Who’s Story is it Anyway?

Some considerations on disability from an aesthetic and narrative perspective of lived experience.

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Abstract

This PaR aims to use film-making and theoretical materials to explore the persistent practical problems of social injustices and inequalities disabled people face in society today. In accounting for prejudices against those with atypical bodies and/or minds, disability is taken up as a core concept in society, that treats it as a symbol for how being human inevitably means embracing debility, dependency and pain.

I examine how this projection upon disabled people is predominantly denied. How, in the failure to acknowledge the symbolic charge they carry on behalf of the whole of society, disabled people are rendered marginal. Their words carry less credibility than those of more powerful agents, and their knowledge is not integrated into shared epistemological resources, which exclusion perpetuates the prejudices they face. Two of the films submitted are exposés of injustices disabled people experience. One tackles the system of mental health; the other, government benefits provision. These injustices are explicitly intertwined with epistemic oppression.

The impaired body (taken to include the mind), lies at the heart of the disabled lived experience, but is displaced in critical disability studies. This shortcoming is traced to a social constructivism that prioritises language and representation over the lived reality of bodily impairment. This exclusion, within theory, risks denying disabled people's agency, leaving their representation to be undertaken by the non-disabled, with a consequent neglect to combat the negative aesthetic judgements that inform prejudices against disabled people, and lead them to be targeted for unfair treatment and, sometimes, hate crimes and violence, a subject another of the films investigates.

The idea of disability as central to social practices generally is examined in a film about art and impaired vision, where the manifestly extensive contribution of disability and disabled artists is recorded.

Disabled people, by claiming agency and owning their own narratives, are able to show different representations of disability (and of humanity), that are not derogatory or dehumanising. The work specifically made for this PaR - the ‘Untitled’ film - seeks to reclaim the silence surrounding disability, and exemplifies the recommendations made in the text: that disabled people's perspectives be made room for. These narratives are inevitably also critiques of unacknowledged ableism, which makes them subversive.

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List of Figures:

Table of Contents

INTRODUCTION

As I sit here in this dun-coloured hotel room in Cardiff in the process of making yet another current affairs documentary for television, I am thinking and mulling over my six

Figure one. That hotel room.

decades of disabled life - as a physically disabled boy then man, as a person who never seemed to fit into, or make sense of, the world. The revelation, in 2018, that I am also autistic and have ADHD (via a diagnosis from the Maudsley Hospital) shone a new light on many previously confused thoughts and feelings - the optics had changed and the topsy turvy nature of my existence came into focus. To be sure it was not a particularly pleasant kind of picture. I have a constant feeling of being separate from, and different to, other people; despite any intellectual ability and logical thought I may have, I don't feel part of humanity. It's like living in an invisible glass jar which separates me away from other people.

This is now comprehensible because this feeling is a neurological difference and not the failure it had always been presented to me as (although it encompasses failure as well). My journey to knowing and understanding my impairments has been full of obstacles set up by both a structurally ableist system determined to minimise all disability in very unhelpful ways, and an early family environment not conducive to acknowledging, let alone speaking about, disability at all. This work is a kind of exorcism - an attempt to remove the demons of dysfunction and replace them with understandable reasons for the events, actions and feelings which have bedevilled my life. It is also a work of reflection on twenty years of practice of making films about and around the subject of disability, and on writing and making artworks informed by my own disabled state. It is a kind of 'total' - of six decades of lived experience as a multiply disabled man encompassing childhood abuse and trauma, multiple spells in both orthopaedic and mental hospitals, bullying, beatings, substance abuse, physical incompetence, unrecognised autism and so on and so forth.

