specials* and our co-analysis could be understood as examples of one of the 'positive takes upon human dependency' that Goodley (2020, p.61) discusses. *The Specials* work towards transforming prevailing assumptions around dependency and vulnerability and offering an alternative visualisation of how a life with Down's syndrome might look.

~ Chapter Six ~

## Representing Down's Syndrome, Relationships and Sexuality

### Introduction

In Chapter Two, I outlined much of the key literature surrounding disability and sexuality, particularly in relation to people with learning disabilities. This chapter will examine how people with Down's syndrome are represented in terms of relationships and sexuality in a documentary series called *The Undateables*. This chapter combines my multimodal analysis of *The Undateables* with the co-analysis conducted with co-researchers and examines the discursive practices evident in this television programme, arguing that 'freakery' and 'supercrip' representational conventions are present within the docuseries. Before introducing the analysis, I will provide a brief outline of the docuseries, discuss some of the pertinent critiques that have been advanced in reviews of *The Undateables*, and provide the rationale for selecting this text for analysis.

### Background of *The Undateables*

*The Undateables* is a reality television docuseries that first aired in the UK in 2012, with a new season broadcast yearly until 2020. There have been 53 episodes to date, split into eleven seasons (plus some additional special episodes). Each episode follows three cast members as they navigate the world of dating as a disabled person. Each cast member, or 'extraordinary singleton' as the narrator describes them, identifies as having a physical, sensory or developmental impairment, disfigurement or other long-term medical condition/s. Each episode combines fly-on-the-wall shots, interviews and voiceover narration from actress and comedian Sally Phillips.<sup>30</sup>

The docuseries is commissioned and broadcast by Channel Four, the same television network initially interested in broadcasting *The Specials*. *The Undateables* is now also broadcast by Netflix and is popular in the UK and beyond. As noted in the previous chapter, Channel Four is a long-established television network with various subchannels, such as E4 and More4 and a digital streaming platform, All 4, which amassed 1.25 billion streams in 2020 (Channel Four Television Corporation, 2020). As

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<sup>30</sup> Phillips is also the writer and presenter of the documentary under analysis in Chapter Seven, *A World Without Down's Syndrome?*

we saw in the previous chapter, Channel 4 is renowned for broadcasting more alternative, often controversial, content and has a strong reputation for creating content that is committed to inclusion and diversity (Channel Four Television Corporation, 2020). Netflix has an even more extensive reach—it is the leading subscription video-on-demand service in the UK, and approximately 13 million households in the UK subscribe to the service (Equality & Diversity, 2012). There have also been adaptations of the docuseries in other countries, including Belgium and the Netherlands (Vertoont, 2018; Boross and Reijnders, 2019). Consequently, *The Undateables* has a much wider audience than *The Specials* and thus much more potential to educate and inform more broadly.

### **Critiques of *The Undateables***

Since the first season was aired, *The Undateables* has prompted fierce debate over its inclusivity and potentially exploitative nature within the public realm (Morrison, 2012; Ryan, 2012; McGeorge and Cockerell, 2015), the activist arena (Caulfield, 2012; Deafie Blogger, 2016), and in academia (Soorenian, 2014; Richardson, 2017; Vertoont, 2018). Following the first season's release, the UK Disabled People's Council and European Disability Forum released a press statement condemning *The Undateables* as 'unwatchable' (Equality & Diversity, 2012, no pagination). Their summary of the show captured what many disability activists and scholars were articulating at the time:

If *The Undateables* seems an offensive title for a show, then that is probably the marketing aim for a TV channel in the quest for an audience. Through a patronising voiceover, viewers are told from the opening that they're about to see a group of 'extraordinary singletons' when in fact we see the opposite: six single people who happen to be disabled. (Equality & Diversity, 2012, no pagination)

For Soorenian (2014, p.48), *The Undateables*' producers had an opportunity to 'bring disabled people's romantic and sexual needs into the mainstream', but the show achieved the opposite of this, instead framing disabled people as 'apart from the non-disabled society'. Soorenian (2014, p.48) argues that the series falls in line with dominant readings of disabled people in print and visual media, which involve 'patronizing, dehumanizing and negative stereotypical assumptions' of disabled people, and that cast members of *The Undateables* were framed in terms of 'difference, dependence, asexuality, and unattractiveness'. Soorenian's (2014) reading chimes with the literature discussed in Chapter Two, specifically the writings around disabled sexuality as a matter of deviance or asexuality (Winges-Yanez, 2014). Like Soorenian, Vertoont (2018) acknowledges that



docuseries like *The Undateables* can, in many ways, be seen as progressive programming in contrast to most mainstream television that rarely focuses on the personal issues of disabled people, such as dating. She argues that although many disabled people consider relationships and sexuality (and the power to express desires regarding relationships and sexuality) amongst the most challenging aspects of their everyday lives, this is an area that has been neglected on a societal level, as well as within the realm of disability activism and academia (Vertoont, 2018, p.2). In line with Tom Shakespeare's work on disability and sexuality, Vertoont (2018) accepts that inattention to disabled people's sexuality and love lives may be in part due to society's tendency to view disability through the lens of the medical/personal tragedy model, but also points out that even through the lens of the social model, sex and romance is often overlooked due to significant focus being placed on structural and social inequalities. The prioritisation of social and legal disability rights over sexual exclusion seems logical when considering Shakespeare's (2000a, p.160) assertion that tackling social exclusion is seen as more pertinent than ensuring disabled people have 'good' sex, although the issue is far more nuanced and complex than his statement implies.

Broadcasting *The Undateables* on mainstream prime-time television certainly puts the sexual oppression of disabled people on the agenda. For some, however, the premise and content of the show caused a degree of unrest and apprehension on behalf of the disability community. Three years after the series began, a number of medical professionals raised concerns during the British Medical Association (BMA) annual representatives' meeting, stating that factual programming such as *The Undateables* is offensive to disabled people and ethically questionable (British Medical Association, 2020, p.204). During this meeting, medical professionals questioned whether people with autism or learning disabilities could give informed consent to appear on the dating show. This was countered with the argument that challenging the capacity to provide informed consent is to discriminate further (McGeorge and Cockerell, 2015). Indeed, it is unknown whether the BMA were in consultation with the disability community before formally raising an issue with *The Undateables* on their behalf. Following the comments made during the BMA conference, Channel 4 released a statement rejecting all claims of exploitation and argued that the show intends to challenge misconceptions, ensuring that producers work closely with cast members, 'families and carers to ensure that they are fully aware of what taking part entails' (McGeorge and Cockerell, 2015, no pagination).

Writing in the wake of the sixth series, Richardson (2017, p.330) also questions whether *The Undateables* raises awareness of disability and sexuality or simply conveys 'new strategies of enfreakment'. Richardson's concerns are shared with Soorenian (2014, p.48), who posits that *The Undateables* 'trades on sensational entertainment through the spectacularization of disability'. As summarised in Chapter Three, the spectacularisation of disabled people's bodies is an issue that continues to trouble disability activists and scholars, and the audience's introduction to cast members of *The Undateables* as 'extraordinary singletons' bears a resemblance to the 'show-world' hyperbole described by Bogdan (1990). The narrator's invitation for the audience to observe 'these extraordinary singletons [who] are throwing themselves into the world of dating' resembles the 'roll up, step right up', which was the original freak show's invitation to stare and marvel at difference.

Describing the cast members as 'extraordinary' also fits within Schalk's (2016) supercrip typology. The disabled people featured in *The Undateables* are framed within the 'regular supercrip' narrative in that they are being presented accomplishing an ordinary occurrence (going on a date), but their impairment means it is portrayed as exceptional. In so doing, the cast members are being both 'normalised' and Othered: 'because although the representation shows a person with a disability doing something "just like everyone else", the creation of the representation is premised upon the ableist assumption that people with disabilities do not do these things and thus are not just like everyone else' (Schalk, 2016, p.79).

Given the issues outlined in Chapter Two in relation to narratives based on supercrip and freakery conventions, it is not difficult to understand why some disability activists claimed *The Undateables* was another form of freak show. The voyeuristic nature of the documentary genre and the framing of the cast members as 'spectacle' (Garland-Thomson, 1997, p.60) using the descriptor 'extraordinary' indeed invites the audience's (or spectator's) curiosity. The theoretical connections between freakery, normalcy and supercrip are evident within the critical responses to *The Undateables* discussed thus far, and this parallel will emerge throughout the analytical discussions below. While Channel Four maintains that *The Undateables* is about raising disability awareness and challenging misconceptions, it is important to remember that, like the freak show, 'exhibiting people' through the medium of film and television, 'although often treated as an educational and scientific pursuit, was always first and foremost a for-profit activity' (Bogdan, 1990, pp.8-9). The marketing of the show and its title has arguably caused more controversy than the contents of the show itself (Ryan, 2012). Channel 4 is

renowned for broadcasting television programmes with provocative titles.<sup>31</sup> Semiotically, the 'hyper-ironic coding' of *The Undateables* is problematic on many levels (Richardson, 2017, p.330). The opening credits display the text 'The Undateables', with the 'Un' from 'Undateables' subtly knocked off by an animated Cupid's arrow at the end of the sequence (see Figure 3). Channel Four contend that this 'reflects how society often views these people and is intended to challenge misconceptions' (McGeorge and Cockerell, 2015, no pagination).

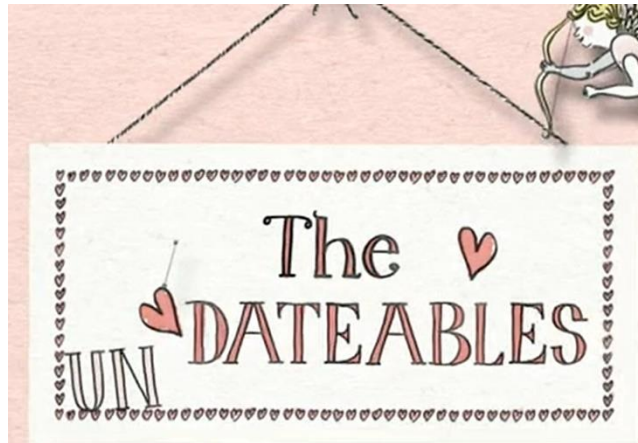


Figure 3

Still of the image from the opening credits of *The Undateables*.

While Channel Four maintains that the ironic branding of the show and its title sequence suggests that participants *are* dateable, the irony could easily be missed for those who have not viewed the series and only encountered billboard or television advertisements or newspaper headlines. Presenting the word 'Undateable' alongside images of disabled cast members has also (see below) been identified as contentious by many (Caulfield, 2012; Biressi, 2017; Richardson, 2017), even those who support the docuseries for including the dating lives of disabled people on mainstream television (Morrison, 2012; Ryan, 2012). To question the 'dateability' of the cast through its title, despite the producers' supposed intentional irony, is to jeopardise an already marginalised group whose sexuality is now potentially being further stigmatised.

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<sup>31</sup> Another example of this is *Beauty and the Beast: The Ugly Face of Prejudice* (2011-12), a documentary series that explores the 'extremes of dissatisfaction and discrimination by bringing together two people defined by the way they look': someone living with a facial disfigurement and someone who identifies as a 'beauty addict' (Channel Four, 2023).

## Why *The Undateables*?

*The Undateables* is one of the first disability dating shows to be broadcast in the UK, with long-running success and steady viewing figures. Owing to its longevity, *The Undateables* is clearly popular with its mainstream audience, verified by its high ratings figures and annual one-off special episodes.<sup>32</sup> Shortly after the first two seasons aired in 2012 and again in 2015, the show was nominated for a Bafta TV award.<sup>33</sup> The series was also nominated for a Diversity in Media Award in the 2017 National Diversity Awards. As we saw in Chapter Two, Davis (2013, p.2) has suggested that normalcy is being replaced by diversity in the sense that 'the mythos of the normal body' is gradually being rejected, making way for the concept of diversity. From this perspective, diversity is much better suited to neoliberal agendas whereby citizens are understood as consumers (Davis, 2013). In other words, rather than being stigmatised as 'abnormal', disabled bodies and minds are being categorised (and commodified) as *diverse*. Attempts to represent disability as diversity are often tokenistic and typically involve 'photogenic' disabled people, such as the 'looks-forward wheelchair user' (Davis, 2013, p.5). While *The Undateables* casts people with a variety of impairments and conditions, both visible and non-visible, if these representations are one-dimensional and based on ableist, non-disabled perspectives, it too could be thought of as a tokenistic gesture to fulfil bureaucratic diversity agendas, driven more by a neoliberal market than emancipatory aspirations. The subtle removal of the 'Un' from 'Undateables' with no further explanation as to the aim of this branding could certainly be construed as diversity-led tokenism.

If diversity continues to become the 'new normality', as Davis (2013, p.1) suggests, and the popularity of reality dating programmes continues to soar, enquiry into how disabled bodies and minds are being represented on screen is more important than ever. There is now an abundance of romantic reality television shows available to audiences (such as *Love Island*, *First Dates*, *Love is Blind*, *Married at First Sight* and *Love in the Dark*). A docuseries that appears to be following in the footsteps of *The Undateables*, called *Love on the Spectrum* (2019), is now streamed on Netflix. Indeed, Netflix also began streaming a disability documentary series based in New Zealand that specifically follows adults with Down's syndrome as they navigate the dating world, with the unfortunate title *Down for Love* (2022). As other versions of disability-related dating shows (hopefully) present themselves over the coming years, it is more timely

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<sup>32</sup> For example, the first season of *The Undateables* attracted 2.7 million viewers (Sweney, 2012).

<sup>33</sup> The British Academy of Film and Television Arts (BAFTA) is a world-leading independent arts charity which hosts yearly awards ceremonies. *The Undateables* has been twice-nominated in the Reality and Constructed Factual category (BAFTA, 2016).

than ever to conduct an in-depth analysis of this genre and present alternative, less ableist, ways of presenting dating and disability.

## **Analysis**

Throughout the eleven series of *The Undateables*, five episodes featured an individual with Down's syndrome. I analysed three of these episodes with co-researchers – Sam (Season 1, Episode 3), Kate (Season 2, Episode 3) and Zena (Season 11, Episode 5). These were the episodes with the most content (in terms of the number of minutes featuring a cast member with Down's syndrome), giving us more data to analyse. Out of the three Film Clubs, the theme of romance and relationships and our analysis of *The Undateables* seemed to be where co-researchers had the least to say. The co-researchers were encouraged by the premise of the show and found it empowering to see people like themselves featured in the show; therefore, they had less to say during this group analysis. This is perhaps because, for the co-researchers, the affirmative aspects of seeing people like themselves on screen *and* dating outweighed any potential critique of the show, an outcome that I will shortly discuss in more detail. Therefore, for the purpose of this chapter, I have chosen to focus on the two episodes the co-researchers commented on the most – Sam and Kate.

### **Sam**

#### **Introduction to Sam**

Episode three in the first season of *The Undateables* features Sam, a 27-year-old white male from Devon, UK. The episode's opening scene has Sam in frame, leaning against a flipchart as he explains, 'We are drawing my ideal girlfriend' (*The Undateables*, 2012). The voiceover narration tells us that 'Sam is 27 and has Down's syndrome'. The narration pauses as Sam continues to describe the image he is drawing: 'with some boobs'. Sam draws breasts underneath the chin of a large cartoon-like head he has sketched, and the narration continues: 'He's never been on a date or even kissed a girl'. The audience's first glimpse of Sam, in a scene which has a playful, cheeky musical overlay, depicts him in an immature light and is the first sign that Sam's portrayal appears to be embedded in the 'forever young' Down's syndrome stereotype. As previously mentioned, Soorenian's (2014) critical reading of the show highlighted that negative stereotypes were used as a framing device, and the introductory scene in Sam's episode certainly corresponds with this reading. Many disabled people voice the damage that infantilisation can have on one's sense of self-worth and esteem. For people with Down's syndrome, in particular, assumptions about infant-like behaviour and innocence can be especially harmful. In framing Sam as childish and possessing a childlike understanding of sex, these simplistic stereotypes are being compounded, and

many viewers, based on this scene, might question whether Sam (or people with Down's syndrome more generally) is mature enough to engage in romantic relationships.

As the scene continues, the narrator informs viewers that Sam has 'never even been kissed' in a somewhat condescending tone, which continues throughout the episode as the audience navigates through Sam's 'first steps into the world of dating'. As alluded to earlier, *The Undateables* has been criticised for its patronising tone and for reinforcing many simplistic stereotypes around disability and dating, such as the implication that disabled people need to be 'rescued' by non-disabled people – they are incapable of establishing relationships without the intervention of non-disabled people (in this case, the dating agency) (Vertoont, 2018, p.832). Further dominant stereotypes being reinforced include the notion that disabled people only date other disabled people in 'private spheres' and the assumption that disabled people are not valued as romantic partners with sexual desires (Vertoont, 2018, p.832). With a voiceover that would not sound unbecoming in a children's television show, along with scenes that depict Sam as infantile, *The Undateables* also reinforces the common stereotype that adults with Down's syndrome are 'forever young' and sexually innocent. As the episode continues, it is clear that Sam does indeed understand sex and relationships despite his apparent lack of experience, which I will return to in the next section.

The frame shifts from Sam drawing his ideal girlfriend to him being asked what love means to him: 'Love feels like a palace, because a palace is full of romance and hearts and smiles and kisses'. As the frame shows Sam and his father (Malcolm) striking poses with their saxophones (an earlier scene established that Sam 'was not a good saxophone player'), a voice overlay of Malcolm being interviewed can be heard. As melancholic music fades in, the narrator states that Sam's mother passed away three years ago, leaving Malcolm to 'single-handedly guide him through the complex world of boy meets girl'. Shortly after, a scene shows Sam answering more questions from the producer behind the camera.

These scenes were played at the beginning of Film Club Two. When I asked the group their thoughts on this opening scene, Kevin stated that he thought Sam 'made a good speech'. The speech Kevin was referring to was Sam's answer in a direct-to-camera interview when asked why he would like a girlfriend: 'I'd like to have a girlfriend to keep me company. Make love to them and to look after me. It would change my world completely'. In this scene, Sam is lying on a bed, hands behind his head, looking relaxed and talking directly to the camera. This has been framed as spontaneous and natural dialogue, as though Sam often lies down to ponder what life with a partner

would be like. Yet, Kevin's reading of this is that Sam is making a speech, almost as though what he is saying has been prepared in advance. Boross and Reijnders (2019) conducted a study using *The Undateables* as an example of how different 'modes of participation' can be seen in the show. They interviewed several cast members from the British and Dutch versions of *The Undateables*, questioning how they dealt with their position in the process of production as well as how their experiences of the show reflected the 'emancipatory claims' of the programme and its producers (Boross and Reijnders, 2019, pp.1-2). Kevin's interpretation of this scene aligns with Boross and Reijnders's (2019, p.13) assertion that film producers often manipulate or even censor participants on *The Undateables* for aesthetic reasons: 'instances of censorship—including what they would *normally* do and how they would *normally* act—are generally accepted in the name of "what looks good on TV"'. Sam may have chosen to lie down for his on-camera interview, and he may have answered the question instinctively, yet the framing of the scene made it appear contrived, to Kevin at least.

### **Sam's pre-date preparations**

Following a scene showing Sam meeting his friends, the narrator confirms that in order to help find the cast members a date, an introductions agency called Stars in the Sky is used. This introduction agency specialises in finding potential romantic matches for people with learning disabilities. Cheerful, upbeat music fades in and the scene shifts to Sam's introduction with staff from Stars in the Sky. After obtaining the information they need (such as details of hobbies and interests), it is not long until the agency finds a match for Sam and arranges a 'blind' date with a woman called Jolene.

I screened the scenes depicting Sam's preparation ahead of his date with Jolene to co-researchers. As part of his preparation, Sam has questions for his father and starts a conversation as they wash and dry the dishes. The scene is shot from the outside of Sam's house, with the camera looking in through the kitchen window. This fly-on-the-wall perspective is often used in documentary filmmaking and adds to the sense of voyeurism (Wickham, 2007)—the outside-looking-in shot shifts between this frame and a side shot from inside the kitchen. The voiceover narration reminds us that this will be Sam's first date: 'After meeting with the other introductions agency, Sam has a blind date arranged for tomorrow. But it's all new for Sam, so he's seeking some fatherly advice'. Sam begins the conversation by asking his father what love feels like, which prompts the following exchange:

Dad: What does love feel like? I think you'll know when you feel it. It's a kind of warm feeling. It's about being able to laugh together.

Sam: True.

Dad: Cry together and support each other when things aren't so good.

Sam: Yeah.

Dad: That you don't want to be apart from somebody sometimes. It's about feeling a physical attraction for somebody as well.

Sam: Yeah.

Dad: How do you think a relationship would develop?

Sam: Physical.

Dad: A sexual relationship?

Sam: Yeah.

Dad: Would you like to have a physical, sexual relationship?

Sam: I don't mind.

Dad: You don't mind?

Sam: No.

Dad: That's a funny thing to say.

Sam: Is it?

Dad: Is there anything that would worry you about that?

Sam: No.

Dad: As long as you were careful and that sort of thing.

Sam: Yeah.

Dad: You know what I mean. Do you know what I mean when I say "be careful"?

Sam: What?

Dad: What sort of thing do I mean?

Sam: Condoms.

Dad: Yeah.

For producers to include Sam's candid conversation with his father about sex and protection is encouraging and could be considered progressive. At the time of production, there will have been very few examples of an adult with Down's syndrome discussing sex on mainstream British television. Nevertheless, as progressive as this content appears, as Sam utters the word 'condoms', a playful musical overlay begins, which could be read as a way to reassure viewers of Sam's perceived innocence and lack of sexual awareness. An alternative reading might suggest viewers are being invited to laugh at (or with) Sam and interpret this as mockery. Richardson's (2017, p.334, emphasis added) analysis of *The Undateables* discusses how comedy is used in the docuseries, particularly how cast members' actions are being *coded* as 'comic'. In coding the behaviour of the cast members, the series is shifted into 'questionable territory of enfreakment' (Richardson, 2017, p.334). Citing Hevey (1992) and Garland-Thomson (1996), Richardson (2017, p.331) explains that the term 'enfreakment' describes the 'mechanism through which bodies that were different or strange were represented in a variety of media as "freaks"'. He asserts that 'nobody *is* a freak'; rather, the techniques used to portray different bodies render them as 'freaks' (Richardson, 2017, p.331, original emphasis). Sam's discussion of sex with his father could be read as a strategy of 'enfreakment'. Although it is possible to unravel ironic shows in multiple ways, and while it could be argued that the music acts as a transitional technique, it makes it difficult for the audience to take Sam seriously in this moment, suggesting that he is subtly being coded as comic.



During our co-analysis of the 'father and son' conversation, my co-researchers did not remark on the content of the scene or the techniques used to present this dialogue. For two of the co-researchers, seeing Sam talking with his father about dating prompted them to think about losing their own fathers, and it was, therefore, difficult for them to engage with this scene.<sup>34</sup> When I asked whom they might turn to for advice if they were nervous about going on a first date, Kevin said he would probably talk to his mother, but he did not think he would be nervous.

The next scene I played to co-researchers showed Sam getting ready for his date. The scene starts with an establishing shot showing the outside of Sam's countryside cottage, with the ambient sound of sheep and a soft musical overlay. The frame then shifts indoors to Sam putting on his jumper as the narrator, once again, tells us today is the day of Sam's 'first ever date'. As Sam places the jumper over his head, it becomes slightly stuck as he puts it back-to-front. At this moment, the narrator continues: 'but he is totally in the dark about who she is and what she looks like'. The scene was edited so that at the precise moment the voiceover says 'totally in the dark', the frame shows Sam with his head stuck in his jumper. Again, this attempt at light-hearted humour can be read in different ways. It is certainly no coincidence that the timing of Sam's head becoming stuck syncs with the line 'totally in the dark', perhaps to convey incompetence. By repeatedly stressing that this is Sam's 'first ever date' and suggesting he is 'totally in the dark', the voiceover invites the audience to view Sam as incompetent at dating (and dressing) and extrapolate outwards to how he might act on his date. The audience is being manipulated to anticipate some kind of disaster, encouraged to watch on and see how Sam fares on his 'first ever date'. Sam was presented as unable to dress independently, which, in itself, could be viewed as a strategy of enfreakment: 27-year-olds are 'supposed' to be capable of dressing themselves. In order to emphasise this point, the frame then transitions to a shot of Sam as he heads down the stairs carrying a belt, with Sam's father's voice heard saying, 'Need a hand with your belt?'. The shot then shows Sam's father leaning over to loop Sam's belt through his trousers as Sam watches him and holds up his jumper. This framing of Sam vastly differs from how cast members in *The Specials* were represented. If documentary audiences ascribe truth to visual representations of 'fact' about impaired bodies, as suggested in Chapter Three, it is important to consider in what ways these 'facts' betray the vast manifestations of impaired bodies (Markotić, 2016). What 'facts' about people with Down's syndrome are audiences being told by highlighting Sam's need for assistance with his belt? This scene constructs

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<sup>34</sup> Albert excused himself and went to the bathroom shortly after we started discussing this scene.

in(ter)dependence as dependence and suggests to viewers that Sam's pending date might not be a success.

The music during this scene is gentle and melodic. The producer asks Sam from behind the camera (as his father continues to put on his belt), 'How are you feeling, Sam?'. He responds 'ecstatic' and then, as the frame continues and the dressing is still taking place, a voiceover of the producer asks Sam's Dad if he thinks it is important for people to experience love and romance, to which he replies: 'I think it's important for Sam to seek that experience. I think it's important for him to have the opportunity of the kind of happiness that that can bring'. The common misconception that disabled people cannot (or should not) embark on sexual relationships is portrayed in this scene, albeit subtly, and the content may embody what mainstream audiences already perceive in terms of the asexuality of disabled people (Shakespeare et al., 1996). There is a gesture towards being progressive as the dating experience of disabled people is being centred; however, simultaneously, there is a reinforcement of common stereotypes that suggest the date is out of the ordinary or will be unsuccessful. The freak show has craftily been repackaged into a more palatable version – viewers are able to feel broad-minded while still being allowed to stare or laugh at disabled people.

### **Sam's date**

Sam's date with Jolene takes place in London Zoo and is chaperoned by a staff member from Stars in the Sky. Whereas in *The Specials*, scenes foregrounding the support staff were avoided, in *The Undateables*, the chaperone is always nearby, and several scenes spotlight her presence. As Sam nervously waits for Jolene to meet him by the penguin enclosure, he can be seen looking around and saying, 'Is it them, is it them?'. The shot then shifts to a close-up of Sam's head and the flowers he bought for Jolene. The narrator says, 'Sam has no idea who she is or what she looks like' and then introduces Jolene as being '28 years old and [someone who] also has a learning disability. She lives alone and works for a youth charity'. The voiceover narration accompanies an upbeat, suspenseful musical overlay that intensifies Sam's nervousness as he waits for Jolene to arrive. As the frame shows Sam looking from one direction to another in anticipation, the frame quickly shifts to a meerkat and then a llama in the zoo moving their heads in a similar fashion to Sam. As we saw in Chapter Three, it is not uncommon for disabled people to be framed as animalistic in cultural representations. For people with Down's syndrome, the implication that they are somehow less than human has been entrenched in cultural discourses since at least the nineteenth century, when 'comparisons between intellectual disability and animality' were entangled in racist, colonial and ableist assumptions (Davies, 2021, p.107). The

framing of Sam and the zoo animals moving in the same way suggests they are in some way comparable.