It is also a critical examination of society's attitudes towards disability. Society has shifted considerably over my lifetime and the one thing I am sure of is that we are now all commodities, products which are bought and sold. Individualisation has replaced many notions of collectivism, and the term ‘community’ has become corporate, to be leveraged for profit and influence (for more on this issue, see Hall's 2023 critical examination of the idea that 'everything' has become commoditized). Similarly Gruson-Wood argues 'The normalization of contemporary culture inverts democratic citizenship to simulacratic citizenship, reduces the phenomenology of existence, and shrinks modes of doing and feeling into the sum total of replication (of ableist embodiment) and consumption (of internalizing, purchasing, and enforcing ableist embodiment)...' [Gruson-Wood 2009, p. 20]). I have watched, lived, and felt, as disability has become a fungible asset and impairment viewed as a thing to ‘get over ’or conquer, or occasionally as something for an individual or, more often, a charitable organisation, to celebrate or monetise (see Oliver's 2017 trenchant critique of charities and other bodies, which he characterises as 'parasites' and 'bleeding hearts' [n.p.]). It has taken many years of hard collective effort to place the disabled anywhere near an equitable position in society and we are still not there. As someone who has carried out their education in a backwards fashion – leaving school aged 16 with a handful of nothing and now jumping into the deep end of a PhD - it is disturbing that I have, during the time of making this Practice as Research dissertation, run up against examples of oversight and exclusion in both academic perceptions and in theories of disability (which I examine in chapters two and three). This was a surprise, but on reflection it shows that a full understanding of disability has a long way to go. The disabled person is still very much ‘other’.

This intense period of study has shown me that I can think of my work around disability before undertaking this PhD as a form of ‘research’. The deep investigative research I did in making my commercial documentary work was, in many ways, a preparation for this very undertaking. In it I examined the poor treatment and status of disabled people in our society and disabled people’s sense of isolation and separateness, and the deep and hidden feeling of not belonging to, or being part of, a society geared for the most part to an able world. The struggles of activists to right and to change this have been long, tumultuous, and to some extent successful. Since the disability rights movement began in the 1970s, many oppressive barriers we used to face have been removed, making social participation possible, and Oliver's formulation of the Social Model (which I discuss in chapters one and two) has shown our private troubles with impairments are also public issues of disability. One can plot a change in the position of disability in society, at least in a superficial sense, but the fear of debility still dominates approaches and attitudes towards those of us with impairments.

The persistence of this problem informs the dissertation as a whole. I have been perplexed by the knowledge that, although there has been a great deal of social and political progress, there are still widespread prejudices towards disabled people, apparent in how we are currently treated in society, that harm us in various ways. This is examined in more detail in chapters two and three in particular (and for a scholarly overview of how UK government policies affect us, see Ryan 2019). At the same time, I have also developed my own understanding of disability, from my lived experience as a disabled person and professional, which has given me the wherewithal to critically engage with this perplexity at an academic level. This has brought me to the undertaking this PaR degree represents.

Theoretical framework

On the one hand, the dissertation is a critical examination of disability as disadvantage. In this sense, it is pessimistic and bleak because it is an exposition of practical problems of injustice and inequality as I ponder the degree to which some of these problems persist. In conjunction with this, it is also a search for a clearer and deeper conceptual understanding of disability so that I can articulate and extend my own developing perspectives. As such, academic clarity over the thesis emerged relatively late - once, as a result of my research and the act of writing itself, I had better understood my own subject matter. The theoretical materials examined here are treated as a means to that better understanding of the
social and lived experience of disability in an ableist society and I have taken an experimental approach in my use of them.

The other side of this is an evaluation of the optimism suggested by a whole range of historical achievements, especially since the 1970s, through disability action, including within the academy (although the degree to which the founding of disability studies as an academic discipline has been positive is disputed by Shakespeare [see in particular, chapter one of his 2014a book]). Disabled people organised themselves, founded UPIAS and used Oliver's social model to argue that disability was not due to medical impairments so much as to social barriers against them. Their campaigns led to the 1995 Disability Discrimination Act as well as the 2010 Equality Act, which acts made it illegal to discriminate against disabled people, with variable success. The valuable social and political space for disabled people is strengthened by these achievements. One important expression of this strengthening is to be found in cultural productions such as writing, film, performance and so forth, that represent disabled 'agency' (giving more room for disabled people's perspectives).

As well as permitting alternative, disability-led, representations of disability more generally, the agency of disabled people - given the context of disability as disadvantage - may also undergird the notion of disability as a 'subversive' value[1] (Siebers 2008 & 2010). Siebers claims that disability is subversive because all 'social and political categories of oppression', such as racism, sexism, homophobia etc., 'are informed by the idea of bodily and mental inferiority, i.e., disability' (Grue 2011, p. 240) so that, should disability be the lens through which we examine these other categories, they would be thoroughly destabilised.

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[1] In chapter four I examine a film I made [The Last American Freak Show] in 2008. It is an example of this focus on the agency of disabled people. In it the film participants subverted, by 'reclaiming', the idea of the freak show - but in what senses this all counts as reasons for optimism is very much in question.

Siebers' claims are an example of optimism that I can interrogate and, in so doing, may help me to develop conceptual clarity. Across his two books *Disability Theory* (2008) and *Disability Aesthetics* (2010), he proposes that disability should be made 'an inevitable ...category' (Grue 2011, p. 240); that it holds the promise of transforming our understanding of human variation and of what constitutes beauty. Nevertheless, I am pessimistic because his argument, while suggestive of optimism, at the same time seems incomplete and, in practical terms, unrealised. One imagines Siebers would have developed his theories further, had it not been for his untimely death in 2015.

Siebers' theoretical stance can be located within critical disability studies. This branch of disability studies involves examining the political role of knowledge production and cultural representations in maintaining ableism. The work of many critical disability studies scholars (for example, Rosemarie Garland Thomson, Shelley Tremain, Dan Goodley, Robert McRuer) are influenced by their engagement with the theories of post-structuralists such as Judith Butler (1993) and Michel Foucault (1995, 1980), but Siebers is very critical of the influence of these post-structuralists, specifically in how the impaired body is treated in critical disability scholars' work (see for example, his 2001 paper, which I examine below in chapter two, in which he advocates for a 'new realism'). These scholars tend towards a social constructivism that risks making their ideas irrelevant, sometimes patronising, and occasionally offensive, by leaving out the lived experiences of disabled people, especially the reality of the impaired body, because they hold that 'truth' and/or 'reality' can only be criticised as ideological products and not accepted as true or real. Siebers' critique of this tendency and his attempt to restore the impaired body to theoretical significance makes his work intriguing, as it is able to interrogate the surface-level ideological dominance of ableism but at the same time, to take into consideration what disability is, in terms of lived experience in particular, by acknowledging the impaired body/mind.

Given how he believes disability to be a subversive value, Siebers' claim that 'disability ...(is) a significant value in itself worthy of future development' (Siebers 2006, p. 64) can be interpreted as a twofold idea. In the first sense, we can say that Siebers views disability as 'itself', a lived reality for people with impairments (and also a manifestation of human variation); in the second sense, disability is a central category that stands for the precariousness of the human condition (and thus, that is relevant to everyone). Here, disabled people carry a symbolic weight, as they come to signify what it means to be fully human. In this sense, disability can be used as a key idea in relation to other marginal identities, because these are founded on the idea that a person is in some sense, biologically or physically inferior (i.e. disabled). Because of this, disability should be given prime place in our theorising about society (and about aesthetics[2]) as it has positive transformative potential - Siebers reckons perspectives upon human diversity and all artistic productions will be radically changed for the better through a recognition/application of disability as this central category. He also suggests that the disabled perspective is the most valuable one from which to make social, political and cultural critiques, which one can see follows from considering disability as such a core value.

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[2] Aesthetics is an important field in critical theory generally, as it is regarded as a possible location for a critique of an ideologically dominated social world.

For Grue (2011), Siebers' claims are afflicted by the problem of his '...willed refusal... to acknowledge that disability, as a category, can meaningfully encompass only the kind of variation that implies the lack of certain faculties or functions: Disability is disadvantage' (Grue 2011, p. 240). Siebers views disability as (mere) difference, which seems neutral of him. One wonders whether this problem makes his argument less realisable. I follow Siebers in interpreting disability as a symbol of the fully human body, reminding us all of our human frailty, dependence and mortality; and this is one of the reasons the dichotomy of impairment/disability cannot be left unchallenged. This distinction was first proposed in Oliver's social model, as a way to challenge the idea that disability was purely a question of individual pathology (impairment), and it served to focus attention on social structures that oppress disabled people instead (disability). Critical disability theorists sought to complicate this binary dichotomy but, in so doing, they deny the reality of the lived impaired body. I agree with Siebers that the body is a real lived experience, not just an ideological social construction. As Siebers also says: disability is itself. This twofold perspective is critical because disabled people live with the various ways ableist society needs to deny this aspect of its own humanity and consequently, to ostracise those of us who are disabled. In relation to this denial, it is relevant to note that Siebers also argues that the centrality of disability is unacknowledged.