Finally, the frame shifts to Jolene and the chaperone exiting their car and finding Sam near the penguins. After a somewhat stilted first introduction, the chaperone asks if she should leave them to say hello, and Sam and Jolene soon become more talkative. A montage of shots shows the pair enjoying their date, and after a commercial break, the narrator provides a quick recap: 'Over at London Zoo, Sam's on his first-ever date with Jolene. So far, it's been going well, but he's forgotten something crucial'. It transpires that Sam has forgotten his money, and he does not realise this until they are in the cafe and ordering drinks. As the scene plays out, a close-up shot of Sam searching through his wallet for money with a perplexed look is accompanied by tentative music. In the background, the barista can be heard asking if Jolene was just paying for one drink, but she also agrees to pay for Sam's. As this transaction takes place, Sam continues to look through his empty wallet, and the volume of the music intensifies. The camera shifts from Sam to the chaperone, who smiles and then tells Sam: 'Say thank you. Lady buying you a drink'. Sam responds, 'Yeah, I will ... thank you for that'. The narration then plays as Sam and Jolene run towards the merry-go-round: 'Sam might have to work on his gentlemanly conduct, but he won't let that stop him from showing a girl a good time'. The frame then transitions to a long shot of the merry-go-round as Jolene and Sam sing loudly. Sam's voiceover from his post-date interview can then be heard: 'Today was the very best day ever'. Jolene agrees that the date was a success in her post-date interview: 'I've just had the best day ever. He's funny character. I don't think any boy has made me laugh that much'.

After I played Sam's date to the co-researchers, I asked what they thought about what they had just watched. Albert said, 'Ooooooh that's-I'd like to do that me one day'. I asked Albert if he would like to go on a date at the zoo, to which he responded: 'No, somewhere romantic, picnic ... And a bottle of champagne, flowers.' Interestingly, Albert suggested a more romantic (and arguably more adult) location for a date than the zoo – and it could be that this kind of trip is usually more suitable for families or children than a typical date location. The producers perhaps chose the zoo as a venue for the date for this reason – to provide a location that would elicit less mature behaviour and, therefore, to emphasise Sam's perceived childlike nature. Additionally, there is much more potential for comedy at a zoo as opposed to Albert's suggestion of a picnic date. While it is impossible to know for sure why the producers made loose connections with animals and children, the overall effect is the same – the

infantilisation of Sam is undermining his position as a consenting adult on a date with another adult.

The co-researchers agreed that the date seemed to go well overall and commented on the importance of couples making each other laugh. Albert also commented on the music accompanying the scenes: 'Nice romantic erm music ... Erm it's nice to have love songs'. Albert's interpretation of the music used in these scenes differed from my reading. What I considered to be playful, light-hearted music, Albert considered romantic. This prompted a discussion about how shows the group watches on television often use music to add to the sense of romance, and the co-researchers all agreed that if they were to be filmed on a first date, they would like romantic music to play in the background. Albert referred to this as a 'love theme'. During our breaks, we often listened to different songs of their choosing; spontaneous karaoke sessions even became a regular part of our lunch times. Music was clearly significant to the group, and this will later be explored in Chapter Eight.

The musical element of the show was also discussed following the scenes showing Sam after his date. Sam initially called Jolene to ask her out on a second date, but later, he appeared to be having doubts. He suggested to his father that he might text Jolene saying, 'Hi, can we be friends, not lovers? Sorry to upset you'. His father urges him to think about how he might phrase this differently before sending the text, and shortly after, an on-screen interview with Sam takes place. Sam talks about how he feels, having never been in a relationship before:

Producer: So, Sam, does the physical side of love... is that something that makes you nervous or unsure?

Sam: Yeah. I don't like the word "sex". Because I get red-faced and nervous and embarrassed.

Producer: You don't like the word "sex"?

Sam: No. I'm really friendly around girls, but if you keep saying, "having sex" or whatever, I get nervous.

As the close-up shot of Sam's face fades out, the scene shifts back to Sam and his father having a conversation about texting Jolene. Sam agrees to see how things go and asks Jolene what kind of food she likes. As this frame fades out, the narrator states, 'This is Sam's big chance for romance, if he can hold his nerve'. Emotive music then begins as the narrator continues: 'Sam has never had a girlfriend, but in his search for love, he's fallen on his feet'. The narrator's repeated reminders of Sam's relationship experience (or lack thereof) continue throughout the episode and are included in the narration script on six occasions. The producers clearly felt it important for the audience to remember that this is Sam's first date, which could be read as a characterisation device to present Sam as incompetent in matters of love. It could also

be read as a further strategy of enfreakment – portraying Sam as in some way unusual because he is 27 years old and has never been on a date. The emotive acoustic guitar continues as Sam prepares for his second date, with close-up shots of him applying deodorant and brushing his teeth. As Sam continues to prepare for the date, he answers questions coming from behind the camera:

Producer: Do you think you'd ask her to be your girlfriend?

Sam: I would. But I don't know what her answer will be.

Producer: How will you feel if she says "yes"?

Sam: I'd be ecstatic.

Producer: Why is that, Sam?

Sam: Because I've never had a girlfriend before.

The audio of this interview plays as Sam stands in front of the mirror, brushing his hair and then chin, despite not having any facial hair. The visual then shifts to Sam being interviewed, and as he says he has never before had a girlfriend, the close-up shot of Sam's head then becomes a longer shot of Sam sitting on his bed, looking away from the camera and back to it with a somewhat sad expression on his face. As this happens, the volume of the poignant music increases, and the frame slowly fades out. This scene was played to co-researchers, and I asked what kind of emotions the music roused:

Kevin: Happy

Researcher: Happy?

Dawn: Happy ((signs 'happy' using Makaton))

Albert: Happy, respecting people.

Researcher: Mmmm. So you thought that was nice, happy music?

Albert: Yeah ... If it's me, if I go on a date it's gonna be a love song ... If I erm take someone out I take me erm tablet and put on a love theme song.

Where I interpreted the musical overlay and camerawork as forlorn, the co-researchers construed this as happy. Their focus may well have been on the dialogue rather than the background music – after all, Sam was saying how happy he would be if Jolene agreed to be his girlfriend. Our opposing interpretations reiterate the subjective nature of multimodal analysis and how one person interprets music can be very different to the next. Sam and Jolene eventually arranged a second date, this time unaccompanied by a chaperone from the dating agency.<sup>35</sup> They meet at the White Cliffs National Trust Park, and as they window shop to avoid the rain, the anticipation (and accompanying music) builds as Sam prepares to ask Jolene to be his girlfriend. Jolene says yes, and the narrator confirms, 'For the first time in his life, Sam has a girlfriend, and even the

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<sup>35</sup> I attempted to find out whether it was part of the Stars in the Sky rules and regulations to ensure a chaperone accompanies its clients on all first dates, however I have been unable to locate Stars in the Sky on the web and it is unclear if the agency is still in operation. I would speculate that all first dates must be chaperoned and any further dates do not require a chaperone unless the client requests one.

weather isn't going to dampen their first romantic stroll'. The camera then follows Sam and Jolene as they hold hands and enjoy the rest of their date, with the audio alternating between a tender and hopeful musical overlay and excerpts from interviews with Sam and Jolene. The conventions of romantic reality television are being adhered to, and Sam's 'happy ending' is arranged such that the audience feels satisfied and uplifted.

## **Kate**

### **Introduction to Kate**

While the format and genre conventions of *The Undateables* were still being established in Sam's episode (Season One), by Kate's episode in Season Two, the 'formula' was in place. The audience's first glimpse of Kate shows her standing on the balcony of her apartment, overlooking the communal gardens, while a voiceover from an interview with Kate plays: 'Yeah, I would love to get married. I'd like to wear a cream, white dress – with frills in' (*The Undateables*, 2013). As Kate describes her ideal wedding dress, the shot transitions from Kate standing on her balcony to an extreme close-up of her face as she gazes beyond the camera. The narrator states, 'Kate is 29 and has Down's syndrome. She's single and longs to find a husband'. Within the first thirty seconds of Kate's introduction, the audience is primed to view Kate as a 'hopeless romantic' desperate to be married. The narration continues: 'When she's not planning her perfect wedding, Kate spends hours writing love poems', with another frame of Kate's face as she recites poetry. A close reading of these scenes suggests that Kate is being framed as younger than her age. Kate is portrayed as almost adolescent in age as she recites one of her poems, talks excitedly about her favourite boy band, and shows off her collection of romantic comedy DVDs. Like many illustrations of teenage girls, Kate is portrayed as desperate to grow up and get married – before the audience even finds out her name, Kate's first utterance is, 'I would love to get married'.

The gendered differences in how Sam is represented in comparison to Kate are prominent from the outset. While Sam talks openly about sex, visual appearance and the physical aspects of a relationship, Kate only appears to be interested in finding a husband. Sam is portrayed drawing breasts on his 'ideal girlfriend', whereas Kate is shown writing and reciting romantic poetry. Disability and gender are both social constructs (Butler, 1990; 1993; Oliver, 1990) and the techniques used to frame Kate and Sam uphold dominant understandings of disability and sex in gendered terms. In his comparative analysis of disability narratives in various media forms relating to sexual surrogacy, Bartholomy (2019, p.59) talks about how texts often 'fall in line' by

'emphasizing common ideas connected to disability narratives'. What we are seeing in the representations of men and women in *The Undateables* is another example of how, through media, the non-disabled, gender normative perspective is being favoured. Bartholomy (2019, p.59) refers to his analytical work as 'cripping', defining this as 'the act of revealing the overarching norms within a society that reinforce the dominance of the non-disabled perspective and its exclusionary practices'. In criping Kate's representation in *The Undateables*, my analysis highlights ableist reflections being portrayed in a show *about* disabled people. Audiences are being welcomed into the world of disability, but rather than educating viewers on the nuanced, complex realities of (in this case) Down's syndrome, they are being offered stereotypical images of both disability and gender.

As Rainey (2011, p.67) suggests, 'disability is intimately bound up with gender in our cultural imagination', and this complex intersection can often be overlooked in mainstream media produced from a non-disabled perspective. Kate's apparent fixation on getting married makes sense in a world where women are 'typically viewed as natural caregivers' (Rainey, p.67). Gender expectations tell us that in order to fulfil their gender role, women require a man to marry and take care of; therefore, it makes sense that Kate is persistently framed as being in search of her 'dream man'. Throughout Kate's episode, marriage is referred to at least eight times (either by Kate or the narrator). The scenes featuring Kate comprise a total of 14.5 minutes; therefore, eight mentions of marriage and finding a husband could be read as excessive. The producers intend to stretch the hopeless romantic narrative, and framing Kate as marriage 'obsessed' is an effective way of achieving the desired narrative.

During our analysis, the group considered why Sam and Kate were represented differently, and I asked them why sex might have been included in Sam's episode and not Kate's. No definitive conclusions were drawn, but Albert did suggest possible reasons for omitting any talk of sex and intimacy in Kate's representation:

Albert: It's not popular

Researcher: Yeah...why do you think they showed Sam talking about sexuality but not the women?

Albert: Erm because it's about erm thinking about it.

Researcher: Cos he's, do you think he's thinking about it? What-and you don't think the women were thinking about the sexual side of the relationship?

Albert: Yeah

Albert suggested that, as a young man, Sam would have been thinking more about sex, which is potentially why his episode featured the topic of sexuality. For Albert, the reason marriage and romance were emphasised in Kate's episode and sexuality in

Sam's is because Sam will have been thinking about these things more than Kate would have. I take Albert's suggestion to mean that the producers perhaps recognise that it is more socially acceptable for men to talk openly about sex, and for this reason, whether consciously or not, their interview questions to Kate avoided any talk of sex. Albert's claim that 'it's not popular' for women to talk about sex corresponds with outdated gender regulations confirming what is and is not appropriate for women to talk about. Additionally, *The Undateables* has been produced in a 'society [that] has placed a person who identifies as a woman and disabled as a victim; conversely, a person who identifies as a man and disabled is viewed as aggressive, unable to keep his sexuality in check' (Winges-Yanez, 2014, p.108). It seems that the representations of Kate and Sam are embedded within these misconceptions. Although Kate has not overtly been framed as a victim, emphasising her 'innocence' implies vulnerability and exposure to victimisation, a common narrative in discourses around sex and disability, as I outlined in Chapter Two.

Following the introductory scenes, the hopeless romantic narrative shifts (temporarily) to a narrative of dependence. In a scene where Kate is washing her dishes, the narrator tells viewers she lives alone but has a part-time helper called Daryll. Kate is standing at the sink while Daryll, a tall man in his 40s, stands directly behind her, holding a tea towel and watching Kate closely. Interestingly, there is no musical overlay with this scene, only the voice of the narrator followed by a short audio clip where Daryll can be heard saying, 'Do the pans last, yeah?' as Kate continues with the washing up. The audio from this interaction then fades out as the narrator informs viewers that Kate has not had a boyfriend for nine years, emphasising the word nine. The producer's audio selection in this scene is noteworthy – this is the audience's first insight into Kate living independently, and the producer has opted to foreground Daryll's presence both visually and audibly. Kate could have been shown washing dishes alone while the narrator continued to provide the setup narrative, but instead, the decision to include Daryll's instruction to 'wash the pans first' was included. As a viewer, we do not know whether this is the first time Daryll has assisted Kate with washing dishes (although this seems unlikely as Kate and Daryll appear to be familiar with one another) or whether this was a reminder rather than an instruction. Either way, to foreground Daryll is to remind viewers that although Kate might live independently, she requires the help of non-disabled people in order to do so, feeding the narrative that disabled people are dependent and in need of able-bodied 'saviours'.



The producer's choice to foreground Kate's support worker seemed to have the intended effect on the co-researchers. Once we had watched the introductory scenes, I asked the group what their take on Kate was:

Albert: Erm, she's alright

Kevin: I think she needs support

Albert: Support

Researcher: She needs support? What do you think she needs support with?

Kevin: From a support worker.

The first thing Kevin and Albert noticed was that Kate required support. After several attempts to ascertain what else the group had noticed in Kate's introductory scenes, including how the narrator had described her, Kevin and Albert continued to come back to Kate's need for support:

Researcher: And when you were watching it did you listen to what the narrator said about Kate? You know the woman speaking in the background?

Albert: Oh yeah

Researcher: Can you remember what she said about Kate, how she described her?

Kevin: ((quietly)) erm ...

Albert: Erm

Kevin: She needs a support worker

Albert: Support worker

Albert and Kevin reiterated that Kate had a part-time helper. It appears this was the group's main takeaway from the introduction to Kate. When I asked the co-researchers if they recognised themselves in Kate or knew anybody like Kate, Albert replied, 'She's nice anyway, but needed proper support'. The discussion of support and some people with Down's syndrome needing support did not arise in Film Club One, which is surprising considering the theme of this film club was in(ter)dependence. I contend that the techniques used to foreground support and dependence in *The Undateables* could be at least one reason the group spotlighted Kate needing support in our discussion. Whereas in *The Specials*, the support staff were relatively unseen, one of the first things suggested to viewers in this episode of *The Undateables* is that Kate needs help washing dishes. Whether or not Kate can, in fact, wash dishes independently goes unanswered, as the framing of this scene suggests otherwise.

The next excerpt played for co-researchers featured Kate at her office job where she works full-time 'whilst waiting for her ideal man to come along'. As the narrator finishes this sentence, which frames Kate almost as the female protagonist in a Victorian novel, Kate can be seen picking up the office telephone and going to speak but then forgetting she has not dialled a number. Kate looks directly at the camera, smiles, says 'oh,' and rolls her eyes. Kate's faux pas with the telephone could serve as another strategy of enfreakment and, in addition, resonates with earlier discussions around disability and

technology (Chapter Five). However, as stated earlier, the ironic and deliberately contentious nature of *The Undateables* makes it difficult to make a firm judgement on this (Richardson, 2017). Immediately after Kate's subtle telephone blunder, possibly as a way of adding to the irony, the camera then follows Kate as she performs some of her work duties, and the frame eventually transitions to an interview with Kate as she says, 'I'm actually a lady who knows where she wants to go in life'. The frame then transitions back to Kate in the office as she states that she loves to be busy, with short commentaries from her colleagues discussing her work ethic and relationship goals. While the opening narration undermines the status of Kate's work by suggesting she is only there whilst waiting for a husband to come along, this is challenged by comments from her colleagues who establish her as someone to be taken seriously and who fits in well within the office environment.

Kate signs up with the Stars in the Sky dating agency and receives a call while working in the office two weeks later to say a match has been found for her. Kate is very overwhelmed and cries 'happy tears' at the news. Whilst watching this scene, Kevin whispered, 'I think she's happy' and appeared to be wiping away tears from his eyes. He looked towards Dawn and said, 'Oh, makes me cry'. I asked Kevin why it made him emotional, and he responded, 'Well, she's happy'. When prompted about whether the emotional background music or Kate's actions made him feel emotional, he responded, 'I think a bit of both'. Kevin's display of empathy disrupts the common stereotype that people with Down's syndrome are always happy. Here, Kevin can be seen reacting not only to Kate's happiness but also to her excitement and apprehension. Just like Kate, Kevin feels things on the same spectrum of emotion as anybody else, demonstrating the inaccuracy of the forever happy myth.

The scene showing Kate being informed of her match also provoked an interesting discussion with co-researchers around marriage. Kevin and Dawn both said they would like to one day get married; however, Albert disagreed:

Researcher: Do you think that's important to a lot of people, to get married?

Albert: ((nods head yes)) yeah definitely

Dawn: Yeah

Researcher: Is it important to you guys to get married?

Albert: No

Researcher: No? Why not?

Albert: It's not for me

Researcher: It's not for you?

Albert: No

Researcher: Do you prefer being single?

Albert: Yeah

Albert did not feel it was important for him to get married. As a single man in his 50s, it could be that he does not see the point in having a relationship now, or it could be that he genuinely prefers to be single. Albert mentioned relationships he had been in when he was younger, but none from recent years.<sup>36</sup> During an interview with one respondent during the audience reviews, the topic of support/social workers controlling and even stopping relationships arose:

Yes, and staff do control your relationship, no matter what they say, staff do control your relationship because they say, right you've got no family, they won't support you or anything like that, you're supported by us and we'll tell you what to do and what not to do.

This respondent (also male but slightly older than Albert) had spent the first half of his life institutionalised; therefore, Albert may not have faced similar or comparable restrictions on his relationships; however, at one point in our discussion, Albert did say something that made me wonder if he had ever been berated for inappropriate sexual activity. Albert was discussing his first girlfriend when he said:

Albert: Yeah. She were nice to me and we had our first kiss.  
Researcher: So you and \*\*\*\*\* shared your first kiss?  
Albert: Yeah. Not in bed, on top.  
Researcher: Mmmm  
Albert: Yeah, it were nice and like a sweet ((motions to his mouth with hand))  
Researcher: A sweet?  
Albert: Sweet, yeah. That was a long time ago, I was ups- ((so-so gesture with hand))  
Researcher: Mmmmm  
Albert: It's hard

Albert quickly pointed out that he was not *in* the bed with his girlfriend; they were *on* the bed when they shared their first kiss. For him to clarify this suggests he may have pre-empted some questioning or interrogation from me (or possibly the support worker who was present), which indicates that Albert may have previously experienced interventions in his relationships. After all, it is not uncommon for disabled people, especially people with learning disabilities, to have their romantic lives controlled by others. As discussed in Chapter Two, many parents and caregivers express discomfort when the topic of sexuality and people with learning disabilities arises, and the message often conveyed is that 'sex is bad' – a message that many learning disabled individuals internalise (Swango-Wilson, 2008, p.167). Additionally, a distinct lack of sex education for those with learning disabilities (due to assumptions around asexuality or sexual inappropriateness) can also affect how people with learning disabilities

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<sup>36</sup> It was difficult to ascertain Albert's age when he discussed things from his past. When asked how old he was, Albert referred to any childhood age as four; even when discussing himself as a newborn, Albert would say he was four.

understand what is and is not sexually proper (Rohleder, 2010). While, on the one hand, Albert seems comfortable talking about his first kiss, he felt it necessary to assure me that only kissing was involved and quickly shut down any further discussion around physical intimacy. Following this discussion around marriage and physical intimacy, we watched Kate's date, which the next section will now discuss.

### **Kate's date**

Kate was matched with Simon, a 32-year-old man with a learning disability. Kate is filmed outside the entrance to the Museum of Mazes in a local stately home as she waits for Simon and a chaperone to arrive. Similarly to scenes showing Sam waiting for his date, the framing of this scene creates the sense that Kate's date might not arrive. The only audio is the background noise of birds chirping as Kate stands alone, looking apprehensively at the camera:

Producer: How are you feeling?  
Kate: Excited but nervous.  
Producer: Are you hoping he'll be romantic?  
Kate: I'm hoping that he'll treat me like a lady.

Most of *The Undateables* episodes include this obligatory moment (often featured in dating reality television shows or romantic films) whereby the prolonged moment of suspense – the fear of being stood up – is exaggerated. Additionally, so as to elaborate on the 'hopeless romantic' narrative, Kate is directly asked whether she hopes Simon will 'be romantic'. Shortly after Kate's response, Simon and the chaperone arrive, with the audience sufficiently primed to feel a sense of relief that Kate has not been jilted.

As Kate and Simon make their introductions, the narrator reminds viewers that 'Kate hasn't had a proper boyfriend for nine years, and for Simon, this is his first ever date'. What the narrator means by 'proper boyfriend' is unclear. One might deduce this phrase to mean Kate has not had a serious relationship in nine years and has been on dates but has not found the right person to settle down with. The implication, however, is that Kate has had 'pretend' boyfriends and has struggled to have a 'real' relationship because she has Down's syndrome. As previously discussed, the literature supports the notion that disabled people, particularly people with cognitive impairments, are 'often cast into the role of the eternal child', and the suggestion that Kate has not had a 'proper' relationship serves to reinforce what Dóra (2004, p.79) refers to as a 'biological determinist explanation of disablement'. Oftentimes, when people with Down's syndrome (and other cognitive impairments) transition into adulthood, they are regarded as passive in terms of sexual or romantic relationships, and this can lead to a 'self fulfilling prophesy of passivity' when it comes to seeking romance or relationships (Dóra, 2004, p.79). Such assumptions around love, sexuality and disability result in a

cultural script whereby relationships between two adults with learning disabilities are defined in condescending terms. For Down's syndrome in particular, there are often assumptions that people with the condition are sexually 'innocent' or even asexual. The sexual needs and desires of people with Down's syndrome and how they are understood and upheld are highly controversial social, moral and legal issues (Foley, 2012, p.383). The producers of *The Undateables* are not immune to these cultural contentions, and their framing of Kate has been shaped by the anxieties many non-disabled people feel when faced with the topic of sex and disability.

Kate felt an initial spark with her date, and as they were saying their goodbyes, the narrator states, 'Kate's search for a husband seems to have got off to a promising start, and she's keen to know if Simon feels the same'. Kate then asks Simon if he has enjoyed the date and if he likes her. He replied: 'Yeah, I love you, yeah. You're a nice person, yeah'. Four days later, Kate and Simon have arranged a second date at a local pub for a meal. Kate is filmed getting ready ahead of the date, with the use of extreme close ups as she applies her makeup in front of the mirror.



Figure 4

Still image of Kate applying makeup in the mirror

As the producer is interviewing her from behind the camera, Kate describes her excitement and says she hopes the poem she has written for Simon will help establish them as boyfriend and girlfriend. The shot then transitions to Kate sitting in the pub beer garden while waiting for Simon to arrive. The obligatory moment (where it is suggested the cast member might be stood up) is repeated, as the musical overlay becomes playful but suspenseful as a nervous-looking Kate gazes directly into the camera.



Figure 5

Still image of Kate waiting in anticipation for Simon to arrive for their second date.

The obligatory suspenseful wait is less drawn out in Kate's second date. Shortly after Simon arrives, a lengthy discussion ensues about which types of fish they like eating. Kate then asks Simon how he feels about her:

Kate: I'm not sure exactly how to say this, but how do you feel about me?  
Simon: Yeah, you're nice, I like you.  
Kate: Do you feel anything like [Kate grimaces slightly] love or friendship?  
Simon: Oh, yeah, definitely friendship, yeah ... and take it nice and slowly.

As Simon is answering Kate's question, the camera stays on Kate's face and captures her reaction.

Simon: It's not nice into rush into things.  
Kate: Oh, no.  
Simon: I feel that if you rush into things, things can go quite easily go wrong.

An awkward silence falls over the pair as emotive music plays as they silently drink their wine. The narrator then states, 'Simon's holding back, but Kate's not going to give up easily. She's got something up her sleeve that she hopes will win him round'. Kate then recites her poem to Simon, who appears to be wiping away tears by the end of her recital. He then smiles and reaches across the table to hold Kate's hand. Much like Sam's second date, the obligatory moment expected of the romance genre has been met – Kate's story has a 'happy ending', and she has found a partner, confirmed by additional scenes showing Kate and Simon taking a romantic stroll through the park, holding hands and officially confirming their relationship status.

Richardson (2017) is justified in stating that new strategies of enfreakment are prevalent in *The Undateables*, and several examples apply to my analysis. However, my analysis also shows that cast members often displayed the opposite of the

seemingly intentional attempts of 'enfreakment' by producers; some scenarios highlighting the participants' vulnerabilities or incapacities were turned on their heads by the agency of the cast members. For example, several dates arranged (including Kate's) occur in a maze. Based upon the preceding analysis and existing critiques of *The Undateables*, it could be argued that the producers intended to put two individuals with learning disabilities in a maze to make for comedic or entertaining TV. The interesting irony here is that Kate and Simon showed viewers that they could work together and navigate the maze with relative ease while simultaneously having fun and getting to know each other in the process. A more affirmative version of *The Undateables* might create more scenarios allowing the dismantling of stereotypes about the intellectual agency of people with Down's syndrome. Rather than setting up participants to fail (in the name of comedy), an improved, more educative version might include more examples, such as the aforementioned maze scene. As mentioned earlier, Albert stated that if he were to go on a first date, rather than go to the zoo, he would go for a picnic. I would argue that if the cast members of *The Undateables* were given a choice of where to go on their dates, this would not only make the docuseries more authentic but would also reflect Channel 4's emancipatory claims of producing content that challenges misconceptions of disabled people.

Boross and Reijnders (2019) interviewed previous cast members of *The Undateables* and questioned its emancipatory claims. Their study revealed a lack of autonomy in terms of the production process due to the relationship between producers and cast members. One of their interviewees, Annabel, revealed that cast members typically would not find out they had been matched with a partner until the day before (or even the day of) the date, leaving them no time to prepare (Boross and Reijnders, 2019). Annabel states that the producers deliberately gave cast members short notice about their dates for fear the person they had matched them with might change their minds. She understood this as conformation of the producers' condescension towards her on the basis of her impairment:

They were afraid that people would cancel on me, and then I would feel disappointed...I can imagine doing that to someone with Down[s], but I was like "guys, I'm thirty!" I understand that you can get cold feet when you sign up for something like this. Just be honest and don't treat me like a little kid! (Boross and Reijnders, 2019, p.731).