If disability is a central concept that, when used the right way, disrupts and destabilises both how disability is regarded but also how all other minority and marginalised identities that are based on notions of bodily and/or mental disability of some kind are perceived, then it is not surprising to encounter a resistance against shaking things up. Positing the idea of disability as a central concept seems optimistic. Rather than being faced with having to deal with each problem disabled people encounter on a piecemeal basis (which suggests there will never be an end to our problems with ableism), there is a promise of sweeping it all away through some kind of application of the idea of disability as a singularly critical and significant value. Social and political change has occurred, brought about by disability activists and their allies. So why are there still so many problems? In what way has all this social and political change failed to make more of a difference? What change needs to happen for these problems to go away? Is there another problem that keeps these other problems in place? A possible avenue to explore is this lack of acknowledgement of what disability symbolises.

In chapter one I discuss my own increasingly critical awareness of my social and cultural situation as a disabled person. Being able to come to such knowledge about myself and the world I am in, requires me to have access to collective epistemological resources - 'For a person to perceive, describe, account for, and evaluate experience, she needs a set of epistemic tools...' (Scully 2018, p. 107) including language and concepts that come from the 'community's share epistemic resources' (ibid.). To formulate demands for social and political change requires this too - one has to be able to articulate what the problem is, what needs to be done to solve the problem, and so forth. As I was disabled from a very early age (six months old), it took a long time for me to gain critical awareness of my situation as a disabled person because I'd been brought up to be silent about my disability. One of the obstacles my silence created was my own exclusion from the shared, collective epistemological resources I needed. Gaining a more critical awareness has helped me a great deal at the personal level, but I have also become more critically aware that problems for disabled people persist and there is no reason to believe these problems will not worsen either.

Proponents of the concept of epistemic injustice and oppression, developed in Anglo-American epistemological philosophy (a field of study well beyond the scope of this dissertation), hold that power differentials mean that marginal groups are excluded from collective epistemic resources (Fricker 2006). In some cases (that go under the rubric of testimonial injustice), marginal groups have less credibility than the powerful; in other cases (which the concept hermeneutical injustice encompasses), they are unable to share their knowledge or to use shared knowledge (sometimes even to the degree of formulating their knowledge into concepts, words and narratives) because these are resources from the collective which does not include them. There is the further case of contributory injustice, which describes a situation where, even with the 'relevant resources... that have been developed and used by the marginalised group', these are not taken up by the dominant group (Miller Tate 2019, p. 97). Epistemological resilience refers to how, even when social and political solutions are found that can solve epistemic injustices, an 'epistemic landscape of oppression' persists (Dotson 2014, p. 116). This epistemological set of problems contributes to the maintaining and smoothing over of prejudicial social practices. In this dissertation I posit that Siebers' claim - that disability's centrality is not recognised, in fact, is actively denied (both in society as such as well as in aesthetics) - might be the key element of an 'epistemic landscape of oppression', and I attempt to evaluate if it might be adequate for describing the persistence of problems disabled people face.

In bringing together Siebers' optimistic claims and Dotson's 'epistemic landscape of oppression', and in examining instances of epistemic injustice as well as the denial of the contribution disabled people make, in my films, I hope to gain a clearer understanding about the position of disabled people in the current social and political situation, and to evaluate what difference the recognition of disability's importance can make.

Structure of this work

This exploration takes place across five films and four chapters. In **chapter one** I situate myself - as a disabled person and film-maker - so as to align my personal context with the thesis. Here I also summarise the films I am submitting as part of my PaR degree, and I cross-reference them with the text. In **chapter two** I discuss the social model of disability, how it re-orders cause and effect but leaves a social constructivist problem - the separation of impairment from disability. I argue that it is by bringing the two sides of this dichotomy together and restoring the body and lived experience to theoretical dominance as the key perspective on disability, that we can usefully challenge societal prejudices. **Chapter three** builds on the idea of embodiment in how it outlines an embodied aesthetics and an everyday aesthetics. This enables me to critically discuss not only the importance of aesthetics in relation to disabled people, but also to examine a range of practical problems of injustice and inequality disabled people currently face. In **chapter four**, I make a 'close viewing' of three films on disability. In this chapter I explore the agency of disabled people, returning to Siebers' claims, and I ask whether disability as a critical value provides a 'privileged epistemic' of disability, and what such a perspective - that is very much concerned with disabled people's agency - can achieve. In viewing the films with this idea in mind, I ask whether some of the social problems of injustice, inequality and general discrimination disabled people face can be ameliorated through some kind of engagement with such a perspective. In both **chapters three** and **four**, I locate a problem with Siebers' exposition of aesthetics where he neglects to consider the difference between art and the everyday. In art and other cultural productions the unusual and disturbing is expected, but in the everyday, what is considered 'normal' is also deemed 'right'. It is possible, as Gruson-Wood argues, that art does not have transformative capabilities at all, and acts instead as a 'safety net' in which there can be a 'virtual escape' from the 'humdrum normalization of western culture' (Gruson-Wood 2009, p. 1).