Annabel's narrative is significant in many ways. Firstly, it speaks to the lack of involvement she felt she had in the production of her dating story, and it certainly confirms that she was treated differently on the basis of her impairment. Producers appear to have taken on the protectionist role, assuming that disabled people cannot

emotionally deal with a prospective date being cancelled or do not have the capacity to understand the complications that accompany dating. Secondly, Annabel's comment about 'imagining doing that [being patronising] to someone with Down's' alludes to the infantilisation of adults with Down's syndrome. It would seem the 'forever young' stereotype also exists and is normalised within the disability community.

While a number of couples who have met on *The Undateables* have gone on to have successful relationships (O'Brien, 2019), Annabel's experience did not end well. Her interview revealed that the show's producers had surreptitiously created a Tinder profile on her behalf to match her with a date. It was not until she met the man she had been matched with and asked him (on camera) how he had come to the show that she discovered they had matched on Tinder:

At that moment the director came in and said, "you should not talk about this right now." I was done at that point. I'm more than able to put myself on Tinder. But I don't like Tinder. It should be my choice. The next day, I sent an angry email to them that I'm withdrawing from the show. (Boross and Reijnders, 2019, p.732)

Annabel, understandably, did not return for her follow-up interviews with producers (although her episode was subsequently broadcast), and Boross and Reijnders (2019, p.732) describe the fabricated nature of not only the dates and matching processes but also the 'performances' requested of cast members as well as the censorship of certain behaviours. Given these direct accounts, it calls into question the authenticity of Kate's date. We already know that the producers choose the partners and date locations. However, the extent to which Kate's behaviour was manipulated (or even censored) to fit within the narrative conventions of the show is debatable. As I mentioned earlier, a more affirmative version of *The Undateables* would involve scenes that indeed challenged common misconceptions of people with learning disabilities, and an ideal place to start would be first asking where cast members would like to go on a date. Breaking genre conventions as a means of reflecting the actual reality of a cast member would lead to more authentic stories being told and the all-too-often unheard voices of disabled people being heard.

### **Further reflections**

My analysis has highlighted many problematic aspects of *The Undateables*. In contrast, for the co-researchers, the affirmative aspect of seeing people like themselves on a popular television show about dating, understandably, took precedence over critiquing the series. While I found the show to be problematic, they did not. I found myself grappling with this interesting challenge throughout our co-analysis. I approached the



text as an academic with a particular set of analytical skills grounded in specific critical frameworks, and the differences between all of our educational experiences are, as a result, quite striking in these analyses. I was conscious of the power imbalance between myself and my co-researchers – our roles were different – mine from the perspective of a non-disabled academic and theirs as adults with Down's syndrome who were relatively new to analytical work. I was also mindful of not directing the co-researchers and prompting answers that suited my research agenda and, therefore, did not push co-researchers to find faults with the scenes we analysed. The questions I asked were probing rather than leading. Sometimes, I needed to support co-researchers or make suggestions about issues I thought were worthy of discussion. While some may argue this is steering the discussion, I would contend, in line with Williams (2011), that if I failed to provide this support or guidance to my co-researchers, in-depth group discussions would not have happened, and I would have risked further excluding learning disabled voices in academic research.

I could not ascertain from our discussions whether or not the co-researchers recognised the issues but still found the show to be affirmative or whether they did not see any issues in the first place. Callus (2016, no pagination) states that 'research inevitably calls for a certain level of intellectual skills, and some people's cognitive limitations may prevent them from engaging in it unsupported'. While this is something I recognise in terms of the support my co-researchers required, it would be too simplistic for me to assume that, because of their cognitive impairment/learning disability, co-researchers struggled to recognise the issues I highlighted in my analysis. That would also not explain how the co-researchers are not alone in their thinking. After all, the series was nominated for a diversity in media award in the 2017 National Diversity Awards, and there are many supporters of the show (Anderson, 2012; Kitchener, 2016; Donaldson, 2017) who, like the co-researchers, found it to be diverse and affirmative.

Part of this dilemma involved my wariness of adopting a protectionist role. Regardless of whether or not the co-researchers found the series to be problematic, my analysis highlights issues where TV programmes like *The Undateables* can be improved, and I needed to think about the effects shows such as these have on not just my fellow co-researchers but also the wider audience of the show. A huge source of contention for me was the effect this series might have on non-disabled viewers – while audiences had 'front-row seats' to watch people with Down's syndrome dating, it is important to question what they were learning about this condition, and more importantly, about the lives of the participants being represented. People with learning disabilities have historically been subject to protectionism (especially in the context of sexuality), and I

was mindful that I wanted to avoid repeating such damaging tropes. Yet, I had to strike a balance between protectionism (not raising issues that could potentially harm people with Down's syndrome) and inclusionism (ensuring the voices of people with Down's syndrome are being centred, even if they have not necessarily raised a specific issue). I grappled with concerns that I was perhaps over-academicising the text. I eventually found reassurance in the knowledge that my position as a researcher is to raise potential issues on behalf of people with Down's syndrome because of the possible damaging implications *The Undateables* might have on societal public attitudes towards the Down's syndrome community.

Film Club Two enabled an in-depth discussion about how Down's syndrome was represented in *The Undateables*. It provided a safe space for co-researchers to reflect on past relationships, discuss current relationships and think about their future romantic lives. Co-researchers responded positively to the show and, when asked if they would like to participate in a dating show like *The Undateables*, I received a resounding yes from the group. It was clear from our group discussions that the co-researchers were keen to expand their dating experiences, so much so that one co-researcher asked out another during the session:

Researcher: Wow. And what about you Kevin?

Kevin: I haven't got a girlfriend

Researcher: So you're single?

Kevin: Yeah ((looks sad)) well I was gonna say (5) sorry (5) I just want to support Dawn to be my girl

Researcher: You were gonna ask Dawn?

Kevin: Yeah

Researcher: But now you've just found out she's got a boyfriend?

Kevin: Well I didn't know that.

Researcher: Oh ((Dawn looks to researcher)) What do you think about that Dawn?

Dawn: Yeah ((smiling)). Yeah, so like Kevin now and then erm Kevin now, Kevin, Kevin now and then Kevin now and then erm \*\*\*\*.

Researcher: So you're going out with Kevin now?

Dawn: Yeah

Researcher: But what about \*\*\*\*?

Dawn: \*\*\*\*? \*\*\*\* erm, me and \*\*\*\*, kissed me ((smiling))

Researcher: Did he?

Dawn: Yeah

Researcher: So he's your boyfriend?

Dawn: Yeah

Researcher: Not Kevin?

Dawn: Kevin yeah.

Researcher: So you've got two boyfriends?

Dawn: Yeah ((grinning))

Researcher: Oooohhhh

Kevin: ((Grinning)) you make my day! ((pointing to Dawn))

Dawn: ((motions yes in an air grab))

Researcher: Well I didn't see that coming

Dawn: Yeah

This was an unexpected outcome of the session, and both Dawn and Kevin seemed extremely pleased that they had become boyfriend and girlfriend. Two weeks later, during a storyboarding session with the group, they informed me what scenes they would like to include when a staff member overheard Kevin and Dawn suggesting I could film a sit-down 'couple's interview' and ask them questions about their relationship. I was then taken to one side (out of earshot of the group) by a member of staff and told that Kevin and Dawn were not in a relationship, never had been and that I should not make any reference to a relationship in the mock trailer. I was instructed to 'shut down' any talk of relationships and left to navigate this with Kevin and Dawn. I suggested that we stick to the pre-selected scenes (three group shots and three solo shots) and told them this would be best as we were restricted on time. The group agreed to this, and from that point on, I did not discuss Kevin and Dawn's relationship with them.

I later relayed what had happened to the support worker who had attended the film clubs and was present when Kevin asked Dawn to be his girlfriend. The support worker seemed shocked and stated they 'had no idea it wasn't a real relationship'. This scenario is a real-world example of the 'prison of protection' so many adults with learning disabilities are placed within, 'protected' from relationships for various reasons, some of which may be legitimate, some less so (Hingsburger, 1995, p.27). Chapter Two examined the various ways in which disabled people (especially people with a learning disability) can be restricted or controlled by caregivers or professionals who ultimately have control over what is 'best' for them. Ultimately, I do not know Kevin and Dawn's history, and there could be a genuinely acceptable reason for warning me against including scenes that refer to a relationship (for example, their 30-year age gap); however, I was never offered any explanation.

While the co-analysis revealed that the group found *The Undateables* entertaining and encouraging, my reading of the show identified a common theme often found in disability documentaries that involve 'superficially inspirational and "feel-good" remedies for the lived reality of disability' (Wain, 2017, p.47). Rather than reflecting the everyday lived experience of Kate and Sam's quest for love, the episodes we analysed were heavily constructed and composed to elicit a certain kind of reaction from the audience. The message being portrayed to viewers is one of reassurance: 'we might find contemporary dating culture to be difficult, but at least it's not as difficult for "us" as it is for the bodies represented in the series' (Richardson, 2017, p.334). It is perhaps because of this underlying message that the show has been criticised as a modern-day

freakshow. As Richardson (2017) and Garland-Thomson (1997) have argued, the early freak shows were designed to alleviate the audience's anxieties about their own bodies, differences and abilities by providing them with examples of how much worse they could be. *The Undateables* can be read as doing the same thing, alleviating the viewers' concerns about their inability to find a partner. The Othering processes as described in the earlier discussion of the freak show, are in many ways comparable to this contemporary representation of Down's syndrome. The series is subtle in how it relays its message of reassurance, and many viewers may not even realise they are being solaced by the heartwarming, inspirational representations of people with Down's syndrome. The balance between reassuring the audience and entertaining them is shrewd. As previously discussed, in many of the scenes we analysed, the cast members are coded as comedic – viewers are invited to laugh at Kate's telephone gaffe and squirm at Sam bringing an empty wallet to his date. As Richardson (2017, p.337) suggests, offensive representations of disabled people should not be 'excused on the screen because it has been qualified by an explanation at the start' (in the case of *The Undateables*, the subtle token gesture of knocking off the 'Un' from 'Undateables' in the opening credits).

In an ableist world where able-bodiedness is favoured, and social environments are organised according to idealised notions of such, disabled people find themselves having to prove their value. This is especially the case in the dating world. Albert made various comments relating to Kate and Sam proving themselves during our session. Reflecting on Sam's date, Albert discussed how the episode 'prove[d] you're good enough to take people out'. Albert enjoyed watching Kate's date as she was 'proving how to do it'. Albert's insight here pushes back on the stigma and stereotypes attached to Down's syndrome (and disability more generally), and disability documentaries have a lot more work to do in terms of challenging misconceptions and creating meaningful content for the people they are both representing (subjects) and educating (viewers). While it is disheartening that disabled people feel they have to prove their worth, as long as ableism prevails, then people with Down's syndrome and their allies must continue to provide examples of why they belong. Documentaries can be an effective way of illustrating this. Documentaries have a unique opportunity to offer alternative, nuanced, tangible representations of disability. *The Undateables* was one of the first disability dating shows. While it can be applauded for broadcasting a show on this topic, its formulaic nature fails to capture the diverse lived realities of its subjects and the illusion of inclusion becomes unravelled. Applause must be short-lived if the show lacks any kind of agency from its participants and rigidly follows the genre conventions of romantic reality television. If representations of disabled people are not appropriately

handled and fail to involve participants in the production process, ultimately, they can be more damaging to the disabled population as a whole. *The Undateables* serves as an example of the harm inclusionism can do – tokenistic, manufactured representations of different impairment groups have failed to capture the diverse reality of the lives of each cast member.

*The Undateables* purports to have been produced from an emancipatory standpoint – to challenge misconceptions about disability in an attempt to achieve greater inclusion. This is a complicated feat when trying to mould ‘distinct voices into a single story’ (Boross and Reijnders, 2019, p.16). By adhering to rigid genre expectations and narrative arcs and refusing to navigate alternative plot points, it is difficult to accurately represent disability *and* achieve emancipation. *The Undateables* ran for eleven seasons in the UK and, from an early point in production, successful and obligatory moments were established, and producers were unwavering from these format points. Throughout every season, cast members were moulded to fit the formulaic narratives and were often misrepresented in the process.

A prime example of this can be found in an episode that was not analysed with the co-researchers, but that featured a cast member from *The Specials*. In season two of *The Specials*, Lucy dated a young man with an unnamed learning disability called Daniel. Daniel was later approached by recruiters from *The Undateables* and featured in several episodes in different seasons. He was represented as lonely and desperate for love in *The Undateables* and received a crash course on dating etiquette from his mother. In stark contrast was Daniel's representation in *The Specials*, where he clearly had an active romantic life and took Lucy on several successful dates. In order to fit within the prescribed narrative arcs of *The Undateables*, Daniel's history, character, and behaviour had to be totally falsified.

Rainey (2011, p.27) states that ‘representations reflect social attitudes, but they also set limits of possibility – they help define what is socially imaginable’. When television is produced by non-disabled people, for non-disabled people, then it will be lacking in accurate representation of its disabled subjects. Documentaries are an excellent way of educating mainstream audiences about the nuances of disabled lives; however, as this chapter has shown, if they only adhere to normative and limiting scripts and do not involve disabled people beyond the point of recruitment, they will always fail to challenge misconceptions. Instead, misconceptions will be echoed.

## ~ Chapter Seven ~

# Representing Down's Syndrome, Screening and Selective Abortion

### Introduction

The complex topic of screening for and terminating pregnancies prenatally diagnosed with Down's syndrome has already been broached in Chapter Two. The following chapter addresses some of these issues through a multimodal analysis of a documentary film called *A World Without Down's Syndrome?* (Clare Richards, 2016). I will explore how Down's syndrome and the complex entanglement of prenatal screening (PNS) and selective abortion (SA) are presented in this documentary. Before introducing the analysis, I will briefly outline the film, discuss its background and context of production, summarise pertinent critiques of *A World Without Down's Syndrome?* in relation to this thesis, and provide the rationale behind the selection of this text for analysis.

As a point of departure, it is important for me to address that this chapter, for several reasons, includes less of the co-researcher's reflections than the previous two chapters. Firstly, the co-researchers had less to say during Film Club Three, perhaps because they had no prior knowledge of the subject of PNS and SA or any of the issues surrounding the ethics of disability-selective abortion. The co-researchers may not have been comfortable with the subject matter, or it is possible that the topic simply did not interest them. Secondly, the text itself did not introduce the topic of PNS, NIPT or SA in relation to Down's syndrome in an accessible manner. I, therefore, had to use responsive methods to ensure that the co-researchers could engage with the text. Where in the previous two Film Clubs, I was able to define important terms at the beginning, and this was sufficient information for the participants to understand the concepts under analysis, for Film Club Three, this was not feasible. Due to the complexity of the themes being discussed and because the co-researchers had no prior knowledge of PNS or SA, a considerable amount of time was spent at the beginning of the session explaining in an accessible manner what the documentary film was examining and why. How I went about doing this will be discussed in more detail later on in the chapter, but it is important that I acknowledge this early in the chapter in order to clarify why my voice is more prevalent in this chapter than that of the co-researchers.

## **Background of *A World Without Down's Syndrome?***

*A World Without Down's Syndrome?* is a documentary film broadcast in October 2016 by the BBC (British Broadcasting Corporation). The BBC is renowned for its vast selection of documentaries – priding itself on providing ‘programmes that inform, educate and entertain’ (BBC, 2010, no pagination). It is worth mentioning that the BBC is the only ‘public service broadcasting’ medium in the UK and, therefore, has a quite different relationship with its audience than competing broadcasters (Wickham, 2007). As a public service broadcaster, the BBC does not ‘operate as part of a free market motivated by profit’; instead, it is characterised as ‘a service for the good of the people in a similar way to healthcare or state education’ (Wickham, 2007, p.30). The BBC does not make revenue from advertising – its programmes are funded by a licence fee payable by all UK households who use television receiving equipment to use streaming services or watch live TV. For this reason, BBC viewers feel a sense of ownership of the BBC and feel they have a ‘personal stake’ in what kinds of programmes are being produced, often querying the level of government involvement and their political stance (Wickham, 2007, p.31).

*A World Without Down's Syndrome?* was directed by Clare Richards, who was also the co-writer alongside Sally Phillips (the narrator of *The Undateables*). Phillips also presented the film and provided the narration. The film was made during the implementation of non-invasive prenatal testing (NIPT) in the UK for pregnant people, available both through private health care providers and the NHS. Described by the BBC as a documentary dealing with the ethics of pregnancy screening in relation to Down’s syndrome, the film ‘explores the science and thinking around the proposed new screening test for Down’s syndrome and its possible availability on the NHS’ (BBC, 2016, no pagination). As stated in Chapter One, NIPT is a blood test offered to pregnant people whose baby has been identified as having a higher chance of having Down’s syndrome, as determined during prior screening tests. During filming, the UK government were in the process of deciding on the Down’s syndrome screening pathway, and the Nuffield Council for Bioethics was debating the introduction of NIPT in the NHS sector (Nuffield Council on Bioethics, 2016). The film was made in response to the lack of public debate about NIPT and an attempt to report on the issues for public audiences.

Phillips has worked in film and television as a comedian and actress for most of her career. With the exception of her narration on *The Undateables* and *Beauty & The Beast: The Ugly Face of Prejudice* (2011), *A World Without Down’s Syndrome?* was Phillips’s first endeavour in the documentary genre. During the film, Phillips states that

she decided to make this film because she has a son with Down's syndrome, Olly, who was 11 years old at the time of filming. This personal motivation drove Phillips to make the film, along with a distinct absence of public debate and a concern that the new screening programme may result in an ever-diminishing number of people with Down syndrome being born. Her invested interest in the subject matter was acknowledged from the outset:

Although Olly was the reason I started making this film, you'll be relieved to hear it's not just about him. It's not just about Down's syndrome either. It's a film that asks what kind of society we want to live in and who should be allowed to live in it? (*A World Without Down's Syndrome?*, 2016, 00:59-01:15)

Veronica Wain, an Australian scholar and documentary filmmaker, made similar assertions regarding a film she made about her own child with a genetic condition. Her essay discussing the making of the film *18q-: A Different Kind of Normal* confirmed that her interest in making the film was not to 'solve' the 'problem' of the chromosomal condition under discussion (18q-) but rather to problematise dominant ideologies surrounding the concept of normalcy, as well as question what a valuable life might look like (Wain, 2013, p.194). These existential concerns about disability and social worth are prevalent in academic discourse (as we saw in Chapter Two) but are less visible in the public realm. I would suggest that Phillips, in a similar vein to Wain (2013), is attempting to address related concepts of human value and normalcy whilst acknowledging that the birth of her child triggered her initial interest in the matter.

During the film, Phillips interviews several 'experts in the Down's syndrome community' and some of the 'world's top scientists', as well as people with Down's syndrome, to gain a variety of perspectives in the debate, as shown in the following figure:

Professor Sue Buckley (expert educationalist whose pioneering research has enabled thousands of children with Down's syndrome to be educated alongside their peers in mainstream schools).
Karen Gaffney (Wild swimmer, special Olympian and Down's syndrome self-advocate from Oregon, USA) and her mother, Barbara.
Hayley Goleniowska (blogger, author, speaker and mother of a child with Down's syndrome).
Halldóra Jónsdóttir (author of an article defending her right to life and one of the few remaining people in Iceland with Down's syndrome) and her mother.
Kari Stefansson (Icelandic geneticist)
Liam Bairstow (actor with Down's syndrome from Coronation Street).



Kypros Nicolaides (world expert on maternal foetal medicine).
Lyn Chitty (professor of genetics and foetal medicine based in the UK).
Jane Fisher (director of a UK-based charity supporting women through pre-testing and diagnosis).
Razib Khan (first person in the world to sequence an unborn child's DNA – his son's)
Professor George Church (American geneticist who pioneered DNA genome sequencing – often referred to as the "Godfather of Genetics")
Emma (a woman carrying her second child and whose first child has Down's syndrome)
Kate (a woman who had opted for termination upon gaining PNS results that confirmed her baby had Down's syndrome).

Figure 6

List of interviewees featured in *A World Without Down's Syndrome?*

### **Critiques of *A World Without Down's Syndrome?***

The film generated critical ethical debate regarding PNS in the public domain due to its provocative questioning of what kind of society we want to live in. In an article written shortly after the film's release, Leah Burch (2017, p.1085) examines the online debates and subsequent resistance incited by *A World Without Down's Syndrome?*. According to Burch's (2017, p.1086) analysis, the Twitter hashtags #worldwithoutdowns and #justaboutcoping were influenced by the 'affirmative and resilient nature of this documentary' and represent a form of online resistance to narratives of Down's syndrome that assume tragedy and dependency. The hashtag #justaboutcoping was intended as a tongue-in-cheek commentary that was usually accompanied by an affirmative image or video of an individual with Down's syndrome. The hashtag and imagery contradict the narrative that parents of children with Down's syndrome find it difficult to parent a child with Down's syndrome. An example of such an image used with the hashtag #justaboutcoping can be seen in Figure 7. Burch (2017, p.1086) suggests that the documentary and the platforms of resilience formed on Twitter in response to the film 'disrupt normative assumptions of the human, and call for a long hard consideration of the type of world that we want to live in'. The online resistance Burch describes stems from the ongoing social media conversations taking place between activists, advocates, academics, parents, family and friends within the Down's syndrome community. Many parents, activists and allies of people with

Down's syndrome applauded Phillip's documentary, thanking the actress for raising such crucial and previously overlooked questions regarding the ethics of screening. For example, Burch (2017, p.1086) cited the following tweets in response to the film: 'Thank you for making a brilliant documentary. You raised poignant issues which are rarely discussed' and 'Thank you ... for courageously & poignantly asking what kind of society we are building if it were to be a #worldwithoutdowns'.



Figure 7

Example of the Twitter hashtag #justaboutcoping (Ups and Downs, 2016)

Burch (2017, p.1086) asserts that *A World Without Down's Syndrome?* has 'real world' impact in terms of opening up debates that encourage critical understandings of humanity and diversity. Several media reviews of the film, however, criticised Phillips for making an already difficult decision that much harder (Freeman, 2016; Greenhill, 2016; McVeigh, 2016). In an interview with the *Observer*, Jane Fisher, the director of the charity Antenatal Results and Choices (ARC)<sup>37</sup>, one of Phillips's interviewees, stated that the film adds 'an extra layer of difficulty for couples and families who might be making the decision now about whether to end their pregnancy. It risks offering the suggestion to those who have

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<sup>37</sup> ARC is a registered charity that provides information and non-directive support to parents before, during and after prenatal testing. ARC was founded in 1988 under the name 'Support after Termination for Abnormality' (SATFA). The context of the charity began as support for anyone who had undergone terminations on the basis of 'fetal abnormality' but now encompasses support at every stage of pregnancy regardless of what decisions a person makes (Fisher, 2008, p.58). Fisher stated in 2008 (p.59) that 'most people who contact the organisation after a diagnosis are considering or have undergone a termination, while those continuing the pregnancy tend to veer towards condition-specific support groups ... ARC will always provide most of its ongoing support to those who choose to end their pregnancies after an antenatal diagnosis as there is no other support available to them'.

[decided to end a pregnancy] that they have made the wrong decision' (McVeigh, 2016, no pagination). Fisher goes on to say:

Full respect for Sally ... You can see her empathy and her love for her son, and wish for people to have a more positive attitude towards the condition. But it's important we don't get too simplistic about this. There will always be people who choose not to screen, who choose to have the child. The point is choice. We want to make sure that women who take the decision to end the pregnancy are not perceived somehow as saying they do not value people who are here – they are saying this is not something *they* can do, that it is not right for *them* or for their families. Not only does no one know how their child would be affected by Down's, but the big conflict for women is the adult the child will be 20 or 30 years down the line. For most women, that is the bit that tips them to end the pregnancy. An adult who will be, at best, vulnerable. (McVeigh, 2016, no pagination, original emphasis)

It is significant that Fisher states the importance of avoiding over-simplification, as she then goes on to claim 'the point is choice', as though this issue of 'choice' is a straightforward one. Within feminist and reproductive discourses, the term choice 'generally refers to the availability of abortion' (Piepmeier, 2013, p.176). Piepmeier (2013, p.176) warns that "choice" needs to stop being used as a universal, easy answer' because the reality of choice can be quite the opposite – choice can be messy, painful and often involve difficult negotiations with the self and with reproductive partners. Fisher's statement uses the rhetoric of choice, which in an abortion rights context is often used to manipulate disability issues into feminist issues. Within the context of reproduction, feminism is often weaponised, which inevitably dismisses disability rights-based perspectives and overly simplifies disability issues.

Fisher's blanket statement that any adult with Down's syndrome 'will be, at best, vulnerable' harks back to Brown's (2011) assertion, discussed earlier in Chapter Two, regarding the concept of vulnerability determining how certain groups of people (in this case those with Down's syndrome) are governed. From Fisher's perspective, Down's syndrome comes with an automatic classification of vulnerable, and it is therefore justifiable to intervene (by way of genetic screening and selective abortion) in the lives of those living (or soon to be living) with the condition.

Furthermore, Fisher's comments on the film's warning of a potential 'world without Down's' are also problematic. She states that the message in the film that NIPT could

lead to fewer people with Down's syndrome being born is an over-simplification.<sup>38</sup> Notably, Fisher has financial links to commercial companies responsible for marketing NIPT. In a co-authored paper written for the *British Medical Journal*, the 'competing interests' section at the end of the article states that ARC (the charity that Fisher is the director of) 'receives small amounts of funding from some commercial companies marketing NIPT' (Chitty et al., 2016, p.11). Fisher told the *Observer*: 'There are five biotech companies that sponsor us. It is a tiny amount of money. We make it clear we are not promoting any individual product' (Greenhill, 2016, no pagination). Fisher's claim that the documentary is unbalanced seems somewhat disingenuous, given her financial link to the NIPT industry. Furthermore, as noted in the documentary, the sole counselling referrals the NHS make for patients contemplating termination after screening are all to ARC. The ARC's financial links to the NIPT industry constitute a conflict of interest and certainly raise questions about the neutrality of the information and support this charity offers to those deliberating termination or continuation.

### **Why *A World Without Down's Syndrome*?**

In the year the film was released (2016), I was approaching the end of my combined honours undergraduate degree (English Language and Special Educational Needs). One of the questions set for my Special Educational Needs exam involved an exploration of the ethics around screening, using the pregnancy of a woman who found out she was having a baby with Down's syndrome as a case study. This was my first in-depth examination of the bioethical debates surrounding PNS, and the topic fascinated me. Several months after this exam, *A World Without Down's Syndrome?* was aired on the BBC. This was one of the first documentaries about Down's syndrome that I had watched, and it immediately solidified my interest in the subject. The online debates this film had sparked, and the subsequent surge in public dialogue following its release, confirmed to me that the documentary genre (and its perceived 'truth-telling' qualities) were worthy of attention and academic inquiry.

More importantly, *A World Without Down's Syndrome?* was also the first documentary film about PNS and SA I had encountered that included people with Down's syndrome. For this reason alone, the film would be crucial to include in my analysis. As Figure 2 in Chapter Three shows, multiple documentaries involve

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<sup>38</sup> More studies are required to determine whether selective abortions will increase with NIPT as a screening option, however, the prediction that fewer people with Down's syndrome will end up being born as a result of NIPT is, according to Kaposy (2018), is a very likely result.

people with Down's syndrome in different contexts in conversations about a range of issues; however, none that focus specifically on the topic of PNS and disability-selective abortion.<sup>39</sup> Furthermore, the film focuses specifically on PNS and SA for Down's syndrome (as opposed to disability generally), making this a text that is altogether relevant to my co-researchers as the topic under discussion (directly and indirectly) involves them and people like them.

## Analysis

### Intended audience and cognitive ableism

I had hoped to be able to use the introductory scenes from *A World Without Down's Syndrome?* as a way of explaining to the co-researchers what the film was about and introducing the topic of PNS in relation to Down's syndrome. This, however, was not possible because, although the film is about Down's syndrome, the intended audience did not include people with learning disabilities. The complex language and medical jargon, together with the relatively fast-paced dialogue, meant that using these scenes to explain the subject matter was not feasible. It is not uncommon for media productions to be permeated by cognitive ableism, even texts specifically about learning disabilities. Carlson (2001, p.140) defines cognitive ableism as a

prejudice or attitude of bias in favor of the interests of individuals who possess certain cognitive abilities (or the potential for them) against those who are believed not to actually or potentially possess them.

The term 'cognitive Others' is often used to describe those who do not possess certain cognitive capacities and to draw attention to the 'workings of cognitive ableism' (Sandberg et al., 2021, p.1422). Cognitive ableism is apparent within *A World Without Down's Syndrome?* as its intended audience was non-learning disabled people who possessed at least some prior knowledge of ethical debates around PNS. This conclusion is drawn from the continued use of medical language without explanation throughout the film. Compared to the rest of the film's dialogue, the narration sequences used much clearer language and appeared more suitable for people with a learning disability. Yet, despite this film being about Down's syndrome, the co-researchers were rendered cognitive Others in that the rest of the film did not use accessible language.

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<sup>39</sup> In 2022, after the fieldwork for this thesis had been completed, Channel 4 broadcast a documentary entitled *Disability and Abortion: The Hardest Choice*. This documentary film was presented by a female actor with spina bifida (Ruth Madeley) and a male actor with Down's syndrome (Ruben Reuter). Together they explored the ethical issues around disability SA after the 24-week cut off point in the UK. This would have been a useful text to analyse had it existed prior to me commencing my fieldwork.

Early on in my analysis, I realised that the concepts and debates being explored in *A World Without Down's Syndrome?* were complex and would require accessible explanation before any co-analysis could take place. For this reason, I decided not to use scenes from the film to explain PNS and SA, as none would sufficiently break down these concepts in a straightforward manner. In order to overcome this cognitive barrier, I developed an easy-read PowerPoint presentation defining and explaining some of the important terms that co-researchers would hear throughout the session.<sup>40</sup> Figure 8 shows two examples of the simple, easy-to-read slides I used to describe potentially complex or ambivalent terms.

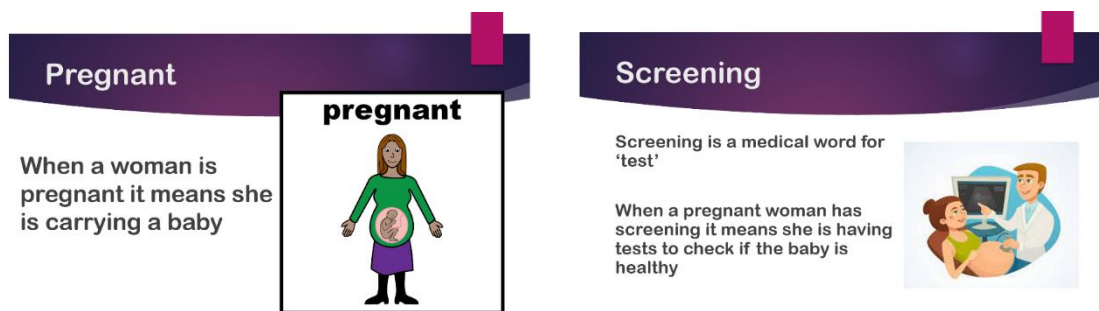


Figure 8

Example PowerPoint slides used in Film Club Three – Screening for Down's syndrome

Pregnancy, PNS and selective abortion are abstract concepts that can be difficult to process cognitively, especially for people with learning disabilities. This, however, should not be a reason for overlooking learning disabled people, and more accessible language to explain these concepts at the start of the film might have excluded fewer people with Down's syndrome.

As well as using easy-read descriptions and images, I used two storylines from the co-researchers' favourite soap opera to explain some of the concepts we would discuss during the film club. Before hosting the film clubs, I spent time with my co-researchers in order to get to know them, and during this time, they mentioned how *Emmerdale* was one of their favourite programmes to watch on television. Ruth Garbutt's (2010, p.88) work with the learning disability community also revealed how many people use media sources, especially television, as a key source of information, possibly because of its

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<sup>40</sup> 'Easy-read' refers to the presentation of text in an accessible, easy to understand format using images and short, straightforward sentences. It is often useful for people with learning disabilities, and 'may also be beneficial for people with other conditions affecting how they process information' (Foundation for People with Learning Disabilities, 2023, no pagination).

accessible format. *Emmerdale* is a popular British soap opera that has been aired on ITV (the UK's oldest commercial network) since the early 1970s and is a show the co-researchers have grown up watching. In more recent years, two *Emmerdale* storylines relating to Down's syndrome have made their way into public dialogues around reproduction and disability. In 2011, a character called Rhona discovers her unborn child has Down's syndrome, and after deliberation, she decides to continue with the pregnancy, eventually giving birth to her son, Leo. In 2020, another character, Laurel, discovers she is pregnant with a child with Down's syndrome and decides to terminate the pregnancy.

Before this divisive *Emmerdale* storyline aired, it prompted much debate from the general public, with a petition with over 30,000 supporters calling on ITV to cancel the upcoming plot (Mewes, 2020). While some *Emmerdale* fans expressed support for the representation of such a sensitive subject (Sulway, 2020), many members of the Down's syndrome community condemned the show for reinforcing discrimination (Parker, 2020). Shortly after ITV's press release announcing the controversial *Emmerdale* storyline, the Down's Syndrome Association (DSA) confirmed they had no involvement in the storyline's development and had expressed to the show's producer their concerns, including how audience members with Down's syndrome might be affected by the termination storyline (DSA, 2020). The ITV press centre stated that this storyline, while emotional, was important to highlight, confirming the writers had worked in consultation with parents with lived experience as well as the ARC (the charity discussed earlier in the chapter) (Lindsay, 2020).

Despite the aforementioned controversy, these episodes worked as pertinent learning supports within Film Club Three. When I showed the co-researchers images of the characters Laurel, Leo and Rhona, they instantly recognised them from *Emmerdale* and were aware of the storylines involving Down's syndrome. I informed the group that the reason I was showing them Laurel and Rhona was that these characters were both pregnant with a baby with Down's syndrome, but they made two very different decisions regarding their pregnancies. I played an excerpt from *Emmerdale* for the group to remind them how the storyline played out. This scene featured Laurel and Rhona having a heated discussion about Laurel's decision to terminate her pregnancy. Once the excerpt had finished, I checked with the group that they understood what was being discussed:

Researcher: So do we all know what they're talking about here?

Kevin: Yeah

Albert: About termination

When I asked why they thought Rhona and Laurel might have been arguing in this clip, Albert replied, 'She's not happy that she's having Down's syndrome', referring to Laurel. Reminding the group of these storylines was helpful in the sense that it gave two fictional examples: one woman who decided to continue her pregnancy and gave birth to a child with Down's syndrome (Leo) and one presenting the more common choice prospective parents make whereby a pregnancy is ended because the baby is prenatally diagnosed with Down's syndrome. As stated in Chapter One, in the UK, 90% of pregnancies where Down's syndrome is identified prenatally are terminated. Using storylines from *Emmerdale* was an effective and more comprehensible way to explain the complex concept of selective termination. This seemed a necessary step before watching and discussing *A World Without Down's Syndrome?*

### **'He's one of them'**

Once I had tackled some of the complex concepts we would be exploring during the Film Club, I played the co-researchers the first scene from *A World Without Down's Syndrome?*. In this scene, Phillips introduces the audience to her family, with a particular focus on her son, Olly, and the joy he has brought to their family. Next, I played a scene where Phillips meets actor Liam Bairstow, who has a six-month contract playing the role of Alex Warner in the popular British soap opera *Coronation Street*. As the scene began, Albert and Kevin had the following whispered conversation:

Albert: He's one of them (3) Down's syndrome

Kevin: ((pointing to screen)) He's one ( )

Albert: That lad yeah

Kevin: ((pointing to screen)) He makes a good point

Here Albert can be seen identifying Liam Bairstow as 'one of them', clarifying after a short pause that he means a person with Down's syndrome. Albert clearly recognises the physical characteristics of a person with Down's syndrome, but I am unsure whether he self-identified as someone with Down's syndrome. Throughout our group sessions, Albert made reference to people with the condition but often as though he did not belong to the same group as them. For example, when discussing the character Rhona from *Emmerdale*, Albert stated 'She's got a Down's syndrome'. On separate occasions, Kevin and Albert also referred to Down's syndrome as a 'virus' and 'disease', positioning Down's syndrome as an exclusively medical 'problem'.

Similarly, when reflecting on his childhood, Albert began one of his anecdotes with 'when I was Down's syndrome', almost as though it is something he has grown out of and no longer has. Todd and Shearn (1997, p.342) talk about the ways in which



learning-disabled people are ascribed identities and how these 'attributed social identities' are shaped, in part, by how their parents or caregivers communicate knowledge about the social implications of a learning disability. Albert's awareness of his assigned social identity is unclear, and I did not press him to clarify his choice of wording as this did not seem relevant at the time. It may also be possible that Albert referred to his having Down's syndrome in the past tense because, at that point in the session, we were talking about children with Down's syndrome more than we were about adults with the condition. While interesting and important, how the group relates to their Down's syndrome identity is beyond the scope of this thesis.

### **A country without Down's syndrome?**

After watching several scenes from *A World Without Down's Syndrome?*, I explained to the group that, because of the accuracy and effectiveness of the new tests being used to detect Down's syndrome (NIPT), a lot of people in the Down's syndrome community (including the woman presenting the film) were concerned that it might mean fewer people with Down's syndrome end up being born. One of the interviewees in this film is a young Icelandic woman named Halldóra Jónsdóttir, described by Phillips as 'one of the few people with Down's syndrome in Iceland'. Phillips explains that in Iceland, almost all pregnant mothers undergo prenatal screening. She continues:

It's a land of contradictions. Here they provide some of the best care and opportunities for disabled people in the world. But over the last five years, 100% of people have chosen to terminate for Down's syndrome. 100%. That's, like, everyone. If this is the direction that the UK is heading, then I wonder what it must be like to have three copies of chromosome 21 and live here.

The accuracy of Phillip's above statement cannot be confirmed, as the sources are not cited in the film credits; however, it is recognised that screening for chromosomal conditions is a 'well-established element of prenatal care' in Iceland (Burke, 2021, p.197). Shortly after the film's release, Iceland's near 'eradication' of Down's syndrome became a prevalent feature in the global news circuit. An article from CBS News in 2017 reported that 'Down syndrome is disappearing' in Iceland (Quinones and Lajka, 2017), and several reports of a similar nature prompted a renewed debate about the ethics of screening for Down's syndrome (Burke, 2021). Following this renewed public interest, the Government of Iceland issued a press release firmly disputing any claims that Iceland strives to be 'Down's syndrome free', presenting 'facts' to correct the 'misleading' information being circulated (Embassy of Iceland, 2018, no pagination). In this statement, they stipulate that between 2008 and 2018, on average, two to three babies with Down's syndrome have been born each year and also confirm that, as per their UN Declaration on the Rights of Disabled Person's objectives, it is a 'core

principle of Icelandic society to respect people with disabilities as part of human diversity' (Embassy of Iceland, 2018, no pagination).

The Icelandic government's statement was not released until two years after the release of *A World Without Down's Syndrome?*. The decision to interview Halldóra was based on her publicly expressed concerns over the alleged 100% termination rates in an online article. Following a brief conversation with Halldóra and her mother, Phillips's narration states that Halldóra is an accomplished woman with a job, speaks two languages, and soon hopes to marry her long-term boyfriend. This justification of Halldóra's 'worth' resonates with what the group talked about in Film Club Two in terms of disabled people having to 'prove themselves' in an ableist world. Phillips clearly also feels it important (or necessary) to justify Halldóra's existence but does not address the idea of cognitive ableism directly. Perhaps because of her 'cognitive privilege', Phillips is unaware she is tangentially justifying Halldóra's existence (Carlson, 2001, p.140).

When faced with the proposition of a world without Down's syndrome during the Film Club, the following discussion took place:

Researcher: So we know what the film is about. So it's been made because people are worried that if we keep doing these tests then it means fewer and fewer people with Down's syndrome will be born, and we don't want that. We don't want a world without Down's syndrome do we?

Albert: No

Dawn: No

Researcher: What would a world without Down's syndrome be like?

Albert: Yeah I know

Researcher: It would be rubbish wouldn't it?

Dawn: Yeah

Albert: Yeah

Kevin: I was gonna say something else! Starts with a C

Researcher: Ahhhh ((laughs))

Albert: I agree

The co-researchers unambiguously demonstrate their sense of self-worth in this conversation, as well as their humour. The co-researchers, I believe, represent the every day – they are not famous actors with Down's syndrome or politically active warriors for disability rights, nor have they appeared on children's television or been fashion models. Nevertheless, the above transcription tells us they do not need to be any of these things to recognise their own self-worth or express their feelings about identity, citizenship or bioethics. In Chapter Two, the review of literature relating to the supercrip confirmed that supercrip narratives tend to emphasise over-compensation for a presumed 'deficit' created by disability. The above interaction with co-researchers reveals that supercrip representations do not need to be relied upon in order to represent a disabled person's worth or place in the world. Cognitive ableism tells us

that the co-researchers do not possess the necessary cognitive abilities to undertake research in this area. Yet, the above conversation rejects this notion and demonstrates the significance of including people with Down's syndrome in academic research. The co-researchers' lived realities are presented without the distraction of an inspirational, expectation-defying narrative.

### **The complexity of 'choice'**

As I briefly mentioned earlier in the chapter, at the start of the film club, I used easy-read presentation slides to explain some of the complex terms associated with reproduction, including what choices women have when their child is prenatally diagnosed with Down's syndrome. It transpired that the co-researchers were unaware of reproductive screening, although they did recognise the image of a woman having an ultrasound scan, as they agreed they had all seen this on television. The group understood that a pregnant person has different medical tests to check the health of the baby, but until our group session, they did not realise that many pregnant people undergo screening tests specifically to find out whether their baby has Down's syndrome.

After explaining different types of screening tests, such as ultrasounds and NIPT, I went on to clarify that if a woman finds out from medical tests that the baby she is carrying has Down's syndrome, she has the choice to continue with or terminate the pregnancy. As I explained this (using an image of a baby with Down's syndrome and one without), Albert stated: 'You know what I think? One take that one off and keep the other one on, I think ... You know them two photos ... If you had one, that would be the best one to be born'. Albert pointed to the image of the baby with Down's syndrome, confirming that if *he* had a choice, he would choose to have a baby with Down's syndrome. The methods I used to describe 'choice' were somewhat simplistic so as to aid understanding; however, the concept of 'choice' in the context of reproduction is far more complex than the continue/terminate dichotomy.

The concept of 'choice' features heavily in *A World Without Down's Syndrome?* – verbal references to choice and decision-making appear at least 23 times in the film transcription. The narrative of reproductive choice becomes most apparent in Phillips's interview with Jane Fisher. Phillips asks Fisher how educated the charity's helpline advisors are about Down's syndrome. Fisher's response is far from reassuring:

I wouldn't pretend for a moment – we've got a small helpline team of four of us – and I wouldn't ever pretend, and we wouldn't pretend, that we are absolutely up to date with what living with Down's syndrome means in all its aspects.

As the only current charity to which the NHS signposts prospective parents and those who have recently terminated a pregnancy, it would be reasonable to expect a broader team of advisors, all of whom are up-to-date in terms of training. Phillips presses for a more specific example and asks:

Phillips: So let's say to you, "I'm worried about how the learning disability is going to affect this baby", what do you then say to me?

Fisher: Well, we're not going to say, "You'll be able to cope", we'll say, "How worried are you? Do you feel you could continue the pregnancy and deal with that? Can you deal with that level of uncertainty, or do you feel you need to end...?"

Phillips: There's a gap there in the logic, isn't there? So if I say, "I'm worried about the learning difficulty", you go straight to termination from that. Whereas, I'm saying I'm worried about the learning difficulty.

As well as being director of ARC, Fisher has authored and co-authored several academic articles and reports. Following the release of *A World Without Down's Syndrome?* Fisher published an opinion piece for the *Nursing Standard* outlining her response to the film. While she respected the film for its 'heartfelt personal exploration of the ethics of prenatal screening', Fisher (2016, no pagination) suggests that it overlooked the potential benefits of screening. She states that her two-hour interview with Phillips was edited down to two minutes, although she claimed she was not surprised by this as Phillips's intent was to 'encourage inclusivity' and 'focus on the positives of living with Down's syndrome' (Fisher, 2016, no pagination). This positive focus, according to Fisher (2016, no pagination), left little room for discussion of the challenges faced by families with family members with Down's syndrome, especially those with 'more severe learning disabilities or debilitating associated health issues'. In a culture where narratives of Down's syndrome are predominantly deficit-based, and fetuses with 'genetic abnormalities' are often dehumanised (Piepmeier, 2013, p.163-4), one might argue that a more nuanced exploration of living with Down's syndrome, such as this film, ought to be considered refreshing rather than limited or biased.

Phillips also explores the notion of choice in an interview with Kate, a woman who had received screening and diagnostic tests and subsequently terminated her pregnancy upon discovering her baby had Down's syndrome. When asked if she felt she had an informed choice about terminating her pregnancy, Kate replied that she had and that rather than researching the clinical aspects of Down's syndrome, Kate watched family stories on YouTube and read news articles and blogs written by parents of children with Down's syndrome. While much of this research informed Kate of the hardships that can come with raising a child with Down's syndrome, she claimed that it 'was the

positive stuff that really kind of threw me'. Later in the scene, Phillips and Kate watch a clip of a successful young American gymnast with Down's syndrome who has won countless medals, again reifying the supercrip narrative. Once the clip ends, Phillips looks at Kate, laughing while she says:

Phillips: I wonder if we have very different reactions to that.

Kate: Probably. Yeah.

Phillips: You think that's...?

Kate: It's very inspirational, and she should be so proud of herself, and she's worked very hard to get there, but it was that that kind of made me realise how much harder they have to work to reach their goals. That's not what I want for my son. Even the best-case scenario isn't potentially what I want for my son. And, you know, I just...I don't...

Phillips: Do you mind if I ask you the really difficult question?

Kate: Go on.

Phillips: So you think her life would have been better not happening?

Kate: No, not at all. I believe it's every parent's choice to decide what's right for their child. I don't believe it's wrong to bring Down's syndrome children into the world. She's got a great quality of life, she's loving life, she's at the top of her game... Yeah. No, I don't believe that's wrong at all, it's just not what I would want for my child.

Following this undeniably difficult conversation, Phillips maintains eye contact with Kate, nods as the frame fades out, and transitions to a shot of Phillips outside Kate's house post-interview. Phillips acknowledges that Kate is correct in that the choice is hers to make but disagrees with Kate's suggestion that an 'increase in choice means greater happiness'. She supports this statement by reaffirming one of the more common stereotypes about people with Down's syndrome: 'And I think if you want a happy child, you can guarantee you're having a child that's predisposed to happiness'. While many myths about Down's syndrome are gradually being debunked, the 'forever happy' stereotype still lingers. The reason this particular stereotype is yet to be disavowed may, in part, be due to the desire to reject inaccurate assumptions about poor quality of life for people with Down's syndrome. Indeed, Kate's main concern about having a child with Down's syndrome was based on how difficult the child's life might be and how guilty she would feel about this, knowing she had the choice to prevent it. This scene resonates with Schalk's (2016) evaluation of supercrip narratives, and it would seem Phillips is using the regular and glorified supercrip trope as a narrative device. Perhaps the 'forever happy' stereotype is helpful to those advocating for people with Down's syndrome. If a general disposition of happiness is associated with Down's syndrome, then surely this can only bolster arguments that suggest people with this condition report happy and fulfilling lives. This would account for studies being conducted that measure the happiness levels of people with Down's syndrome and their families (Acharya, 2011; Skotko et al., 2011b; a; c; Sheldon et al., 2021). It may be that this inaccurate stereotype that all people with Down's syndrome

are happy is useful in arguments against claims that Down's syndrome equates to a poor quality of life. Following this logic, the strategic deployment of the 'forever-happy' stereotype is constructive in that it affirms the existence of people with Down's syndrome.

The concept of choice was also present in the film during an interview with Emma, the mother of a child with Down's syndrome who is pregnant for a second time and opted out of any prenatal screening. Having already experienced having a child with Down's syndrome, Emma informed her doctor and midwife to include a note on her medical records to state that she had chosen to decline screening. Despite Emma's wishes, medical professionals continued to press for screening:

Um, I went in to see a consultant at the hospital and straightaway, first question - 'What are you doing about screening?'  
So I said, "Well, actually, I've asked for it to be put on my notes "that I don't want to discuss it anymore," and she said, "Yes, I did see that, but I wanted to talk to about it anyway."

It would seem Emma's experience of informed choice (that is, the less common decision *not* to undergo screening) was disregarded by this medical consultant, who Emma believed was trying to make her feel irresponsible for declining screening. Emma states that one of the reasons she declined screening was due to concerns that if medical professionals found out her second baby had Down's syndrome, they would press for termination:

Emma: Now, cos I know the attitude of the medical profession, if this baby does have Down's syndrome, almost to protect ourselves, I don't want them to know that, so that they can't then...  
Phillips: That's so interesting. You are choosing not to know, not because YOU would do anything with that information, but to protect yourself from the doctors...  
Emma: Yeah. Yes.  
Phillips: Who you feel would harass you.  
Emma: It totally comes from their, really, lack of understanding of what it's actually like to have a child with Down's syndrome.

As alluded to earlier, in a medical context, reproductive choice is generally associated with termination and access to this if so desired. Emma's account of her experience with medical professionals corresponds with this link between 'choice' and termination, and her struggles fighting the momentum of routine PNS are evident. In a UK context, the routinisation of PNS means that the informed choice *not* to screen does not always occur. PNS, particularly NIPT, is considered appealing to pregnant women due to its ease and effectiveness, and narratives of routinisation present this screening test as customary. How this complicates the informed choice of women is an issue being

raised by many in the bioethical arena (Silcock et al., 2015; Lewis et al., 2017; Kater-Kuipers et al., 2018; Kater-Kuipers et al., 2020). According to Kater-Kuipers (2018, p.626), one of the key drivers for PNS is the promotion of reproductive autonomy, and routinisation is thought to compromise this:

Reproductive autonomy in the context of prenatal screening presupposes that women make informed choices, and also that they are free to choose from a range of options, which should be varied, realistic and valuable. This implies that women or couples should have the freedom to choose between screening and not-screening, and, more importantly, between termination and continuation of the affected pregnancy.

While Emma was free to choose between undergoing screening or not, she felt a certain level of judgement from medical professionals when she opted out of any PNS. Despite already having lived experience of Down's syndrome, Emma's consultant questioned her decision not to screen, calling into question her freedom to choose. As Kater-Kuipers (2018, p.627) suggests, the routinisation of PNS might form a social norm whereby pregnant people are responsible if they test and reckless if they do not – generating social pressure to undergo screening, which ultimately impacts informed choice.

The scope of pregnancy-related choices can be overwhelming; unsurprisingly, many women struggle to manage 'information overload' during pregnancy (Tommy's, 2022, no pagination). With all of this information comes a great deal of responsibility. Pro-choice/pro-life binaries make the decision-making process even more complex. Debates put forward by reproductive rights advocates argue that a pregnant person's right to reproductive freedom *relies* on access to prenatal screening and selective abortion (SA) at any stage. On the other side of the debate, disability rights activists highlight the discriminatory nature of SA. Saxton (1998, p.375, original emphasis) aptly describes this ethical clash: 'The reproductive rights movement emphasizes the right to have an abortion; the disability rights movement, the right *not to have* an abortion'. Regardless of what side of the debate a prospective parent might find themselves on, 'choice' is very much individualised. Feminist pro-choice narratives tell us this is righteous and empowering, but this individualisation fails to take into account the socioeconomic context in which these decisions have to be made. The routinisation of PNS and the glossing over of its socioeconomic motivators (triggered by ableist and neoliberal agendas) mean that many pregnant people could find it 'very difficult to opt out of this kind of testing regime, particularly when it is presented as being in everyone's best interest' (Burke, 2021, p.195).

Piepmeyer's (2013, p.176) response to dominant reproductive rights narratives, which she describes as simplistic and 'politically strategic', was to develop a scholarly and activist framework called 'reproductive justice'. This model 'makes room for messier questions and concerns' and tackles the individualisation of choice (Piepmeyer, 2013, p.176). By displacing the decision-making process from an individualised space to a collective space, reproductive justice necessitates an acknowledgement of how reproduction, PNS and choice (and the narratives used to encompass these concepts) are shaped by social contexts. Reproductive justice draws attention to stigma and stereotypes associated with reproduction, recognising that these narratives play a significant role in reproductive decision-making (Piepmeyer, 2013, p.176).

*A World Without Down's Syndrome?* does not touch on the widespread social and economic disparities among prospective parents in the UK, in terms of access to resources and services. Many prospective parents facing the decision to continue or terminate their pregnancy on the basis of disability will have very different circumstances to Phillips in terms of opportunities and financial security. The reproductive justice model accounts for the complexity of reproduction within a social context in a way that the rhetoric of choice does not. 'The language of choice fails to take into account how different women have different access to different choices' whereas reproductive justice rhetoric emphasises the 'relationship of reproductive rights to human rights and economic justice' (Kafer, 2013, p.162). *A World Without Down's Syndrome?* does not move beyond the rhetoric of choice and fails to acknowledge the relationships between reproductive rights and economic disparities. Human rights and disability rights perspectives are not acknowledged within the film save for a brief mention of the UK abortion laws. I would argue that the film may have provided more nuance had it taken a reproductive justice approach and would have conveyed one of the significant issues within the Down's syndrome community (discriminatory abortion laws) in doing so.