Chapter one - Practice makes imperfect…

Introduction

In this chapter I examine how I came to my present understanding of my own disability and I introduce the reader to the films I am submitting as part of my PaR degree.

My personal and professional trajectory as a disabled film-maker run together since the time when I started to develop a more political consciousness of myself as a disabled person in the 2000s. I had been brought up during the 1960s & 1970s, with no special treatment; my visible impairment was not permitted to be used as an explanation, let alone an excuse, for any difficulties or problems I experienced - unsurprisingly then, this lack of engagement with my disabilities continued well into my adult life. My early personal and professional life seemed to be quite separate from my present life as a documentary film- maker although, with the benefit of hindsight, I can see that both my impairment - in terms of my limited physical ability - and my disability - in how society viewed and positioned me - informed my early life in a muted, muffled way. I had always managed to get by, albeit with very little money, despite my visible impairment (I have a withered arm due to childhood polio), and my autism and ADHD had not yet been diagnosed (and at that time, in the early 1960s, medical understanding of these conditions were still poorly developed). Once I started to make films, this began to change. I was surrounded by disabled people in both my personal and professional life, and, through many friendships and intense discussions, I became acquainted with an array of perspectives on disability and on myself as a disabled person. Furthermore, I received a late-adult diagnosis (of autism and ADHD) which provided me with a great deal of explanatory power when thinking about my life.

In the first part of this chapter, I examine all this, sometimes using auto-ethnography, to highlight the problem of silence over disability, and my need to find ways of thinking better, more clearly and with more balance, about disability. I use literature about disability identity and epistemic injustice as a way to frame my increasing awareness of disability issues. In chapter two I return to some of these ideas as I explore disability studies and the dichotomy of impairment and disability.

Cultural representations of disability are pertinent to me both as a disabled person and as a film-maker working to make representations of disabled people in films about disability. In chapter three I examine aesthetics in more depth and seek to show some of the repercussions of cultural representations of disability for disabled people, whilst in chapter four I examine three films about disabled people (one of which I made), in order to more directly engage with film and cultural representations. However, in part two of this chapter I consider the issue of representativeness, exploring the question of who is entitled to represent disabled people and who disabled people consider able to speak of disability in a way that is truthful and relevant.

As I am looking into my own experiences of disability, a subjective and qualitative approach makes sense and I have adopted an interpretive and exploratory attitude here. Studies of disability have formulated various 'models' to discuss disability, both within the academy and in society more generally. For example, the 'medical model' approached disability as a matter confined solely to the impaired individual and it was medical authority that defined disability. This model is in contrast to the 'social model' (see Oliver 1990, see also UPIAS 1976 [Priestley, Finkelstein & Davis 1987] for discussions about the social definition of disability), which makes a dichotomy between disability and impairment, locating disability in society, rather than in the private sphere of the impaired individual. This model, drawing on Marxist perspectives of historical materialism, focused on barriers in society that resulted in the exclusion and oppression of disabled people. However, this focus led to there being an inability to account for the important emotional and psychological work that takes place in the private sphere but that helps to sustain the public sphere's barriers (see Watermeyer 2008, 2009, 2014, 2016). This unacknowledged cross-over also means the public relevance of the impaired body was denied. Embodiment helps us to see how culture, rather than simply economic and other 'structural' matters, plays a significant part in how disabled people experience their personal and social worlds. Informing this is the idea that, while social attitudes may express a devaluation of disabled people, it is at the aesthetic level that disabled people are identified and imagined in this degrading way. This is a topic I examine in more depth in chapter three in particular.

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Part one: Is a political disability identity valuable?