Towards the end of the film, Phillips questions 'whether choice is always the wonderful thing it's cracked up to be' and deliberates as to where 'all these individual choices are going to take us'. The frame then transitions to a shot of Phillips outside the home of Razib Khan. Phillips travelled to America to interview Khan – the first person in the world to sequence an unborn child's DNA. Khan performed DNA sequencing on his son's embryo and was able to screen for 'anything he liked'. Whilst discussing the controversy of his actions, Khan stated, 'You have to understand, I know for a fact that within ten years most people are going to be doing this'. Concerns over where the line is drawn in terms of genetic technologies and embryo selection are present within



academic and public discourse. The implications of new genetic technologies for the lives of disabled people are a genuine concern that perhaps cannot be adequately addressed in the final ten minutes of a documentary film and are far beyond the scope of this chapter. Phillips goes on to interview the American geneticist responsible for pioneering DNA genome sequencing, Professor George Church, and asks him:

Phillips: What do you think the future holds for us?

Church: It's all about education. It's not the technology that's the problem. No. It's the societal pressures and market forces that are at work. If you want to instil certain values, spread the word that these are actually valuable members of society, valuable in a very broad sense.

Professor Church may be right – if science and technology are an unstoppable force and eventually, it will become routine practice to screen for more and more impairments and health conditions, then education and representation are paramount. For attitudes and assumptions around Down's syndrome to be successfully transformed, now more than ever, we need to engage people with Down's syndrome in not only conversations relating to issues explored in this thesis but in the process of research itself.

### **A World Film Without Down's syndrome?**

While *A World Without Down's Syndrome?* includes people with Down's syndrome in the film itself, the extent to which they are being included in the conversation is worthy of consideration. Before concluding this chapter, the following section will explore the balance of voices being represented in *A World Without Down's Syndrome?* and how the structure of the film impacts whose voices are more prominent. At the beginning of this chapter, Figure 6 listed all individuals interviewed by Phillips in *A World Without Down's Syndrome?*. We can see from this table that, in total, Phillips speaks with 13 people throughout the film. Only three of these interviewees were people with Down's syndrome – Liam Bairstow (actor from *Coronation Street*), Halldóra Jónsdóttir (Icelandic woman speaking out against screening policies) and Karen Gaffney (a special Olympian and self-advocate from America). The balance between the voices of people with Down's syndrome and medical experts and Down's syndrome experts (for example, parents or educators) is disproportionate. It would seem the film focuses more on capturing views from within the medical field than the thoughts of people with Down's syndrome.

Figure 9 (see below) shows the total amount of screen-time each group of interviewees has in the film. Within the sixty-minute film, the total time presenting interviews with medical experts is just under twelve minutes. Time spent interviewing Down's

syndrome experts is just under six and a half minutes and the total screen-time interviewing people with Down's syndrome is just over three minutes.

Type of interviewee	Duration of screen-time
Medical expert	11 minutes 52 seconds
Down's syndrome expert	6 minutes 26 seconds
Individual with Down's syndrome	3 minutes 6 seconds

Figure 9

Table showing total screen-time for interviewees in *A World Without Down's Syndrome?*

In addition to the limited screen time for interviewees with Down's syndrome, the types of questions they were being asked were quite different to those put to the medical and Down's syndrome experts. For example, in her interviews with medical professionals and parents of children with Down's syndrome and other experts, Phillips spoke with them directly about PNS and NIPT, whereas this was not the case when speaking with people with Down's syndrome. When interviewing actor Liam Bairstow, the topic of PNS was not discussed; instead, they were shown discussing Liam's career:

Phillips: Your family must be very proud.

Liam: Every time I watch Coronation Street with my mum, she can't stop crying. It's like every single time I'm on TV, she really embarrasses me like, saying, 'Oh, look at my baby son.' I'm like, 'Mum, will you pack it in?'

Phillips: Do you feel that people see your Down's syndrome first or they see you as an actor first?

Liam: They see me as an actor.

Phillips: And how's it going?

Liam: Really well.

Phillips: Fantastic, do you love it?

Liam: I love it here. Part of my dream is getting, like, an award.

Phillips: Yeah.

Liam: And probably get a girlfriend out of it and all, which would be decent enough. That's all I want, really.

Phillips: An award and a girlfriend.

Liam: Yeah. That's all I want, really.

It is noteworthy that Phillips does not ask Liam his thoughts on the new NIPT screening, although there could be several reasons for her not discussing this topic with him: it could have been agreed pre-interview that this topic was 'off-limits', Liam's understanding of the subject could have been assessed beforehand and he may not have known about NIPT, or it could be that Phillips and Liam did discuss screening for Down's syndrome but this never ended up in the final cut of the film. Nevertheless, I would argue that the purpose of interviewing Liam was not to meaningfully involve him

in the ethical debates around screening but rather to show the audience that people with Down's syndrome can be successful and live fulfilling lives, following the supercrip narrative often found in media representations. While I do not object to Liam's success being presented in this way, and, like Schalk (2016), do not dichotomise between 'good' and 'bad' supercrip representations, I would posit that Liam's interview veers towards inclusionism. That is, Liam is included in the documentary but excluded from voicing his thoughts about (or perhaps learning for the first time) what is happening in bioethical arenas in terms of screening for Down's syndrome. Liam is dismissed from the debate and instead shown to be discussing his desire for a girlfriend. As the previous chapter has shown, the right to a relationship is an incredibly important aspect in the lives of many people with Down's syndrome and a crucial social issue to be dealt with; however, in a film about the potential screening out of Down's syndrome, it perhaps seems a little off-topic.

The disproportionate balance between the voices of people with Down's syndrome and 'experts' could also be explained by the assumptions of the filmmakers. If Phillips and the team producing the film assume that people with Down's syndrome either do not (or should not) know about PNS and SA, then it would make more sense to interview people with knowledge on this topic. I, however, contend that bioethical debates about reproductive technologies and SA should at the very least involve those whose lives are being targeted, not merely as a tokenistic gesture or to humanise the debate, but to unequivocally allow for people with Down's syndrome to express their views and, if so inclined, problematise screening programmes or reproductive laws that directly involve them.

By contrast, Phillips's interviews with the further two individuals with Down's syndrome (Karen Gaffney and Halldóra Jónsdóttir) *do* include talk of NIPT and screening in general for Down's syndrome. In a short scene with Phillips discussing the Icelandic screening programme with Halldóra and her mother, Halldóra has a brief opportunity to voice her concerns:

Phillips: How does it feel to know that people discuss whether or not...Down's syndrome is OK to live with?

Halldóra's mother (In Icelandic): Can you tell her why you wrote the article?

Halldóra: I can try, it isn't easy! It made me feel bad, aborting all Down's syndrome fetuses ... We have lives just like anybody else.

Halldóra's mother: She thought that they were coming after her life.

Although brief, this scene is powerful and encapsulates the impact that screening policies and laws can have on members of the worldwide Down's syndrome population. Halldóra clearly has a lot to say about PNS, as evidenced by the article she had

previously written that was picked up by the Icelandic press. Indeed, it was the same article that garnered the attention of an artist who went on to work with Halldóra and twenty other Icelandic people with Down's syndrome for a portrait exhibition. This captured Phillips's attention, resulting in Halldóra and her mother being interviewed for the documentary. Yet, the scene depicting Halldóra's interview was limited to two lines (one of which was a voiceover of Halldóra questioning, in English, who deems what lives are of worth and who is perfect. As mentioned earlier, voiceover narration from Phillips informs the audience of Halldóra's 'regular supercrip' (Schalk, 2016) status, confirming that she 'speaks two languages, she's got a job [and] she's hoping to marry her long-term boyfriend this summer'. Phillips comments on how upsetting it is that Halldóra has to justify her existence while herself justifying her existence to the audience. This harks back to previous discussions (in this chapter and Chapter Six) in which co-researchers felt that *The Undateables* helps cast members justify their value and 'prove' how they can be successful in the world of dating. With people with Down's syndrome and their families having to continuously justify why they belong in the world and how they can contribute to society, it is unsurprising that the three people with Down's syndrome that Phillips chooses to interview for the film are highly successful individuals who have achieved in extraordinary ways.<sup>41</sup>

*A World Without Down's Syndrome?* has framed the representations of three people with Down's syndrome in terms of the regular and glorified supercrip. I suggest this has been done to accentuate the argument that people with Down's syndrome bring value to society and a world without them would be worse off. By relying upon the supercrip narrative, this documentary provides real-world examples of the kinds of people being affected by discriminatory abortion laws and screening policies, although I would argue that the overarching message in the film would have been strengthened if more people with Down's syndrome were involved in the film – everyday people who live ordinary lives and have a lot to say in relation to PNS and SA.

In a film that questions whether we are heading towards a world without Down's syndrome and what that might look like, we are presented with a film without Down's syndrome. The rationed screen time for those with Down's syndrome, in comparison to

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<sup>41</sup> The final person with Down's syndrome that Phillips interviews was Karen Gaffney, famous for her successful Paralympian career and also as a self-advocate who has performed a TED Talk fighting for the rights of people with Down's syndrome. Again, this individual falls under the supercrip categorisation and would be classed as a 'glorified supercrip' – not many people are prized athletes or deliver TED talk presentations, and here is somebody with Down's syndrome doing both (Schalk, 2016).

others, excludes the much-needed commentary from the Down's syndrome population on matters relating to national screening programmes. The producers of *A World Without Down's Syndrome?* have anticipated audience/societal expectations and delivered representations of people with Down's syndrome that rely on the supercrip narrative. These supercrip representations are intended to justify the ethical questions that are being raised in the film. Why should a viewer care about the implementation of NIPT? *A World Without Down's Syndrome?* is framed in such a way that the dominant medical arguments around PNS and SA are being questioned, and supercrip imagery and brief interviews with people with Down's syndrome serve as a reminder to viewers that real people with good lives are existentially vulnerable and at risk of being screened out.

### **Further reflections**

Dominant narratives of PNS and what it means to live with Down's syndrome are medically orientated. Assumptions around quality of life (for parents and children with Down's syndrome alike) are often embedded in Down's syndrome narratives, particularly discourses around PNS and SA. The film analysed in this chapter attempts to present nuance to the complex entanglement of prenatal screening and Down's syndrome and does this by incorporating varying perspectives, including some individuals with Down's syndrome. As discussed throughout this chapter, the involvement of people with Down's syndrome in this film appeared to be minimal. With little screen time allocated to their interviews, the film did not provide a sufficient platform through which Halldóra, Liam or Karen could express their views on PNS, SA or NIPT. This thesis aimed to provide a space for the co-researchers to express their views on existential questions about value and PNS. This chapter has demonstrated the value of creating such a space and providing learning opportunities for open discussion about PNS for the people it concerns the most. While the co-researchers did not express strong views on the topic of PNS and SA, they did establish two very significant issues: the importance of self-worth and the meaningfulness of seeing people with Down's syndrome in the media.

Throughout our co-analysis, co-researchers demonstrated their self-esteem and provided several examples of how they valued themselves and Down's syndrome. In many of the discussions, including general ones about the notion of a society without Down's syndrome and Albert expressing a preference for a baby with Down syndrome, it is clear that the co-researchers 'maintain favourable self-images' (Todd and Shearn, 1997, p.344). The co-researchers do not agree that their lives are of any less value than anyone else. Despite my observations that people with Down's syndrome did not

have an equal amount of screen time, the co-researchers made clear their appreciation for Liam, Halldóra, and Karen's contributions to the film. That being said, the co-researchers would not have known the imbalance between Down's syndrome representations and other interviewees, as I decided only to screen the scenes that included people with Down's syndrome. I felt it was more important for them to analyse the cultural work taking place in the scenes that included people with Down's syndrome, and, additionally, these scenes were the most accessible and used less complicated language. Much like in previous Film Clubs, it was apparent how seeing other people with Down's syndrome on television improved the self-esteem of the co-researchers. As I realised this during the group session, I decided to include an activity whereby participants could put into written words what it meant for them to see people with Down's syndrome being represented in the media, as shown in the figure below.

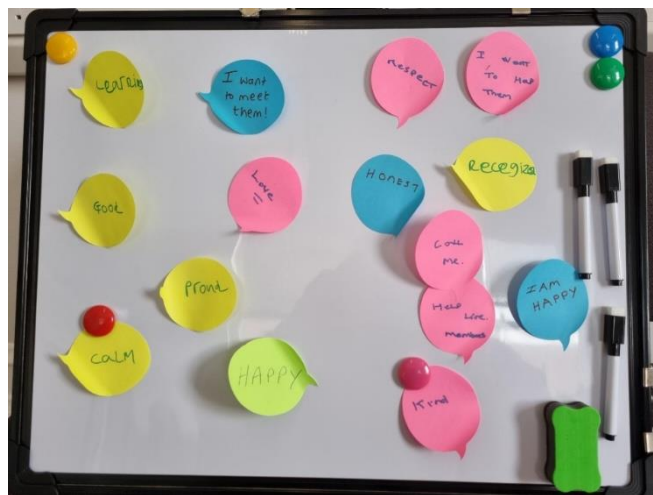


Figure 10

Image of post-it notes written by co-researchers to describe how they feel when they see someone with Down's syndrome on television

Figure 10 makes clear the co-researchers' reactions to seeing people with Down's syndrome: co-researchers felt respected, recognised, proud and happy. During this activity, I asked Dawn to think of how she feels when she sees Down's syndrome being represented, and she responded, 'I am calm', making a happy moaning sound as she wrote this down on a post-it note. Some critiques of participatory research with learning disabled people suggest that it can lead to the privileging of some voices over others, specifically when there are 'tame' participants and respondents who are more 'politically challenging' in the same group (Nind, 2011, p.351). Nind (2011, p.351) also explains another assumption commonly made in critiques of participatory research whereby those 'individuals with stronger communication abilities' are 'included more often and more readily than those with profound impairments'. Throughout our Film

Clubs, Dawn appeared to be more of a listener than a discussant. Although it could sometimes be difficult to assess her level of understanding, Dawn's non-verbal expressions spoke volumes. For Dawn, the main point she wanted to articulate was how happy and calm she felt when watching people with Down's syndrome on television; her non-verbal gestures communicated this entirely. I went to great lengths to make our group sessions as accessible as possible, but Film Club Three and the topics raised within this session were challenging. I do not presume that the co-researchers' difficulties in engaging resulted from impairment effects. Rather, I believe the topic under discussion would be difficult and potentially even painful for most people to talk about, learning disability or no learning disability.

I would argue that the issues described above are reasons why people with Down's syndrome have been (and continue to be) excluded from public (and private) conversations around PNS, SA and NIPT. If parents of children with Down's syndrome choose to shield them from learning about screening for Down's syndrome, or if, during their education, young adults with Down's syndrome are not taught about such issues, then this will, of course, impact their knowledge and understanding. For many people with Down's syndrome (and this was the case for the co-researchers on this project), the only knowledge they have of PNS or SA is what they see or read in the media. This tells us two things: firstly, that it is crucial for Down's syndrome narratives to be handled sensitively, appropriately and authentically in the media, in direct consultation with people with Down's syndrome and the Down's syndrome community. Secondly, the Down's syndrome community (especially people with Down's syndrome – not just their family members) need to be directly and meaningfully included in public debates around screening, policies and laws regarding PNS and SA.

Reproductive ethics, abortion and screening are difficult and emotive topics for anyone to learn about, but this is not reason enough not to avoid educating people with Down's syndrome. It is both unsurprising and understandable why people with learning disabilities are so often shielded from such complex debates, and, for many individuals, it may be completely necessary and appropriate to protect them from information that may cause unnecessary harm or distress. This does not, however, mean that people with Down's syndrome should not be afforded the opportunity to learn about important social issues and policies in places that could have a direct impact on their livelihoods *and* attitudes towards them as a specific group of people. The co-researchers in this project by no means represent all people with Down's syndrome, but the reality that none of them were aware of screening for DS or SA says a great deal.

The way *A World Without Down's Syndrome?* is framed suggests that Phillips anticipated that the viewing public would be unaware of these bioethical debates. The foregrounding of medical experts over people with Down's syndrome was, I contend, for the benefit of the audience. Viewers were informed early on in the film that medical institutions are responsible for decisions regarding screening laws and policies. Phillips wants to prove the worth of people with Down's syndrome in this film. To this end, therefore, the individuals being presented are people who achieve more than the ordinary person (with or without Down's syndrome). I would intimate that this was a deliberate production choice, one that would counter traditional medicalised narratives of Down's syndrome. In a scene where Phillips is waiting to meet Karen Gaffney, she is shown speaking with the film producer positioned behind the camera. In this scene, Phillips makes clear her overall intention for making the film when she postulates:

It feels like even if this particular encounter isn't life and death, life and death is hanging around in the air. You know, maybe there will be someone who... watches this programme who decides to have a baby they wouldn't otherwise have had, or maybe there will be someone who watches this programme who might have had a baby, and decides they won't.

For Phillips, this documentary is intended to educate viewers on the complex entanglement of Down's syndrome and screening and to implore the audience to question their assumptions (conscious or not) about people with Down's syndrome. I applaud these objectives and contend that *A World Without Down's Syndrome?* serves as an excellent starting point for public education on these issues. However, in order to make more of an impact and shift attitudes towards screening and Down's syndrome towards a more enlightened understanding that signifies their valued lives, we need to rely heavily on experts-by-experience – people with Down's syndrome.



## ~ Chapter Eight ~

### Reflections on the co-production process

This chapter serves as a supplement to the previous three analysis chapters (5-7). While aspects of the co-production process were discussed in these analysis chapters, it is necessary to expand further on the collaborative process. As outlined in Chapter Four, the analysis occurred in three stages. The third stage involved the storyboarding and creation of a mock documentary trailer. This arts-based activity allowed me to capture how the co-researchers might imagine a documentary about their lives and how this might look. When explaining the activity to the group, I stated that they were completely in the 'driving seat' and had control over the entire trailer production. My only role was to film content, help edit the overall footage and support them where necessary. The co-researchers initially seemed somewhat quiet and inhibited; however, I did not put this down to shyness, as they had already told me they had enjoyed being filmed for several previous projects and documentaries. Perhaps their inhibition was because this was the first time they had been given complete creative control in this context, despite having worked on documentary-style projects previously. Any reservations were short-lived – once I started to remind them of all the excellent ideas they had already generated in Stage Two (as evidenced in Appendix H), the co-researchers' hesitancy soon turned into enthusiasm, and their ideas began to flow freely. The remainder of this chapter will discuss these ideas in more detail, including how decisions were made regarding transferring these ideas into film. In the latter half of this chapter, I will present an argument in strong support of a collaborative approach to research with people with learning disabilities, which I have found to be beneficial. Finally, I will conclude this chapter by reflecting on the trailer-making process and discussing what I would do differently in future collaborative research endeavours.

#### Introductions

During many of our discussions, the co-researchers rejected the common notion that living with Down's syndrome or giving birth to a child with Down's syndrome is a tragedy, and this was reflected in the opening scene of the trailer.<sup>42</sup> A black and white slow motion frame of the three co-researchers standing side by side with serious facial expressions was accompanied by a melancholy piano instrumental and Albert's narration: 'People often think a life with Down's syndrome is a tragedy'. The frame then

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<sup>42</sup> The co-researchers decided to upload the mock documentary trailer to YouTube, and it can be found using the following link: <https://www.youtube.com/watch?v=WAvf3ATrFqQ>

quickly transitions to an in-colour shot of Dawn, Kevin and Albert walking and dancing down a long corridor towards the camera as Kevin narrates: 'We are here to tell those people they could not be more wrong!'. The group chose cheerful music to accompany this scene, which continued as the 'cast' was introduced in more detail.

The co-researchers decided that the beginning of the trailer would portray them introducing each other – a short biographical list of facts about each person was accompanied by a still image of that person. I asked the co-researchers what parts of their identity were important and what they wanted the audience to know. Their answers were compiled into short lists and then read out as I recorded them – Kevin introduced Albert, Albert introduced Dawn, and Dawn narrated Kevin's introduction. For example, as a frame of Dawn walking confidently towards the camera plays, Albert narrates, 'Meet Dawn. She is 27 years old, works in a café, likes going to church and loves to play tennis'.

The brief introductions were helpful in terms of prefacing the trailer and familiarising the audience with its cast members, but they also presented the co-researchers as confident, joyful and assertive individuals with very distinct characteristics and interests. In these scenes, the co-researchers were implicitly debunking the common myth that all people with Down's syndrome are the same. The next scene to play out was more overt in addressing this myth, as Kevin states, 'We are all very different and have our own personalities, but one thing we do have in common is our love for singing'. It was important for the co-researchers to express their individuality, and these introductory scenes certainly accomplished that. Viewers would be left with little doubt that the documentary is about three very different characters with varying interests but a shared passion for the performing arts.

### **'Performing' for the camera**

Many of the suggestions during the storyboarding sessions involved performing musical numbers (see Appendix H). In total, we filmed the co-researchers singing four songs – three solo performances and one group performance. I explained to the co-researchers that because the trailer was intended to be approximately three minutes, we would not be able to include the full performances but that we could edit these down to short excerpts of their songs. That way, we could include their passion for performing but still work within the parameters of a film trailer framework – which is to introduce the characters and give a hint of the stories being told within the film.

During the premiere of the trailer (at the SAG attended by the co-researchers), one staff member commented on the performative nature of the trailer, suggesting that had

I gotten to know the participants better, the trailer would not have felt as 'performative'. This staff member had not been involved in the project at any stage and, therefore, was unaware that the main objective in making the trailer was for the co-researchers to have complete creative control of this process. As this individual was not privy to the context in which this trailer was made, they felt that co-researchers had been performing for the camera rather than following the traditional observational documentary mode. While the trailer was designed and produced for research purposes, arts-based methodologies were employed to ensure the co-researchers were involved in all stages of the research and could express their critical understanding of documentary form and tropes. This was intended to empower the co-researchers through the process of self-representation rather than designing a documentary trailer primarily for public performance to suit the agenda or the sense of selves assigned to them by anybody else. This was an exercise designed to show how co-researchers can be involved in all stages of documentary-making; however, the above comments from this staff member speak to the dilemma that many documentary filmmakers face in terms of meeting audience expectations by adhering to formulaic and familiar modes of documentary and perhaps also to the dilemma people with Down's syndrome face in terms of their self-representation.

Fortunately, we did not need to follow a rigid framework, as audience expectations were irrelevant in the trailer-making exercise. My objective with the trailer was for co-researchers to be filmed doing what they chose to do rather than creating something that *appeared* natural through observational camera techniques. That the co-researchers chose to perform musical numbers for the documentary was not insignificant. Indeed, it was the co-researchers' passion for the arts that inspired their choice of title for the film: *Down's syndrome: This Is Me*. The co-researchers were fans of the music from *The Greatest Showman* (2017) and decided to use the title from a popular song on the film's soundtrack, *This Is Me*.<sup>43</sup> I would argue that this choice of title encapsulates the intention of the proposed film (to educate viewers on the lives of the co-researchers) and signals the shared passion for music the co-researchers enjoy.

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<sup>43</sup> Interestingly, *This Is Me* became popular with many charities and disabled people, many of whom consider it a disability 'anthem' of sorts, due to its uplifting lyrics depicting marginalised groups accepting and embracing their 'differences'. There are, however, critiques of the song (and film) from within the disability community. *The Greatest Showman* has been described by some disability advocates as 'inspirational treacle', whose message acts as a 'salve' for its non-disabled audience (Lopez, 2017, no pagination).

## **Narration**

During the co-analysis stage, participants praised how *The Specials* used the documentary subjects as narrators and were keen to do the same in their trailer. All voiceover narration was shared between the three co-researchers, and they agreed that they would narrate their own solo scenes. Co-researchers told me what they wanted to articulate in the narration, and together, we wrote scripts to be read out individually and recorded. The co-researchers made it clear that they wanted to read from a script as this would make them speak more fluently, and it was important that the audience understood them. Albert, in particular, was concerned about his voice being clear and articulate and insisted that he also read from a script during his 'on-the-go' interview. Albert wanted to be filmed travelling on the bus to show how important independent travelling is to him, and he asked that we produce a short script of the interview questions and answers from which he could read. We attempted to conceal the script from the camera's view by holding it behind the bus seat in front of Albert, although it was apparent that Albert was reading from a script. In conventional documentaries, it is quite possible that cast members may prepare their answers in advance, although it would usually be less noticeable. I did not feel it necessary to steer Albert away from using a script – it was important for him to sound articulate but also that he could fully express his views on independent travel and discuss how restricted travel times impact his life.<sup>44</sup> Had Albert not been able to script his answers, he may not have been able to convey his thoughts on independent travel for people with Down's syndrome, which was the entire point of including this scene.

During my analysis of *The Specials*, I noted that all of the housemates provided voiceover narration for the series, apart from Hilly. It is unclear why Hilly did not narrate any of the episodes, whether this was her choice or a decision made by the filmmakers. Hilly's speech was the least clear of the five housemates, and I wonder whether this was part of the reason she did not provide any narration. The clarity levels of speech with the three co-researchers differed, but I did not deem this to be a reason to exclude a particular voice. Instead, care was taken to include the narration of all co-researchers, and any misread or misspoken words could be supplemented with subtitles. For example, during the voiceover recordings, Kevin struggled to pronounce the word 'personalities', so I gave him the option of continuing with the recording and trying more takes, or we could spell the word correctly in the subtitles, and that way, the viewer would know what word he is pronouncing. Kevin was happy to keep his

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<sup>44</sup> Albert had a free bus pass but was only permitted to travel for free during restricted hours. Any trips in peak travel times were chargeable.

version of the word 'personalities' in the trailer and for the subtitles to clarify his mispronunciation. I would argue that small adjustments such as these can lend more authenticity to documentaries and give more agency and control in the production process to those featured in the documentary.

### **Solo scenes**

The co-researchers decided that as well as having group scenes in the trailer, they would each have solo shots. Kevin wanted to tell viewers about the self-advocacy group (SAG) and what it means to be a member of this organisation. I filmed Kevin giving viewers a tour of the building. When we watched the footage back, Kevin asked if he could record voiceover narration for the tour, so we drafted a script for him to read, which would accompany the shots of the tour. As a founding member of the SAG, it was important for Kevin to explain what the organisation does and give viewers a behind-the-scenes look at some of its facilities. While Kevin did not discuss in these scenes what being a member of the SAG meant to him, it is clear upon viewing them that he holds a sense of pride at being a founding member of the SAG.

As mentioned previously, Albert was keen to show viewers that he was an independent traveller, and we filmed a typical afternoon in his life, including bus travel, a trip around the local market and a visit to his beloved barbershop. These shots were accompanied by his voiceover narration as well as the original audio from Albert's bus trip and chat with the barber. During editing, Albert's trip around the market was played at maximum speed together with fast-paced instrumental music until we arrived at the barbershop, where the music faded to the background and the original audio faded in. All of these creative decisions were made prior to editing, and Albert chose from three options for the instrumental music available on the editing software. I had to explain to the co-researchers that, unfortunately, they could not select songs they knew and liked (for copyright reasons), and they were happy to use the music available through the software we were using.

Finally, Dawn decided to be filmed while working in a local café. This café is run by and for people with Down's syndrome and every Saturday Dawn works there to complete food safety training with the goal of getting employment in the hospitality sector. Dawn asked that I film her as she goes about her work, and we filmed some on-the-go interview scenes during quieter periods. Again, Dawn provided the voiceover narration for these scenes, which are interspersed with the original audio. The audience is guided through a typical shift at the coffee shop, and Dawn's customer service skills and talent as a barista are evident in this sequence.

## **Accessibility**

From the outset, the co-researchers were insistent on the use of subtitles throughout the trailer, and they decided that these should be in large, yellow font. The co-researchers were very aware of different people's access needs and listed several ways in which a documentary film they produced would be accessible. For instance, Kevin asked if we could have BSL interpretation in the corner of the screen. I told him that it would not be possible to include BSL translation in the trailer (as my research budget would not allow for it) but that it was highly significant that he recognised the potential accessibility requirements of audience members.

## **Editing**

My objective was for the editing process to be as collaborative as the storyboarding sessions and filming. Although I completed the editing independently, we made all important editorial decisions as a group beforehand. Any creative judgements I made in the editing of the trailer were later put to the group, who had final approval of the edit. For example, at the end of the trailer, I found a 'FakeFlix' logo, which I thought would be a fun way to make the mock trailer look more authentic to the documentary genre, so I ended the trailer with this logo. Albert then recorded a voiceover stating a fictitious date for when the trailer would be 'streaming on FakeFlix'.

The co-researchers' narratives were decided upon and scripted prior to the editing stage. Once we had finished filming, we were able to co-write the voiceover narration, which I would then refer to when editing the accompanying visual elements. For example, I filmed Dawn working at the café, and we scripted narration that would contextualise this footage, such as introducing the café and stating what working there means to Dawn. This meant that I had to fit the video footage to suit the narration. It is unlikely this is a standard method in film editing, but it was a process that worked for us as it was less time-consuming, and having a narrative plot to adhere to made the editing process more efficient. Had we used more conventional filmmaking methods, it is possible that creative liberty would have been unintentionally removed from the co-researchers, as we would not have had the opportunity to make decisions around production as a group.

## **The benefits of co-production**

Much research about people with Down's syndrome (and learning disabled people more generally) fails to meaningfully include the learning disabled community, and co-production as an approach has enabled me to steer away from 're-product[ing] unequal power relations' (Durose et al., 2012, p.4). The production of a mock documentary

trailer as a research activity (as well as data for analysis) meant that the co-researchers and their epistemologies navigated the process of knowledge production. The stories and content co-researchers chose to include in the trailer were an effective means of collecting rich data; however, producing the trailer also gave the co-researchers tangible documentation of their work, something they could later revisit. I gave each co-researcher a copy of the trailer in DVD format, and they also decided to post the clip on YouTube. In watching the trailer back, I hope the co-researchers might reflect on our group discussions and the critical analysis we carried out and feel a sense of pride and satisfaction with their work.

In imagining what their own documentary film might look like, co-researchers were given the opportunity to creatively express what they liked about traditional documentary representations of Down's syndrome but also suggest areas where they could be improved. For example, co-researchers replicated the narration techniques used in *The Specials* but (unlike *The Undateables*) chose not to include scenes with support staff. The solo and group scenes we filmed did not require assistance from support workers. I posit that the co-researchers were keen to 'prove themselves' within the trailer – something they frequently commented on during the analysis of *The Undateables* (see Chapter Six). This, however, is merely one interpretation, and I do not wish to theorise from the co-researchers' experiences. Rather, the activity aimed to explore representations of Down's syndrome and propose ways to develop these further with the meaningful involvement of people with lived experience of the condition. Had time allowed, I would have conducted a post-production analysis with the co-researchers, which would have given them an opportunity to reflect further on the trailer-making process and the results of their collaboration.

As co-producers, the participants had more control over the research process than conventional research settings typically permit. This gave the co-researchers a sense of ownership of the research product, a feeling reflected during the premiere of the trailer when I asked Kevin and Dawn how they felt about what they had created:

Kevin: I think it's perfect  
Researcher: Do you feel very proud?  
Dawn: Oh yeah  
Kevin: Yeah

When answering these questions, both Dawn and Kevin had big smiles on their faces, and Dawn was signalling two thumbs up as she spoke, something I observed she did a lot when she was particularly happy or impressed. Although Dawn and Kevin were less verbal than Albert when answering questions, their

non-verbal interactions meant they were proficient in communicating their feelings – a skill often overlooked in research about learning disabilities. Differing communication styles are often cited as a barrier to participation in learning disability research. Yet, this project has shown that with appropriate and accessible research materials (for example, easy-read documents or multimedia methods), people with learning disabilities have the necessary skills to engage both *with* and *in* research (Crook et al., 2016).

Overall, the process of co-production was valuable and enriched the thesis immeasurably. The co-researchers' editorial decisions demonstrate their understanding of documentary form and the power dynamics implicit within the form. Their decision to debunk 'tragic' representations of Down's syndrome and to narrate the trailer themselves demonstrates that this research was successful in enabling them to take control of their own narratives.

### **Future collaborations and final remarks**

Although I considered the project a success and received excellent feedback from the co-researchers, reflecting on the collaborative process has brought to light several areas for improvement and issues of which I will be mindful if I conduct future learning disability research. For instance, in hindsight, I would have built more time into the project to work with the co-researchers during the editing stage in the making of the trailer. This stage was perhaps more rushed than I would have preferred, and participants had to make quick decisions about, for example, what instrumental background music they preferred or font colour in some of the graphics. Had more time been allocated for this stage of the fieldwork, editing decisions could have been made less hastily. That being said, the co-researchers were still briefly introduced to this area of film production, something they had not previously been included in during past projects.

Another impact of time restraints was on the length of the documentary trailer. We filmed hours of valuable footage but had to cut this down to fit within the parameters of a conventional film trailer. The aim was to produce a short two-to-three-minute trailer; however, it was difficult to edit the wealth of footage we filmed, and the run-time of the final trailer was approximately nine minutes. As this activity was designed primarily to engage co-researchers in thinking about representations of Down's syndrome, I did not feel it necessary to trim the trailer down any further – all of the scenes included in the final cut were significant. The co-researchers did not want to condense it, a decision with which I was in complete agreement.



One final reflection on the co-production phase is, again, related to a PhD project's time (and financial) restraints. As I mentioned earlier, the co-researchers would have liked to have included more scenes involving performing arts in the mock documentary. Indeed, performing arts are often used as the research method in inclusive research (Kappes, 2011), and in many ways, the trailer we co-produced could be conceived as a form of art. Nonetheless, had time and budget constraints not existed, it would have been useful (and potentially powerful) for the trailer to have captured the co-researchers communicating their thoughts and feelings *through* their art. One future collaboration with the co-researchers could involve the use of performing arts as a creative channel through which they could express their opinions on Down's syndrome and relationships, what interdependence means to them and how they view the ethical debates surrounding prenatal screening laws for babies with Down's syndrome.

## ~ Chapter Nine ~

### Conclusion

#### Introduction

In this chapter, I offer some concluding reflections on what has been learned from the co-analysis of *The Specials*, *The Undateables*, and *A World Without Down's Syndrome?* as well as the co-production of a mock documentary trailer. I will discuss the value and contribution of the research findings and the methodological contributions. I will also discuss the potential of the documentary genre in transforming narratives about Down's syndrome (and disability) before proposing opportunities for future research and collaborations.

#### Research findings

Reflecting on the research questions posed in Chapter One, this thesis sought to achieve three things. Firstly, it aimed to identify the dominant discourses surrounding Down's syndrome within the documentary genre and consider how the documentary form contributed to these dominant discourses. Secondly, it aimed to find out how co-researchers responded to documentaries about Down's syndrome and discover whether documentary representations had any impact on their sense of self. Finally, it aimed to offer alternative ways of representing Down's syndrome in documentary, which was achieved through the co-production of a mock trailer.

My multimodal textual analysis of the documentaries, combined with the analysis conducted with the co-researchers, revealed several dominant discourses. These discourses differed depending on various factors: the context of production, the target audience, as well as the level of involvement of cast members from the documentaries. Representations of people with Down's syndrome in *The Specials* and *The Undateables* were quite contradictory. *The Undateables* framed cast members firmly within the conventions of supercrip and freakery narratives, and the formulaic structure of the series left little space for nuance. Although producers would hone in on a specific aspect of a cast member (for example, in Sam's episode, the emphasis was on him having never been on a date before, whereas Kate's episode focused on her supposed fixation on getting married), each representation followed similar plot points. Sam and Kate were ultimately being framed as objects of curiosity. Kate and Sam were framed as spectacles for the consumption of the spectators, who, in turn, could reassure themselves of their own normalcy. Despite its emancipatory claims, *The Undateables'* framing of Kate and Sam reinforced the 'forever young' Down's syndrome stereotype

and infantilisation was present throughout both of these episodes. The co-researchers differed in their views somewhat, a point to which I will return shortly.

In stark contrast to this, *The Specials* cast members (housemates) were presented as in(ter)dependent individuals with full and rich lives. Despite its title, *The Specials* housemates were portrayed as ordinary young adults living away from home for the first time; their cognitive differences were not highlighted, but at the same time were not completely avoided. Down's syndrome and learning disability were never mentioned in the series (by housemates or supporting cast) as they were incidental to the storyline (Lock, 2018). This representation of the housemates offered a unique insight into what life with Down's syndrome might be like and countered the dominant narrative that Down's syndrome equates to dependency and vulnerability. Furthermore, the co-researchers borrowed representational techniques from *The Specials*, such as producing their own narration, which highlights the effectiveness and affirmative outcomes of alternative representations of Down's syndrome.

The final documentary we analysed, *A World Without Down's Syndrome?*, differed from the previous documentaries in that the presence of people with Down's syndrome was limited, meaning we had less to analyse in terms of how participants with Down's syndrome were portrayed. This documentary featured different individuals with Down's syndrome, but due to the subject matter (NIPT), there was more emphasis on medical experts and parents of children with Down's syndrome and their take on the ethical debate under discussion. As we saw in Chapter Seven, the people with Down's syndrome who were interviewed fell under the supercrip typology – they were highly successful individuals who had achieved more than most non-disabled people. As I have argued throughout this thesis, Down's syndrome is more visible now than ever before, but this shift in visibility should not give rise to complacency. Tokenism, stereotyping and supercrip narratives of Down's syndrome can misrepresent the lived realities of many people with Down's syndrome and, as we have seen in the analysis chapters, reinforce dominant discourses that can have damaging consequences for the Down's syndrome community.

The co-researchers responded to these documentaries in varying ways. They seemed reassured by the display of in(ter)dependence in *The Specials*, inspired and encouraged by the representation of people with Down's syndrome going on dates in *The Undateables*, and demonstrated their sense of self-worth when included in conversations about the potential consequences of NIPT. In many ways, the co-researchers rejected dominant discourses surrounding ableism and normalcy. Throughout all of the Film Clubs, the co-researchers acknowledged the necessity to

'prove' their value as people living with Down's syndrome. Because of the neoliberal ableist world in which they live, where ideals are based on normalcy, the need to verify their existence is palpable. Whether that is proving that they can go on dates, live independently or justify that they belong in the world just as much as anyone else, it was clear from our discussions that validating their worth was something the co-researchers felt they had to do and something they appreciated seeing on screen. Our co-analysis has confirmed that, when done well, documentaries have the potential to do this validation work – it is a form that has the potential to represent the lived realities of people with Down's syndrome and simultaneously demonstrate social worth.

### **Documentary's potential**

A large part of this thesis was a co-produced documentary trailer made with people with Down's syndrome. Particular editorial and production decisions, and control of the narrative, highlighted the aspects of the co-analysis that really resonated with the co-researchers. These underscore the potential of documentary for projecting empowering narratives, and this process feels particularly democratic, something that is reflected in the broader landscape of documentary.

Indeed, the far-reach of documentaries has massively shifted with the rise of digital media. More documentaries are being created, larger audiences have access to them, and the genre no longer belongs only to professional filmmakers – technically speaking, anyone with access to a smartphone can record footage and make a non-fiction film or web-based series. Sørenssen (2008, p.49) summarises the effects of this technological shift, that is, 'new media', as follows:

1. New technology provides new means of expression. As a result of this the film medium (i.e. forms of audio-visual expression) develops from being exclusive and privileged to a common and publicly available form of expression.
2. This, in turn, opens space for a more democratic use of the medium.
3. It also opens up new possibilities for modern (contemporary) and different forms and usages (avant-garde).

As such, new digital media has the potential to 'offer true democratisation and increased participation, giving everybody the chance to transcend cultural boundaries and share in expression' (Saunders, 2010, p.233). Against the backdrop of this changing media environment, disabled people and their allies have greater representational agency over what is produced, how it is distributed, and who can access it, but caution is required. As Ellis (2016b, p.116) states, 'There is much work still to be done. There needs to be more disabled people working in media to offer alternatives that do not exceptionalise and objectify

disability'. As I have argued throughout this thesis, documentaries about Down's syndrome must avoid inclusionism. It is not enough to cast people with Down's syndrome; there must be some element of control and agency within the production process in order to avoid misrepresentation. The documentary trailer that we co-produced serves as a case study for how this might work.

The 'truth' claims so often associated with the documentary form make this an incredibly powerful vehicle of representation. Media representations and, I would argue, documentaries in particular, play an important role in both shaping and transforming understandings of disability. As already discussed in the opening chapters, Down's syndrome has become synonymous with prenatal testing; therefore, how both people with Down's syndrome and issues dealing with PNS are represented in cultural texts is of great significance, especially at a time when detection rates of Down's syndrome are increasing, and the Down's syndrome population is predicted to decrease. If potential parents have no personal association with Down's syndrome and are faced with a decision to continue a pregnancy or have a termination, their only source of information is what is provided by medical experts or what they learn through media representations of Down's syndrome. The potential role of documentary in both training medical professionals and as an informational source for prospective parents should not be underestimated. Throughout this thesis, I have referred to the impossible positions many pregnant people are placed in when undergoing prenatal screening. This thesis has shown that film could play an important role in how these incredibly difficult decisions are handled in the future. Future collaborative work could involve co-producing documentaries involving people with Down's syndrome and their families and allies. Such documentaries would serve as an informative and educational tool for anyone either faced with a diagnosis of Down's syndrome or for medical professionals delivering these diagnoses. If representations of people with Down's syndrome demonstrating their in(ter)dependence and relationships were more readily available, dominant discourses that presume dependency, deficit, and difference would eventually dematerialise.

### **Methodological contributions**

The tensions between producing research that is reputable, helpful and inclusive mean that when conducting inclusive research, a continual cycle of balance and compromise is required (Walmsley and Johnson, 2003). My thesis must meet the academic standard expected of PhD research, and I strive for academic rigour, but equally, I

hope to have produced research that is of use to the co-researchers, is 'relevant to their needs and can inform and promote needed social change' (Walmsley and Johnson, 2003, p.9). Methodologically, I have sought to be fully inclusive by creating a space in which co-researchers have felt comfortable expressing their views on several complex issues. Co-researchers were encouraged to be in control of production through the use of arts-based methodologies – they steered the storyboarding sessions and directed the documentary trailer. I aimed to empower the co-researchers and break down the barriers between the researcher and participants that are present in traditional qualitative research. In so doing, their experience and knowledge were privileged over my own.

A prime example of this was discussed in Chapter Six during our analysis of *The Undateables*. My textual analysis problematised the use of emotive music as a way of portraying Sam as childlike. In contrast, Albert found that the music helped to evoke romance in these scenes, prompting me to rethink my original critique. I was able to question and reflect on the textual analysis conducted prior to the fieldwork, and my findings were expanded through our co-analysis of the documentaries and our co-produced trailer.

The collaborative process also provided a safe space to think about and discuss potentially distressing topics like sexuality and prenatal testing. Sex can be a difficult subject for many people to talk about, and often, people with learning disabilities can find it confusing, especially around issues of consent and legislation (McCarthy and Thompson, 2010). Learning (for the first time, as it transpired) that many prospective parents choose not to have a baby with Down's syndrome can understandably cause distress. I ensured that I 'checked in' with co-researchers regularly throughout the Film Clubs, and they had communication tools they could use if they ever felt upset (see Appendix J). The space created in the Film Clubs and trailer-making sessions were supportive as well as creative and provided the co-researchers with a unique opportunity to express their views on topics they are usually 'protected' from.

It has never been more imperative to reconsider how, as a society, we attribute social value. At a time when prenatal technologies are able to tell us more and more about the genetic and physical traits of unborn children, it is crucial that the narratives used to discuss and understand Down's syndrome (and disability more widely) are not embedded in ableism. If we are able to rethink what we consider 'normal' and produce cultural representations that position disabled people as of equal value to non-disabled people, this can bring us closer to social change. People with Down's syndrome can and should be included in cultural conversations, no matter their complexity. As I have

previously argued, consideration of the lived experience of people with Down's syndrome is imperative in shifting the attitudes of Down's syndrome towards an affirmative understanding of the condition that reflects their valued lives and that moves away from stereotypes and tropes anchored in dependency and deficit. In turn, such a shift, enacted by people living with Down's syndrome, might make prenatal screening less routine and reactions to it more considered. This thesis illustrates how this can be done in practice, providing an inclusive approach is taken and complex, sensitive issues are handled with utmost care.

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~ Appendices ~

Appendix A

Easy Read Participant Information Sheet

**Information about the project**

**This project is about people with Down's syndrome and documentaries.**

Would you like to take part in this project?

Before you decide it is important that you understand why I am doing this project.

It is important that you understand what taking part might involve for you.



Please read this booklet carefully. You can talk to other people about it if you would like to.



Please ask someone if there is anything you don't understand.

Please tell me if I have not explained something properly.

After you have finished, you can decide if you want to take part.

**Thank you for thinking about taking part in my project!**

**What is in this booklet**



**These are the questions answered in this information booklet. You can look them up using the page numbers on each page.**

**What is the project about? ----- Page 3**

**Why do you want me to take part? ----- Page 5**

**Do I have to take part? ----- Page 5**

**What will happen to me if I take part? ----- Page 6**

**What do you want to ask me? ----- Page 7**

**Will taking part be good or bad for me----- Page 8**

**Will you tell people what I say? ----- Page 8**

**Will I be recorded? ----- Page 9**

**What will you do with what you find out? ----- Page 10**

**Do I have to take part? ----- Page 10**

**Contact information ----- Page 11**

## What is this project about?

I want to find out what people with Down's syndrome think about documentaries.

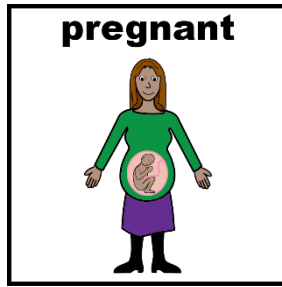
Documentaries are films or TV shows that tell stories about people's real lives.



Video cameras follow people around and film them going about their day-to-day lives, sometimes asking them questions.

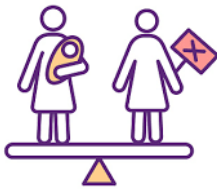


I want to look at how documentaries talk about Down's syndrome and screening tests for pregnant women.



When a woman is pregnant, she has screening tests done to check if the baby is healthy.

Some of these tests can tell if the baby has Down's syndrome.



Some women choose to end the pregnancy when they find out the baby has Down's syndrome.



I also want to see how documentaries talk about people with Down's syndrome living independently.



Finally, I would like to see how documentaries talk about relationships and sexuality for people with Down's syndrome.

I am doing this project because I think that people with Down's syndrome have equal rights to life, relationships and independence.

I hope this project will show what people with Down's syndrome think about documentaries and how documentaries can be made better.

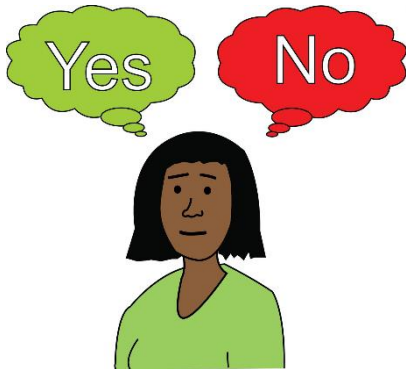
### **Why do you want me to take part?**



I am trying to find out what people with Down's syndrome think about documentaries. The only people who know are people with Down's syndrome themselves.

I need to speak to people who think it is really important how disability and Down's syndrome is shown in films and TV.

## Do I have to take part?



It is up to you if you take part or not. If you would like to take part I will ask you to sign a sheet that checks you understand about taking part.

If you change your mind you can stop taking part at any time. You don't have to tell me why if you don't want to.

## What will happen to me if I take part?



You will come to 3 film clubs where we will watch documentaries together and talk about what we have watched.



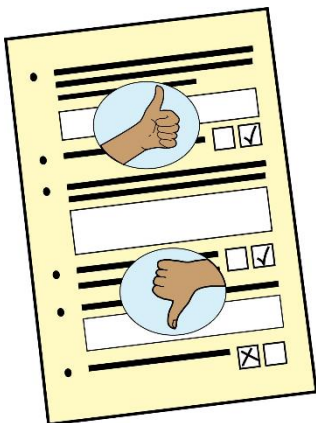


After the film clubs, we would meet up as a group and talk about what you would do if you were making your own documentary film.

Then we will work together to make a short trailer for a documentary film all about your lives with Down's syndrome. A trailer is a short clip from a film to show people what it is all about.

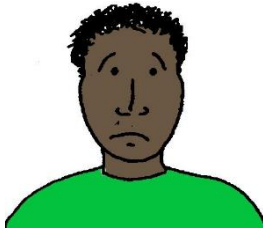
### **What do you want to ask me?**

I will ask you about different ways that documentaries show people with Down's syndrome. I would like you to think about positive and negative ways to show Down's syndrome in documentaries.



Afterwards I will send you a copy of what we said in our group work. If you want to add or change anything you can.

### Will taking part be good or bad for me?



You might find some of the things we talk about upsetting.



You might also find filming a documentary trailer fun! It might be good for you to learn about different ways people with Down's syndrome are shown on TV and in films.

### Will you tell people what I say?

If you take part in a group discussion, everyone in the group (including me) will hear what everyone else shares.

This means everyone will need to agree to keep the discussion private. Your information will not be shared with anyone else.



When I write about what we talk about in group discussions, I will not use your real names or use any of your personal information.

## Will I be recorded?

The group sessions will be recorded using a video camera and a digital microphone.



I will only use the recording to help me to write up what we talked about. No one else will listen to it.

I will keep the recording stored using a password on a computer at the university.



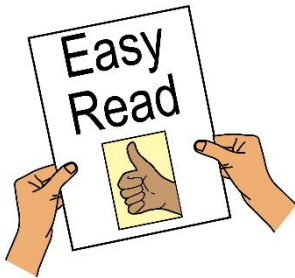
Only I will be able to listen to it because only I have the password for the file. It will be deleted at the end of my project.

## What will you do with what you find out?

I will do 3 things with what I find out:



1) Write a report for the university. They will read this and give me a grade for my work.



2) Write an easy-read summary of what I found out and send it to you. You can also see the full report if you want to.



3) I will try and let other people who might be interested know what I find out.

## Do I have to take part?

No. It is up to you whether you take part in the project.



If you decide to take part, you have 14 days to change your mind. You do not have to tell anyone why you don't want to take part.

## Contact information



Amy Redhead



[ss19alr@leeds.ac.uk](mailto:ss19alr@leeds.ac.uk)



c/o School of Sociology and Social Policy  
University of Leeds  
Leeds  
LS2 9JP



**Thank you for thinking about taking part in my project!**

## Appendix B

### Easy Read Consent Form

#### Representing Down's syndrome in Documentary

#### Agreeing to Take Part



Please tick the box to answer these questions about taking part.

If you don't understand something, please ask me or someone close to you to explain.

Yes

No

Do you understand what this project is about?



Have you been able to ask questions about it?



Do you understand that you can stop taking part if you change your mind?



**Please turn over this page**

Do you understand that after June 2022 I will not be able to delete what you told me from my project?



Do you understand that you don't have to answer any questions you don't want to?



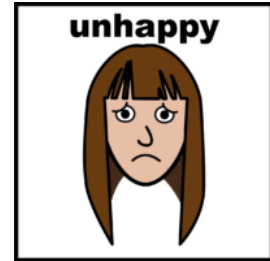
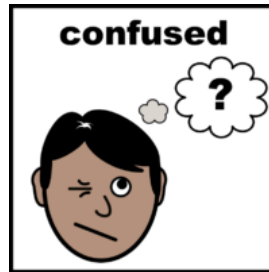
Do you understand that everyone in the group will hear what everyone else shares?



Do you agree to keep the group discussions private?



How do you feel about being involved in this project?



Please turn over this page

Do you want to take part?



Do you agree to provide your data,



including pictures of you?



including videos of you?



Please write your name:

---

Please write today's date:

---

Please sign:

---



Researcher's name: AMY REDHEAD

Today's date: \_\_\_\_\_

Researcher's signature: \_\_\_\_\_

**Thank you!**

## Appendix C

### Easy Read Consent Form for Audience Review Vox-Pop Interviews

Representing Down's syndrome in Documentary project

#### Agreeing to Take Part



If you don't understand something, please ask me or someone close to you to explain.



I will film you and ask you some questions about the trailer.

I will not share videos of you with anyone else.

I may write about what you have said in my report for the university.



Please turn the page

Yes

No

Do you understand that you don't have  
to answer any questions you don't  
want to?



Do you want to be interviewed?



Please write your name:

---

Please write today's date:

---

Please sign:

---

Researcher's name: AMY REDHEAD

Today's date: \_\_\_\_\_

Researcher's signature: \_\_\_\_\_

**Thank you!**

## Appendix D

### Easy Read 'About Me' Handout

#### Representing Down's syndrome in Documentary Project

#### About Me



My name is Amy Redhead.



I am a researcher at the  
University of Leeds.

#### My work

My research is mainly about people with learning disabilities and people with Down's syndrome.

I look at how disabled people are shown on the TV, in films, in books and in the media.

My family

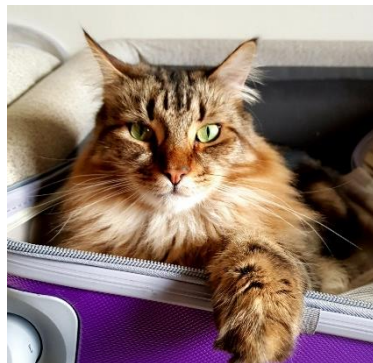
I live in Liverpool with my boyfriend and our 4 cats.



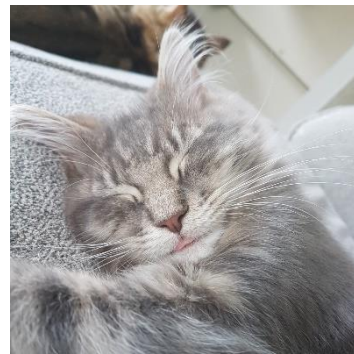
Bruce



Bonnie



Binx



Milo

As you can probably tell – I am obsessed with cats!



My hobbies

I love cross stitching, reading and watching TV.



My favourites are true crime documentaries and romantic comedy films!

I also love going out for walks and taking pictures of nature.



## Appendix E

### Transcription Key

# text #	overlapping speech
,	brief pause
(text)	approximate transcription
(5)	Pause in full seconds
( )	unclear/incomprehensible speech (space between brackets approximately corresponding to length/duration of utterance)
((raises hand))	Transcriber's comments/descriptions of moods and non-verbal utterances or sounds
-	Sudden halt/faltering or self-interruption
=	Rapid speech, words closely linked

## Appendix F

### Film Club Interview Prompts

- Do you think what is shown in x, y, or z is a fair representation?
- Do you recognise or identify with anything you saw in x, y, or z?
- How does this make you feel?
- How would you do it differently?
- What music would you use? Would you use music?
- Would there be narration? Who would narrate the documentary?
- What stories would you tell?
- What do you think the general public needs to know about Down's syndrome/screening for Down's syndrome/relationships and sexuality/independent living?

## Appendix G

### Easy Read Information about Copyright Law

#### Copyright of Trailer

**The trailer we have made needs to be protected.**

We will protect it with a copyright licence.

This means that we have control over how other people use the trailer or share it.



This is the copyright symbol.

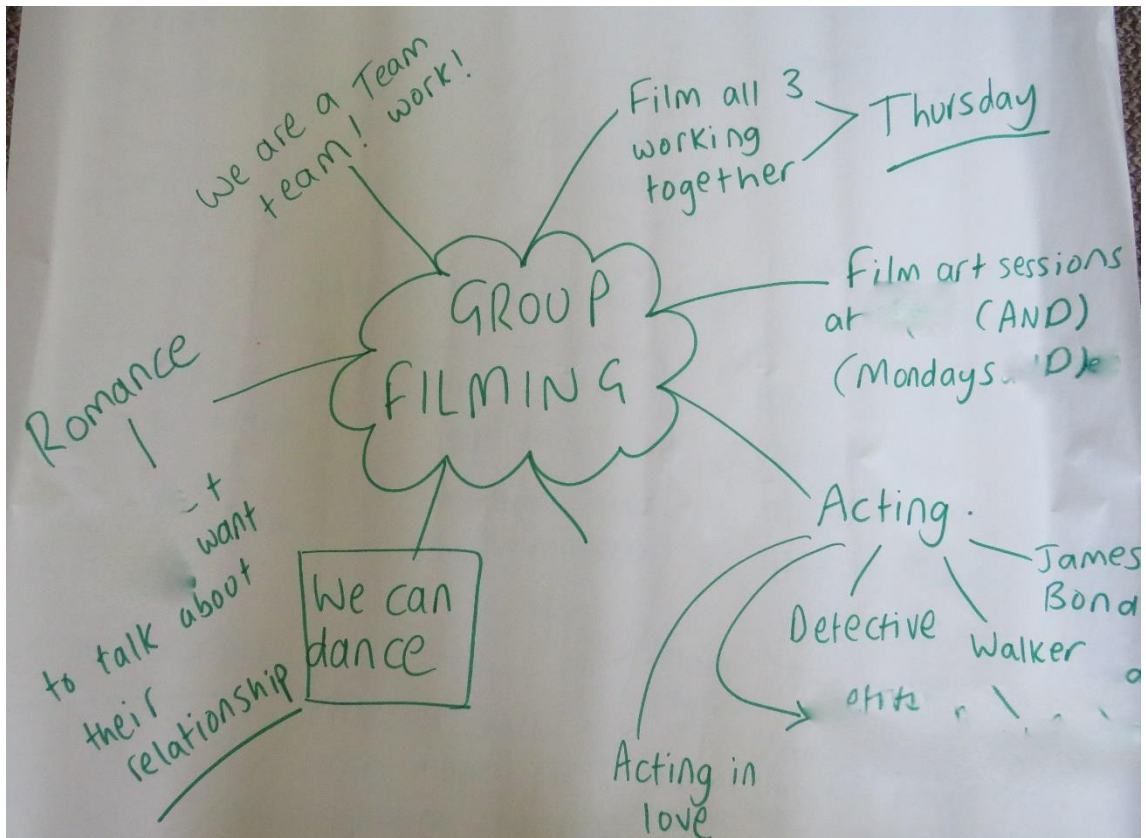
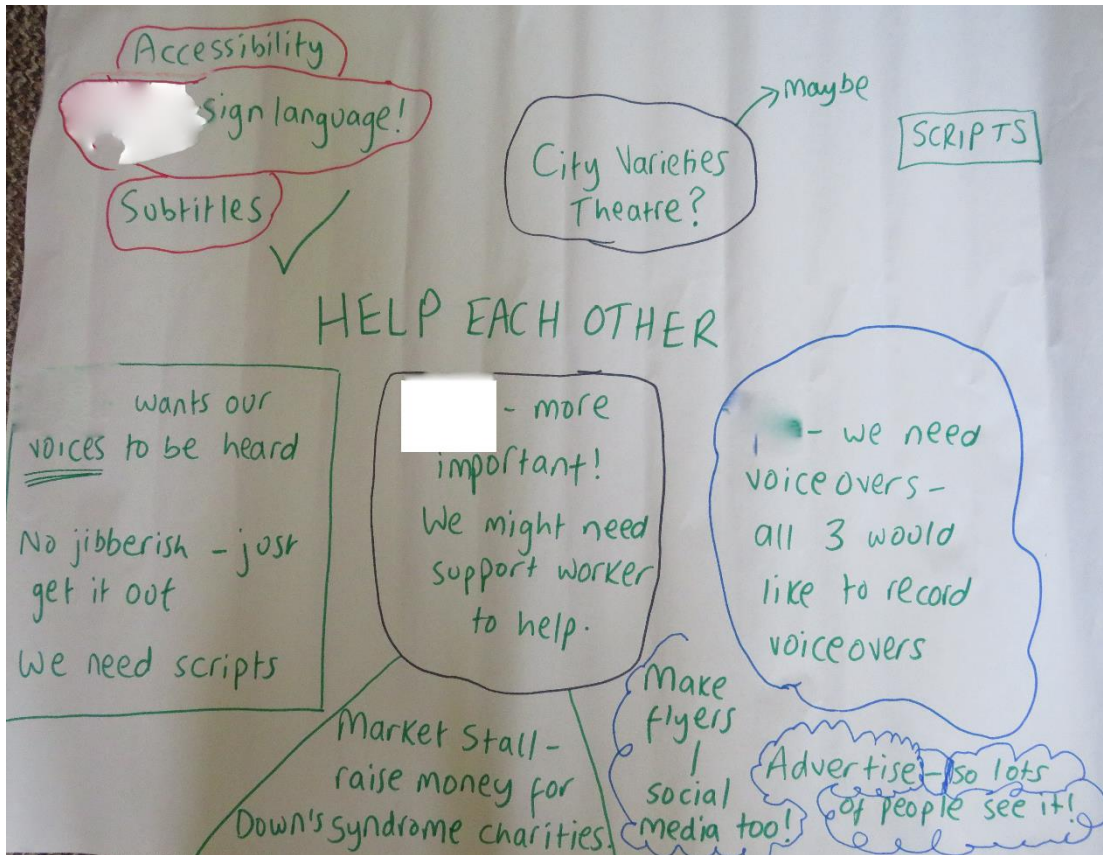
Whenever our trailer is shown online, it will have this box underneath it:





## Appendix H

### Images of Storyboard Activity

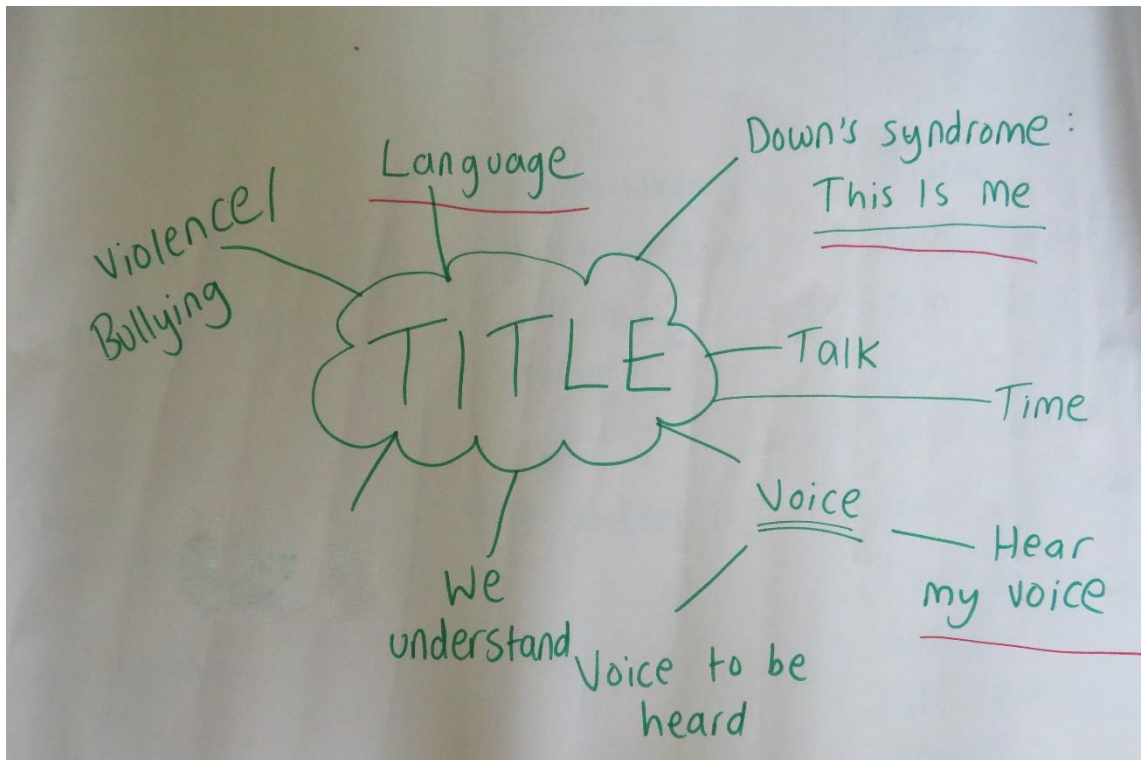


- at work  
in the café

get shots of  
making coffees  
Follow around  
all day

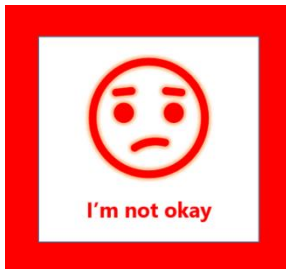
Singing Whitney  
Houston for Louise  
I will always  
love you  
↓  
Film at

Travel  
ambassador -  
film  
being a travel  
ambassador.  
Leeds City Council  
Q+A on the  
buses -  
will have a  
script.



## Appendix I

### Easy Read Support Services Handout



If you have become distressed by anything we have spoken about – please talk to somebody.



You can talk to staff at \*\*\*\*\* if you want to.

Or there are support services you can access on the

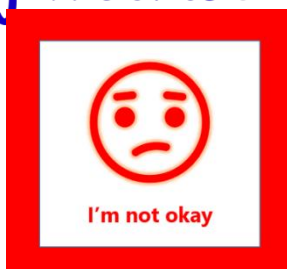


Call us now for free on 116 123

 **mencap** Learning Disability Helpline 0808 808 1111



0845 766 0163



## Appendix J

### Communication tools used in Film Clubs



## Appendix K

### Approved (Amended) Ethics Application Form



UNIVERSITY OF LEEDS

#### UNIVERSITY OF LEEDS RESEARCH ETHICS COMMITTEE APPLICATION FORM <sup>1</sup>

Please read each question carefully, taking note of instructions and completing all parts. If a question is not applicable please indicate so. The superscripted numbers (eg<sup>8</sup>) refer to sections of the guidance notes, available at <http://ris.leeds.ac.uk/UoLEthicsApplication>. Where a question asks for information which you have previously provided in answer to another question, please just refer to your earlier answer rather than repeating information.

Information about research ethics training courses: <http://ris.leeds.ac.uk/EthicsTraining>.

To help us process your application enter the following reference numbers, if known and if applicable:

Ethics reference number:	AREA 21-036
Student number and/ or grant reference:	201348551

#### PART A: Summary

**A.1 Which Faculty Research Ethics Committee would you like to consider this application?<sup>2</sup>**

- Arts, Humanities and Cultures (AHC)
- Biological Sciences (BIOSCI)
- Business, Environment and Social Sciences (AREA)
- FS&N, Engineering and Physical Sciences (EPS)
- Medicine and Health (Please specify a subcommittee):
  - School of Dentistry (DREC)
  - School of Healthcare (SHREC)

<input type="radio"/> School of Medicine (SoMREC)  <input type="radio"/> School of Psychology (SoPREC)	
<b>A.2 Title of the research<sup>3</sup></b>  <b>Representing Down's syndrome in Documentary: exploring independence, relationships, and right to life in the documentary genre</b>	
<b>A.3 Principal investigator's contact details<sup>4</sup></b>	
Name ( <i>Title, first name, surname</i> )	Miss Amy Redhead
Position	ESRC funded PhD Candidate
Department/ School/ Institute	School of Sociology and Social Policy
Faculty	Faculty of Social Sciences
Work address ( <i>including postcode</i> )	School of Sociology and Social Policy University of Leeds LS2 9JT
Telephone number	07974215894
University of Leeds email address	<a href="mailto:ss19alr@leeds.ac.uk">ss19alr@leeds.ac.uk</a>

<b>A.4 Purpose of the research:<sup>5</sup></b> (Tick as appropriate)
<input checked="" type="checkbox"/> Research
<input type="checkbox"/> Educational qualification: <b>Please specify:</b> _____
<input type="checkbox"/> Educational Research & Evaluation <sup>6</sup>
<input type="checkbox"/> Medical Audit or Health Service Evaluation <sup>7</sup>
<input type="checkbox"/> Other

**A.5 Select from the list below to describe your research:** (You may select more than one)

Research on or with human participants

Research which has potential adverse [environmental impact](#).<sup>8</sup> **If yes, please give details:**

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Research working with data of human participants

New data collected by qualitative methods

New data collected by quantitative methods

New data collected from observing individuals or populations

Routinely collected data or secondary data

Research working with aggregated or population data

Research using already published data or data in the public domain

Research working with human tissue samples (*Please inform the relevant [Persons Designate](#) if the research will involve human tissue*)<sup>9</sup>

**A.6 Will the research involve NHS staff recruited as potential research participants (by virtue of their professional role) or NHS premises/ facilities?**

Yes  No

*If yes, ethical approval must be sought from the University of Leeds. Note that [approval](#) from the NHS Health Research Authority may also be needed, please contact [FMHUniEthics@leeds.ac.uk](mailto:FMHUniEthics@leeds.ac.uk) for advice.*

**A.7 Will the research involve any of the following:**<sup>10</sup> (You may select more than one)

*If your project is classified as [research](#) rather than service evaluation or audit and involves any of the following an application must be made to the [NHS Health](#)*

[Research Authority](#) via IRAS [www.myresearchproject.org.uk](http://www.myresearchproject.org.uk) as NHS ethics approval will be required. **There is no need to complete any more of this form.** Further information is available at <http://ris.leeds.ac.uk/NHSEthicalreview> and at <http://ris.leeds.ac.uk/HRAapproval>.

You may also contact [governance-ethics@leeds.ac.uk](mailto:governance-ethics@leeds.ac.uk) for advice.

- Patients and users of the NHS (including NHS patients treated in the private sector)<sup>11</sup>
- Individuals identified as potential participants because of their status as relatives or carers of patients and users of the NHS
- Research involving adults in Scotland, Wales or England who lack the capacity to consent for themselves<sup>12</sup>
- A prison or a young offender institution in England and Wales (and is health related)<sup>14</sup>
- Clinical trial of a medicinal product or medical device<sup>15</sup>
- Access to data, organs or other bodily material of past and present NHS patients<sup>9</sup>
- Use of human tissue (including non-NHS sources) where the collection is not covered by a Human Tissue Authority licence<sup>9</sup>
- Foetal material and IVF involving NHS patients
- The recently deceased under NHS care
- None of the above

**You must inform the Research Ethics Administrator of your NHS REC reference and approval date once approval has been obtained.**

*The HRA decision tool to help determine the type of approval required is available at <http://www.hra-decisiontools.org.uk/ethics>. If the University of Leeds is not the Lead Institution, or approval has been granted elsewhere (e.g. NHS) then you should contact the local Research Ethics Committee for guidance. The UoL Ethics Committee needs to be assured that any relevant local ethical issues have been addressed.*



**A.8 Will the participants be from any of the following groups?** (Tick as appropriate)

Children under 16<sup>16</sup> **Specify age group:**

\_\_\_\_\_

Adults with learning disabilities<sup>12</sup>

Adults with other forms of mental incapacity or mental illness

Adults in emergency situations

Prisoners or young offenders<sup>14</sup>

Those who could be considered to have a particularly dependent relationship with the investigator, eg members of staff, students<sup>17</sup>

Other vulnerable groups

No participants from any of the above groups

***Please justify the inclusion of the above groups, explaining why the research cannot be conducted on non-vulnerable groups.***

Given that the participants will identify with the label of Down's syndrome, it is highly likely that all of the participants will also have some degree of learning difficulty. Some participants may also have physical medical conditions that further categorise them as 'disabled'. Given the nature of this project, it would be remiss to exclude the voices of people with Down's syndrome and for that reason I have decided not to conduct fieldwork with family members, guardians or carers of people with Down's syndrome. Instead it is crucial that I gather my data directly from individuals with Down's syndrome, whose personal narratives are often missed in research surrounding their lives.

I have contacted the self-advocacy organisation I will be working with (\*\*\*\*\*) and their manager has confirmed a DBS check will not be required as at no point during the fieldwork will I be alone with \*\*\*\*\* members - there will always be a staff member present. NB: A DBS check was later carried out.

**It is the researcher's responsibility to check whether a DBS check (or equivalent) is required and to obtain one if it is needed.** See also <http://ris.leeds.ac.uk/healthandsafetyadvice> and <http://www.homeoffice.gov.uk/agencies-public-bodies/dbs>.

#### **A.9 Give a short summary of the research<sup>18</sup>**

*This section must be completed in **language comprehensible to the lay person**. Do not simply reproduce or refer to the protocol, although the protocol can also be submitted to provide any technical information that you think the ethics committee may require. This section should cover the main parts of the proposal.*

Using arts-based research methods and working in collaboration with individuals with Down's syndrome, this research seeks to investigate how Down's syndrome is represented within the documentary genre, specifically in relation to the concepts of independence, relationships and right to life. Six members from \*\*\*\*\* (a self-advocacy organisation ran by and for people with learning disabilities) will participate in the research.

Disability and documentary have a complicated history, with disabled bodies and minds often represented as a cultural 'spectacle'. Documentary serves as a powerful vehicle of representation and has the potential to disrupt and challenge normative notions of a life with Down's syndrome. As part of this research, film clubs will be hosted whereby individuals with Down's syndrome will analyse extracts from the following documentaries: *The Specials* (2009-2014), *The Undateables* (2012-) and *A World Without Down's Syndrome?* (2016). The themes within these documentaries relate to notions of independence and independent living; relationships and sexuality; and the ethics of prenatal screening and right to life. These particular documentaries have been selected as they involve some of the central problematical representations of Down's syndrome: independence and assumed incompetence; relationships and assumed vulnerability; and bioethical debates over right to life.

During group work, participants will be asked to explore these themes in relation to the documentaries and imagine how they would imagine an even better documentary about their lives. Participants will storyboard their ideas and create a blueprint for their own documentary. A short trailer for the imagined documentary will be directed and produced by the participants, with the support of the researcher. Any participants who indicate that they wish to voice their thoughts and ideas further, beyond the group sessions, will be given follow-up opportunities, such as semi-

structured interviews on a one-to-one basis, or creating an art piece to convey their thoughts, such as a collage, drawing or poem.

**A.10 What are the main ethical issues with the research and how will these be addressed?<sup>19</sup>**

*Indicate any issues on which you would welcome advice from the ethics committee.*

**Sensitive topics**

Some of the themes within the documentaries discuss sensitive subjects, such as the ethics around selective abortion on the basis of disability. In order to prevent psychological harms, prior to screening the documentaries, I will describe the types of issues that are raised (using appropriate language, pictures and other helpful materials) and participants will be reminded that they are free to withdraw from the research at any point if they should feel uncomfortable. Participants will be reminded throughout each stage of the research process that if they feel the issues being discussed in the group sessions, or the questions being asked in the interviews, are too intrusive or upsetting, they can decline to watch the documentaries and refuse to partake in group discussions. Additionally, I will limit the number of sensitive questions included in potential interview scripts to only the most essential.

**Participant Confidentiality and Anonymity**

All participants will be asked to select a pseudonym in order to protect their confidentiality and anonymity. A research participant Privacy Notice in line with the Data Protection Act and The University of Leeds Data Protection Code of Practice will be included with the participant information sheet. This is a qualitative study whereby group collaboration and interviews will be audio and video recorded. Therefore, personal data will be collected (classified as confidential) and will be securely stored and managed with care. Data will be de-identified and presented in ways which limit attribution to specific individuals. The nature of the research (video

recorded group sessions and filming a documentary trailer) means 100% confidentiality cannot be promised to participants (the researcher cannot guarantee that confidentiality will be respected by all participants) although best efforts will be made to maintain this and the importance of confidentiality will be discussed with the group. Any recorded footage will only be shared subject to the permission of the participants. Participants are advised that there are limits to their confidentiality due to inadvertent breaches and the informed consent document will outline that confidentiality cannot be 100% assured. For example, if a participant were to disclose information that I believed to be a safeguarding issue, I would first work with the participant to encourage and support them to report this to the relevant authorities. If they were unable or unwilling to do this and I judged that the individual was at significant risk of harm I would be responsible for reporting this safeguarding issue directly to a relevant body.

### **Informed Consent**

In line with the core principles of the ESRC Framework for Research Ethics, participants will be fully informed about the purpose, nature, and possible uses of the research and their data. Participants will be informed about what their involvement in the research entails (including potential risks). Full and informed consent will be sought and consent will be re-visited regularly as the project develops. Participants will be made aware that participation (including group work and answering questions) is voluntary and consent may be withdrawn at any point without negative consequences. Participants will be informed that video and audio-recordings of group work and interviews can be stopped at any time. Participants will also be given sufficient time to fully consider their participation. This information will be explained verbally and through an easy-read participant information sheet sent prior to the group sessions and interviews. An approved consent script will be read out and recorded prior to beginning any group sessions or interviews and will be included in all transcripts.

I do not assume that because my participants will have learning disabilities that they are unable to give informed consent. I intend to show this through the use of easy read and verbal communication. All members of \*\*\*\*\* have previously demonstrated that they can give informed consent as they have completed membership forms which cover all manner of research projects and activities. I am confident in gaining informed consent providing that any information is relayed in an accessible manner. Participants will also have a member of staff from \*\*\*\*\* present throughout the

research who can assist in communicating the meaning of informed consent, if necessary.

**Participants who are ‘vulnerable’**

Vulnerability can lead to the exclusion of marginalised voices from the research process, and people labelled as ‘vulnerable’ are often overlooked as research participants so as not to place anyone under unnecessary harm or risk. Ethical guidelines that protect those labelled as ‘vulnerable’ are reasonable and judicious, however, there are instances where the omission of certain groups of vulnerable people can have negative consequences, and the inclusion of their input within the research is absolutely appropriate. I believe this research project is an example of such research, and the participation of people with Down's syndrome is essential. Vulnerability is a key term in my research, and I will be engaging with it through a disability studies perspective. Therefore, emphasis will not be placed on the assumed ‘vulnerability’ of my participants, but the provision of clear research aims and objectives as well as sensitive management of the research process - ongoing informed consent will ensure their safety and wellbeing.

**Time commitment of research for participants**

I am mindful of the time and energy that this fieldwork will require of participants and will strive to ensure all research activities are designed so as to avoid time-wasting. Participants will not be coerced into taking part in interviews if they feel they have fully expressed their views in the group sessions. Ongoing consent will take place at every stage. Initial discussions with \*\*\*\*\* suggest that potential participants are very keen to become involved in this project and are looking forward to re-visiting the University campus (a place they have visited previously in relation to other research projects).

**PART B: About the research team**

**B.1 To be completed by students only<sup>20</sup>**

Qualification working towards (eg Masters, PhD)	PhD
Supervisor’s name (Title, first name, surname)	Professor Angharad Beckett
Department/ School/ Institute	School of Sociology and Social Policy
Faculty	Faculty of Social Sciences

Work address (including postcode)	School of Sociology and Social Policy, University of Leeds, Leeds, UK, LS2 9JT
Supervisor's telephone number	0113 343 4409
Supervisor's email address	A.E.Beckett@leeds.ac.uk
Module name and number (if applicable)	N/A
<b>B.2 Other members of the research team (eg co-investigators, co-supervisors)</b> 21	
Name ( <i>Title, first name, surname</i> )	Dr Clare Barker (co-supervisor)
Position	Associate Professor in English Literature
Department/ School/ Institute	School of English
Faculty	Faculty of Arts, Humanities and Cultures
Work address ( <i>including postcode</i> )	School of English, University of Leeds, Leeds, UK, LS2 9JT
Telephone number	N/A
Email address	c.f.barker@leeds.ac.uk
<b>Part C: The research</b>	
<p><b>C.1 What are the aims of the study?</b><sup>22</sup> (Must be in language comprehensible to a lay person.)</p> <p>The aims of this study are to listen to and consider the previously unheard voices of people with Down's syndrome in relation to important aspects of their lives. This research seeks to disrupt normative notions of Down's syndrome that are often presented in documentary films and series and offer alternative imaginations of a life with Down's syndrome.</p>	

In order to explore these issues, several research questions relating to cultural representations of Down's syndrome and how they might contribute to disabling discourses surrounding this condition have been developed:

- What are the dominant discourses surrounding Down's syndrome within documentaries? Do documentaries, and the form they take, contribute to dominant discourses surrounding Down's syndrome?
- Do representations in documentaries directly impact individuals with Down's syndrome and their sense of self? How do individual narratives of those with Down's syndrome relate to collective societal discourses surrounding ableism and normalcy?
- How might people with Down's syndrome revise or transform documentaries about living with this condition?

**C.2 Describe the design of the research. Qualitative methods as well as quantitative methods should be included.** (Must be in language comprehensible to a lay person.)

*It is important that the study can provide information about the aims that it intends to address. If a study cannot answer the questions/ add to the knowledge base that it intends to, due to the way that it is designed, then wasting participants' time could be an ethical issue.*

### **Stage One**

The first phase of the research involves a critical analysis of the selected documentaries (*The Specials*, *The Undateables* and *A World Without Down's Syndrome?*). This phase of the analysis will employ multimodal critical discourse analysis (Machin & Mayr, 2012; Kress & Van Leeuwen, 2001). Using the tools within this analytical framework will allow me to examine any linguistic features and visual semiotic elements within the documentaries. My analysis will be revisited once co-researchers have analysed the same documentaries (see Stage Two). One of the most important aspects of this research is that I am relying equally on my own analysis and interpretation of the documentaries as well as the experiential knowledge produced through the participants' analysis of the same documentaries.

### **Stage Two**

The second stage in the research involves collecting empirical data by way of film clubs, post-screening group discussions and potentially semi-structured interviews with participants. Three film clubs will take place whereby the co-analysis of the selected documentaries will occur. This process of co-analysis will be an adapted

replication of my own research process. The film clubs and analytical work carried out within them will be video and audio-recorded (audio as a back-up recording), with any relevant data being transcribed after the event. Co-researchers who feel they need to further voice their ideas, thoughts or opinions will be given follow-up opportunities, such as interviews on a one-to-one basis (using a semi-structured interview script that will be produced in an accessible format) or creating a piece of art that represents their ideas.

The three documentaries screened at the film clubs will have previously been analysed before the fieldwork commences (in Stage 1). The group discussions that will take place in the film clubs are an opportunity to find out how the participants feel about the documentaries; identify whether the documentaries spark any particular emotions; enquire as to whether the themes covered in the documentaries make them think about their own reality and whether there are any similarities or differences. As the co-analysis takes place, I would like to find out from participants what they might do differently (or similarly) if they had an opportunity to produce their own documentary. I will ask questions such as:

- Do you think what is shown in x, y, or z is a fair representation?
- How does this make you feel?
- How would you do it differently?
- What music would you use? Would you use music?
- Who would narrate the documentary?
- What stories would you tell?
- What do you think the general public needs to know about Down's syndrome/right to life/relationships & sexuality/independent living?

During the film clubs, I intend for group discussions to be as flexible as possible; therefore, these prompt questions may change, and I will not follow a rigorous script. Participants need to feel free to explore the idea of making their own documentary without me inadvertently guiding their ideas.

### **Stage Three**

The final phase of the fieldwork will storyboard the participants thoughts and ideas in terms of how they would like a life with Down's syndrome to be presented within the documentary genre. During the film clubs and interviews, participants will be prompted to imagine how they would like their own hypothetical documentary film to be produced. Ideas that emerge from the co-analysis will be collected and storyboarded. Once the film clubs have taken place, participants will be invited to three follow-up sessions where ongoing discussions will take place and a 2-3 minute trailer for this documentary will be created. This phase of the research will be



controlled entirely by the participants, and they will shape how the trailer will be produced and presented.

### **Arts-based research**

An art-based approach to inquiry will be adopted in stages 2 and 3 of the research analysis. An arts-based approach has been chosen for this project, not only so that the invisible can be made visible (an important element in any disability related project) but also because this particular research method allows the space and fluidity for experiential knowledge to flourish. I intend for the data (art) generated within this research to be legitimised as a valid and valued body of knowledge, acquired directly from people living with Down's syndrome. I intend to create a space for participants to explore, reflect on and share their self-knowledge, which in turn should convey relatively unheard 'truths' about Down's syndrome, from the perspectives of the participants. The meanings that the participants give to their reality will be navigated through arts-based research, and their own understandings can be processed in fluid and diverse ways.

### **Film Clubs**

The three selected documentaries will be screened and watched together. Not all of these screenings will project the documentary film or series in full as this would be too time-consuming for participants. Instead, I will select relevant excerpts and these will be played during the group sessions.

In hosting film clubs rather than conventional documentary screenings, I hope this will create a more informal, relaxed space for participants to conduct their analysis and share their thoughts and ideas surrounding the themes explored in the documentaries.

Each film club will focus on a specific theme:

- Film Club One will screen excerpts from episodes of *The Specials* that feature individuals with Down's syndrome who share a house in Brighton. The theme for this film club will be independent living.
- Film Club Two will screen excerpts from the documentary series *The Undateables* that feature individuals with Down's syndrome signed up to dating agencies. The theme for this film club will be relationships and sexuality.
- Film Club Three will screen excerpts from the documentary film *A World Without Down's Syndrome?* This film discusses Down's syndrome and the ethics of pregnancy screening. The theme for this film club will be right to life.

There will be many logistical aspects to consider in terms of the research setting, especially regarding access requirements. The documentaries need to be screened in a COVID-safe, fully accessible room that will accommodate any physical or sensory needs of the participants. I intend to reserve room 12.21/25 in the Social Sciences

building which is accessible in terms of space, has good-quality projectors, a speaker system and hearing loop. If this room is unavailable I will reserve a similar bookable space either in the Social Sciences building or elsewhere on campus. All of the documentaries will need captions and should be played on a good quality projector so that participants can see clearly. Any access requirements will be discussed with participants prior to the documentary screenings. Social distancing will take place at all times and participants will be asked to wear a face covering if possible.

During the film clubs, the idea is to watch the documentaries as a group and participants will have the opportunity to discuss some of the issues raised in the films. Collaboratively, we will analyse the different techniques used in the documentaries to represent these issues and people with Down's syndrome. These techniques could range from the language used to describe people with Down's syndrome to the camera angles used or the use of music within the documentaries. Various materials will be provided so that if a participant wants to make notes, draw or document their thoughts during the film clubs, they will have the option to do so. Additionally, if participants spark a dialogue about the documentaries during the screening, I can pause the projection and let the conversation flow organically. The participants will have the freedom to influence the direction of the discussions, which, in many ways, could influence the direction of the research project. Throughout the co-analysis, my role as the researcher will be to encourage participants to engage in discussions freely. Perhaps if discussions veer off-topic, I can prompt participants to think about the documentaries we are watching. I believe that my previous experience undertaking research with adults with learning disabilities will be beneficial in ensuring that discussions stay on-topic.

Prior to the first film club, I intend to meet with participants in an informal setting to give us the chance to get to know one another. I will schedule a social meeting with refreshments and use this opportunity to explain the project, work on rapport and put everybody at ease with one another. Ideally this social meeting would take place on-campus, to enable participants to become familiar with the University campus and the rooms we will be using to conduct the research. Alternatively, if participants would prefer a different location that was more convenient to them, this can be arranged. From the group sessions, I anticipate that I will build a rapport with my co-researchers and be in a position to identify which individuals may wish to partake in one-to-one interviews. I will use semi-structured scripts for the interviews based on topics and themes that arise within the group sessions. It will be crucial that I adopt flexible and adaptable techniques when conducting my interviews. Ensuring the depth of questioning is adjusted accordingly with each participant will be imperative, as well as

using concrete (as opposed to abstract) frames of reference (Hollomotz, 2018, p.158). Picture cards could also be used as concrete reference tools in both the film clubs and the interviews. Using flexible and adaptable techniques, I intend to ask participants to imagine how, from their perspective, life with Down's syndrome could be represented on-screen.

***If the current Covid-19 restrictions change and socially distanced in-person meetings are no longer permitted, all on-campus activities will be switched to online. I would use Zoom or Microsoft Teams to facilitate online screenings of the documentaries and group discussions.***

**C.3 What will participants be asked to do in the study?<sup>23</sup> (e.g. number of visits, time, travel required, interviews)**

Participants will be asked to meet on seven different occasions. First, an informal meeting, in a location that is most convenient for them, to discuss the project details and get to know one another. This initial meeting will be followed by three separate film clubs, with each session lasting approximately two hours. Finally, three further group sessions will be organised in order to continue the analysis, storyboarding activity and filming the documentary trailer, again lasting two hours. If any participants do wish to take part in interviews, these would take place following the final three group sessions at a location that is convenient for them.

Possible locations for fieldwork: University of Leeds campus or \*\*\*\*\* offices. If participants wish to conduct the research on campus, travel will be required. I cannot foresee this being an issue, as preliminary discussions with the \*\*\*\*\* manager has confirmed that potential participants are very keen to become involved in this project and are looking forward to re-visiting the University campus (a place they have visited previously in relation to other research projects). All fieldwork will take place during standard University opening times (9 am-5 pm).

**C.4 Does the research involve an international collaborator or research conducted overseas?<sup>24</sup>**

Yes     No

**If yes, describe any ethical review procedures that you will need to comply with in that country:**

**Describe the measures you have taken to comply with these:**

Include copies of any ethical approval letters/ certificates with your application.

### **C.5 Proposed study dates and duration**

Research start date (DD/MM/YY): 01/10/2020\_\_\_\_ Research end date (DD/MM/YY):  
\_01/10/2023\_\_\_\_\_

Fieldwork start date (DD/MM/YY): \_17/01/2022\_ Fieldwork end date (DD/MM/YY):  
\_01/12/2022\_\_\_\_\_

### **C.6. Where will the research be undertaken? (i.e. in the street, on UoL premises, in schools)<sup>25</sup>**

Primarily on the University of Leeds campus within the Social Sciences Building.

## **RECRUITMENT & CONSENT PROCESSES**

### **C.7 How will potential participants in the study be identified, approached and recruited?<sup>26</sup>**

*How will you ensure an appropriately convened sample group in order to meet the aims of the research? Give details for subgroups separately, if appropriate. How will any potential pitfalls, for example dual roles or potential for coercion, be addressed?*

A mixed purposeful sampling strategy will be used in this research, combining criterion and network sampling strategies to collect data (Durdella, 2019, p.157). Participants will initially be selected using a criterion sampling strategy, with the required criterion that the participants identify as having Down's syndrome. As the recruitment process progresses, participants may identify further individuals to recruit through their networks.

This research project will recruit 6 participants who are based in Leeds, aged over 18 and have Down's syndrome. This can be any form of Down's syndrome (Trisomy 21, Mosaic or Translocation Down's syndrome) and participants of any gender, culture, or religion are welcomed. I would also welcome a range of perspectives in terms of age, and participants do not need to have watched the documentaries beforehand or have any knowledge of the themes discussed in them.

Having researched different charities and organisations involving people with learning disabilities in Leeds, I discovered a People First self-advocacy organisation called \*\*\*\*\*. Preliminary discussions with the manager and deputy manager at \*\*\*\*\* have taken place, whereby I outlined the aims of my project. The managers (gatekeepers) identified six members who have Down's syndrome that they think would be very interested in taking part in this research.

If, however, members of \*\*\*\*\* decide not to become involved in the project, the Down's Syndrome Association has agreed to post the details of my research project on their website and social media channels. Details of the project could also be shared through my own social media channels and University of Leeds accounts such as The Centre for Disability Studies and School of Sociology and Social Policy.

Once ethical approval has been granted, I will contact \*\*\*\*\* and set up an online discussion with the managers to discuss the project once again and confirm their interest.

**C.8 Will you be excluding any groups of people, and if so what is the rationale for that?<sup>27</sup>**

*Excluding certain groups of people, intentionally or unintentionally may be unethical in some circumstances. It may be wholly appropriate to exclude groups of people in other cases*

I will exclude any individuals who are under the age of 18 and/or do not identify as having Down's syndrome.

**C.9 How many participants will be recruited and how was the number decided upon?<sup>28</sup>**

*It is important to ensure that enough participants are recruited to be able to answer the aims of the research.*

I intend to recruit six participants. The suggested focus group size throughout the methodological literature ranges from six to 12 individuals. I have decided to recruit six participants in order to facilitate meaningful group discussion. This group number is small enough to allow everyone to speak and large enough to facilitate a group dynamic, with the overall goal of capturing a good range of responses.

Due to participant drop-outs, only three participants were involved in the focus group. In order to gather more data, I will visit different organisations that work with people with learning disabilities and screen the mock documentary trailer that was co-produced with the original participants. Post-screening, I will conduct 'vox pop' style interviews with audience members in order to gauge their response to the trailer and to ask how they would choose to be represented on screen if given the opportunity. These short interviews will be collated and edited into one video for the purpose of analysis. This video will not be shared with anyone.

If you have a formal power calculation please replicate it here.

N.A.

*Remember to include all advertising material (posters, emails etc) as part of your application*

**C10 Will the research involve any element of deception?<sup>29</sup>**

If yes, please describe why this is necessary and whether participants will be informed at the end of the study.

No

**C.11 Will informed consent be obtained from the research participants?<sup>30</sup>**

Yes     No

***If yes, give details of how it will be done. Give details of any particular steps to provide information (in addition to a written information sheet) e.g. videos, interactive material. If you are not going to be obtaining informed consent you will need to justify this.***

Participants will be given a written information sheet (as well as an easy-read version of this document). This will also be discussed verbally with the participants, to ensure they have understood the purpose of the research. As previously mentioned, staff members from \*\*\*\*\* can assist in explaining the meaning of informed consent to participants, if required. I do not envisage this being an issue, as members of \*\*\*\*\* have previously displayed the capacity to give informed consent when they completed membership paperwork to join \*\*\*\*\*. A copy of the written information sheet and easy-read version of this document is attached to this application.

***Vox pop participants will be shown an easy-read consent form prior to any interviews (copy attached). They will be asked to read and sign the consent form to confirm that they are happy for me to use their words in write-up of the thesis. They will be assured that their image and video will not be shared with anyone else. They will be provided with a pseudonym if their words are cited in the thesis.***

***If participants are to be recruited from any of potentially vulnerable groups, give details of extra steps taken to assure their protection. Describe any arrangements to be made for obtaining consent from a legal representative.***

Participants will be classed as belonging to a 'vulnerable' group and therefore informed consent will need to be obtained using accessible communications methods, such as verbal communication, easy read documentation or, if necessary, I could make a short vlog explaining the research and process of informed consent. There will always be a member of staff from \*\*\*\*\* present during the research, and therefore participants can be assured that they have an individual they know and trust on hand to explain anything they do not understand.

Consent forms will also be provided in an easy-read format for those that require it (see attached).

In order to ensure that participants do not feel pressured to take part by gatekeepers, I have included a question on the consent forms to gauge how participants are feeling about being involved in the research. They have three options for their answers: happy, confused, unhappy. If any participants select confused or unhappy I will discuss this further with them, and if it is apparent that the individual does not feel comfortable taking part in the research then I will advise them that they are free to withdraw. After a two-week period, I will call each participant to confirm that they are happy to take part in the research. Again, if I consider any individual to be hesitant or reluctant to work on the project, I will remind them of their option to withdraw. Finally, so as not to cause offence to gatekeepers, I will remind them that the reason I will be making frequent verbal consent checks with participants is to ensure my research remains in line with GDPR protocol.

I will not be involving in this project anyone who is not able to give informed consent, so will not need to obtain consent from a legal representative.

***Will research participants be provided with a copy of the [Privacy Notice for Research](#)? If not, explain why not.*** Guidance is available at <https://dataprotection.leeds.ac.uk/information-for-researchers>.

Yes     No

***Copies of any written consent form, written information and all other explanatory material should accompany this application.*** The information sheet should make explicit that participants can withdraw from the research at any time, if the research design permits. Remember to use meaningful file names and version control to make it easier to [keep track of your documents](#).

Sample information sheets and consent forms are available from the University ethical review webpage at <http://ris.leeds.ac.uk/InvolvingResearchParticipants>.

**C.12 Describe whether participants will be able to withdraw from the study, and up to what point (eg if data is to be anonymised). If withdrawal is not possible, explain why not.**

*Any limits to withdrawal, eg once the results have been written up or published, should be made clear to participants in advance, preferably by specifying a date after which withdrawal would not be possible. Make sure that the information provided to participants (eg information sheets, consent forms) is consistent with the answer to C12.*

Participants will be able to withdraw from the study between 01/12/2021 and 01/06/2022 (the estimated date for the data production phase). During the write-up stage, withdrawal of data will no longer be possible. This will be made clear to participants at the outset of the study. However, participants are able to request changes to the anonymity of their data at a later date than this, as changing names should not affect the analysis or write-up.

**C.13 How long will the participant have to decide whether to take part in the research?<sup>31</sup>**

*It may be appropriate to recruit participants on the spot for low risk research; however consideration is usually necessary for riskier projects.*

Participants will have at least two weeks to decide whether to take part in the research after receiving the information forms and meeting for an informal group session to discuss details of the research and what is involved. This project necessitates a considerable time commitment, therefore I want participants to have adequate time to consider how or if they wish to be involved in the research.

**C.14 What arrangements have been made for participants who might have difficulties understanding verbal explanations or written information, or who have particular communication needs that should be taken into account to facilitate their involvement in the research?<sup>32</sup> Different populations will have different information needs, different communication abilities and different levels of understanding of the research topic. Reasonable efforts should be made to include potential participants who could otherwise be prevented from participating due to disabilities or language barriers.**

Initially, all written information will be produced in the format of easy-read documents. Once I have received further details of the participants' communication



needs, I will ensure written and verbal communication will be made available in whichever format they might require.

**C.15 Will individual or group interviews/ questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could take place during the study (e.g. during interviews or group discussions)?<sup>33</sup> The [information sheet](#) should explain under what circumstances action may be taken.**

Yes     No      *If yes, give details of procedures in place to deal with these issues.*

Please see section A.10 for details.

**C.16 Will individual research participants receive any payments, fees, reimbursement of expenses or any other incentives or benefits for taking part in this research?<sup>34</sup>**

Yes     No

***If Yes, please describe the amount, number and size of incentives and on what basis this was decided.***

I intend to provide participants with shopping vouchers at the end of the project to thank them for taking part in the research and as payment for their time and expertise.

#### RISKS OF THE STUDY

**C.17 What are the potential benefits and/ or risks for research participants in both the short and medium-term?<sup>35</sup>**

Some participants might find it beneficial (in both the medium and short-term) to discuss issues around their rights, and gain a deeper understanding of the impact of cultural representations. The prospect of being creative and producing a documentary film trailer provides an opportunity for self-representation which may be beneficial to some participants, as well as a lot of fun!

The potential risks for participants in this study are discussed in section A10. If a participant chooses to not use pseudonyms for their names in this research, there could be risk of them being identifiable by others. I will therefore encourage the use of pseudonyms, but my participants will have agency in what they decide.

Some of the topics raised in the documentaries and group discussions might be distressing for participants as outlined in Section A.10. I will not push participants to talk about anything they find uncomfortable and they will have agency over what they share in the group sessions.

**C.18 Does the research involve any risks to the researchers themselves, or people not directly involved in the research? *Eg lone working*<sup>36</sup>**

Yes     No

***If yes, please describe:*** There may be potential risk to the researcher in terms of psychological distress. For example, if a participant shared an upsetting story or the group discussed ways in which cultural representations of Down's syndrome have negatively affected their lives, this may be distressing to observe as the researcher. I have a strong support network in place and have already discussed this eventuality with my supervisors, who confirmed that any upsetting or distressing feelings that may arise from the fieldwork can be talked through with them. I will be having regular de-briefing sessions with my supervisors and, although lone working is not anticipated as part of this research, should I ever need to visit a participant in their own home to conduct an interview, I will employ a 'ringing in/out' technique with my supervisors-and I will inform both supervisors when and where I will be conducting any interviews off campus. If I fail to get in touch with either of my supervisors within 2 hours of the agreed interview finish-time, my supervisors will have the contact details of my next of kin (Sam Sheppard) who should be contacted immediately, and university protocol regarding missing students will be followed.

**Is a [risk assessment](#) necessary for this research?**

*If you are unsure whether a risk assessment is required visit <http://ris.leeds.ac.uk/HealthAndSafetyAdvice> or contact your Faculty Health and Safety Manager for advice.*

Yes     No    If yes, please include a copy of your risk assessment form with your application.

**RESEARCH DATA**

**C.19 Explain what measures will be put in place to protect personal data. E.g. anonymisation procedures, secure storage and coding of data. Any potential for re-identification should be made clear to participants in advance.<sup>37</sup> Please note that research data which appears in reports or other publications is not confidential, even if it is fully anonymised. For a fuller explanation see <http://ris.leeds.ac.uk/ConfidentialityAnonymisation>. Further guidance is available at <http://ris.leeds.ac.uk/ResearchDataManagement>.**

Anonymising data will be decided on a case by case basis. Participants will be made aware of the potential for identification/re-identification in the information sheet.

Confidential participant information such as demographic participant data, audio and video recordings, participants' artwork, signed consent forms and other personal participant information will be stored securely. Physical copies of e.g. consent forms will be scanned and uploaded onto the University of Leeds M-Drive with original hardcopies stored in a locked cabinet. Digital files will be password protected and stored on my encrypted University OneDrive. Demographic data will be anonymised in my thesis, so as to not make participants identifiable. Any identifying information will be anonymised and safe storage of data collected, either digitally on my University OneDrive, or in a locked cabinet. All confidential data will also be stored securely on my University of Leeds OneDrive as a backup. All recordings will be transferred to OneDrive storage as soon as feasibly possible and deleted from the recording device.

I will create a Microsoft Excel file with participants' real and pseudonym names and their contact details. This will be a password protected file that only I will have access to. This will be stored on my University of Leeds OneDrive. As this will have identifying information within it, this will be deleted after 3 years.

**C.20 How will you make your research data available to others in line with: the University's, funding bodies' and publishers' policies on making the results of publically funded research publically available. Explain the extent to which anonymity will be maintained. (max 200 words) Refer to <http://ris.leeds.ac.uk/ConfidentialityAnonymisation> and <http://ris.leeds.ac.uk/ResearchDataManagement> for guidance.**

In line with ESRC funding requirements, my thesis will be made available on the University's Research Data Repository and UK data archive. I also intend to present my research at conferences, as well as write some short and accessible pieces of writing to reach the wider population, including an accessible blog post relating to the

findings to be published on the Down's Syndrome Association webpage. Care will be taken to ensure anonymity as far as possible. All participants will choose pseudonyms, and potential identity signifiers will be concealed to reduce the risk of identification.

**C.21 Will the research involve any of the following activities at any stage (including identification of potential research participants)?** (Tick as appropriate)

Examination of personal records by those who would not normally have access

Access to research data on individuals by people from outside the research team

Electronic surveys, please specify survey tool:  
\_\_\_\_\_ ([further guidance](#))

Other electronic transfer of data

Use of personal addresses, postcodes, faxes, e-mails or telephone numbers

Use of audio/ visual recording devices (NB this should usually be mentioned in the information for participants)

FLASH memory or other portable storage devices

Storage of personal data on, or including, any of the following:

[University approved](#) cloud computing services

Other cloud computing services

Manual files

Private company computers

Laptop computers

Home or other personal computers (not recommended; data should be stored on a University of Leeds server such as your M: or N: drive where it is secure and backed up regularly:

<http://ris.leeds.ac.uk/ResearchDataManagement>.)

*Unclassified and Confidential University data must be kept on the University servers or in approved cloud services such as Office 365 (SharePoint or OneDrive). The N: Drive or Office 365 should be used for the storage of data that needs to be shared. If Highly Confidential information is kept in these shared storage areas it must be encrypted. Highly Confidential data that is not to be shared should be kept on the M: Drive. The use of non-University approved cloud services for the storage of any University data, including that which is unclassified, is forbidden without formal approval from IT. Further guidance is available via <http://ris.leeds.ac.uk/ResearchDataManagement>.*

**C.22 How do you intend to share the research data? (Indicate with an 'X') Refer to <http://library.leeds.ac.uk/research-data-deposit> for guidance.**

Exporting data outside the European Union

Sharing data with other organisations

Publication of direct quotations from respondents

Publication of data that might allow identification of individuals to be identified

Submitting to a journal to support a publication

Depositing in a self-archiving system or an institutional repository

Dissemination via a project or institutional website

Informal peer-to-peer exchange

Depositing in a specialist data centre or archive

Other, please state: \_\_\_\_\_

No plans to report or disseminate the data

**C.23 How do you intend to report and disseminate the results of the study?**  
(Indicate with an 'X') Refer to <http://ris.leeds.ac.uk/ResearchDissemination> and <http://ris.leeds.ac.uk/Publication> for guidance.

- Conference presentation
- Peer reviewed journals
- Publication as an eThesis in the Institutional repository
- Publication on website
- Other publication or report, please state:  
\_\_\_\_\_

Submission to regulatory authorities

Other, please state:

I intend to share the findings of the research with the Down's Syndrome Association which may then be published on their official website.

No plans to report or disseminate the results

**C.24 For how long will data from the study be stored? Please explain why this length of time has been chosen.**<sup>38</sup> Refer to the [RCUK Common Principles on Data Policy](#) and [http://ris.leeds.ac.uk/info/71/good\\_research\\_practice/106/research\\_data\\_guidance/5](http://ris.leeds.ac.uk/info/71/good_research_practice/106/research_data_guidance/5).

**Students:** *It would be reasonable to retain data for at least 2 years after publication or three years after the end of data collection, whichever is longer.*

\_\_\_\_\_3\_\_\_ years, \_\_\_\_\_0\_\_\_ months

#### CONFLICTS OF INTEREST

**C.25 Will any of the researchers or their institutions receive any other benefits or incentives for taking part in this research over and above normal salary or the costs of undertaking the research?**<sup>39</sup>

Yes     No

**If yes, indicate how much and on what basis this has been decided**

\_\_\_\_\_  
\_\_\_\_\_

**C.26 Is there scope for any other conflict of interest?**<sup>40</sup> For example, could the research findings affect the any ongoing relationship between any of the individuals or organisations involved and the researcher(s)? Will the research funder have control of publication of research findings? Refer to

<http://ris.leeds.ac.uk/ConflictsOfInterest>.

Yes  No

**If so, please describe this potential conflict of interest, and outline what measures will be taken to address any ethical issues that might arise from the research.**

**C.27 Does the research involve external funding?** (Tick as appropriate)

Yes  No **If yes, what is the source of this funding?**

*NB: If this research will be financially supported by the US Department of Health and Human Services or any of its divisions, agencies or programmes please ensure the additional funder requirements are complied with. Further guidance is available at <http://ris.leeds.ac.uk/FWAcompliance> and you may also contact your [FRIO](#) for advice.*

## **PART D: Declarations**

### **Declaration by Principal Investigators**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the University's ethical and health & safety guidelines, and the ethical principles underlying good practice guidelines appropriate to my discipline.
3. If the research is approved I undertake to adhere to the study protocol, the terms of this application and any conditions set out by the Research Ethics Committee (REC).
4. I undertake to seek an ethical opinion from the REC before implementing substantial amendments to the protocol.
5. I undertake to submit progress reports if required.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the University's Data Protection Controller (further information available via <http://ris.leeds.ac.uk/ResearchDataManagement>).
7. I understand that research records/ data may be subject to inspection for audit purposes if required in future.

8. I understand that personal data about me as a researcher in this application will be held by the relevant RECs and that this will be managed according to the principles established in the Data Protection Act.
9. I understand that the REC may choose to audit this project at any point after approval.

**Sharing information for training purposes:** *Optional – please tick as appropriate:*

I would be content for members of other Research Ethics Committees to have access to the information in the application in confidence for training purposes. All personal identifiers and references to researchers, funders and research units would be removed.

**Principal Investigator:**



Signature of Principal Investigator: .....

(This needs to be an actual signature rather than just typed. Electronic signatures are acceptable)

Print name: ..Amy Redhead..... Date: (dd/mm/yyyy):  
.....21/09/22.....

**Supervisor of student research:**

**I have read, edited and agree with the form above.**



Supervisor's signature:

(This needs to be an actual signature rather than just typed. Electronic signatures are acceptable)

Print name: .....Prof. Angharad Beckett..... Date:  
(dd/mm/yyyy): 15/12/21 .....

Please submit your form by email to the [FREC or School REC's mailbox](#).

**Remember to include any supporting material** such as your participant information sheet, consent form, interview questions and recruitment material with your application.