West Bank, December 1987. The dusty street bakes in the sun. The clouds of tear gas waft, hanging in the air where the gas canisters land. There is no wind. I crouch behind a low wall, part of the veranda of a small colourfully painted house, and poke my head and camera above the wall to take pictures of teenagers, as they hurtle towards the heavily armed soldiers manning a crossroads about 200 meters further along the road. They have homemade slingshots and bright coloured scarves covering their faces to give some small protection from the CS gas. The main antidote to the gas is onions; they are cut in half and thrown down to the youngsters by women lining the roof tops; it is comical to see until I try one and realise how effective they are. I carry a couple in my camera bag and when the gas hits I bite hard into the onion and hold it in my mouth; it counters most of the effect of the gas although only for a short time; harsh burning in my throat and floods of tears from my eyes return if I do not get out of the cloud sharpish. But behind this wall I am away from the gas and have a good view of the soldiers, levelling their rubber bullet launchers at the teenagers who are pelting them with rocks.

My colleague, a Danish photographer, stands up and with a long black telephoto lens starts clicking away. The lens catches the sun and flashes bright. I see the soldiers at the crossroads catching sight of the flash and, in alarm, spreading out and crouching down. We are in a zone where the media is forbidden to go and we had sneaked in with the help of a local journalist.

I call to my friend. 'What the fuck are you doing, get down.'

He looks at me puzzled and carries on snapping.

'They think your camera’s a gun – get the fuck down.'

This stops him. I can see his brain trying to process the information as small puffs of dust start to lift from the ground and the wall around us. A whining noise passes my ear like an angry mosquito. My friend drops behind the wall. The soldiers have abandoned the rubber bullets and are firing. Shooting at us with live ammunition.

'We have to leave. Now.' And I scrabble along the floor of the veranda and through the open door of the house. The door is being held open by an elderly woman who beckons us to the back where she opens a window. We clamber through and start to run along an alleyway to… We have no idea...

Both of us scuttle along the alley-way and along a series of other identical alleys until we come to a dead end. The path abruptly stops at six-foot drop into a large pool of water at the edge of an open area. We have no idea how deep the water is, but as we consider our lack of options a dark green helicopter rises above the rooftops heading in our direction. We jump. The water is only a foot or so deep and, relieved, filled with adrenaline and anxiety, I start at full pelt across a dirty rubbish strewn football pitch towards the houses on the far side. The helicopter meanwhile has circled around and a man sitting next to a large machine gun is pointing straight at us. I have no idea why, but my friend stops and points his camera straight at the helicopter and takes a series of shots then continues running. We can hear approaching vehicles and the shouting of soldier’s voices.

As we make the far side of the football pitch a man dashes out of a house and waves us inside. In broken English he tells us to sit down and wait – he will arrange for us to get away. A woman brings us small glasses of tea as we sit there, trying to maintain a nonchalant manner. Soldiers run along the streets outside; we cannot understand them but figure they are looking for us. The elderly woman is joined by a younger woman who speaks some English and is curious as to why we have decided to leave Europe and voluntarily risk our lives just to take some photographs, which she was adamant would not make an iota of difference to the situation they were in. Her advice is for us to go home and photograph weddings. There is no humour in her tone. We are stupid adventurers. More tea, some biscuits. I feel very awkward; my friend, in his Scandi-accent English, explains that we are trying to illustrate the trials and tribulations of their lives. At this she chuckles and translates for the other woman who also lets out a wry laugh.

A car pulls up outside and the man reappears, tells us to leave now and fast, as there is a momentary lapse in the security at the end of the road and if we drive fast, we could be out of the camp and onto the relative safety of the main road. We gather our kit and peek out of the door. All clear. We dash for the car. The engine is running and, as my friend jumps into the driver's seat, I throw myself into the car via the open window. As we emerge onto the main road a helicopter rises above the rooftops right next to us but veers away in the opposite direction. We are out and on the main road. Safe.

Belfast, March 1988. The air vibrates with the rotating drone of helicopters overhead. They are constant, as one buzzes away another takes its place. They watch, directing blunt grey vehicles, their metal bodies encased in even more metal, protecting the bodies inside the metal boxes until it's deemed appropriate to release the incumbents. I am booked into the Europa Hotel, which has the ignominious mantle of being the most bombed hotel in Europe. At night, the whirring is accompanied by disembodied slashes of light; they beam down interrogating the ground below, sweeping back-and-forth till they pinpoint whatever it is they want and then the men from the vehicles stream along the street like dark green scuttling beetles to grab their target. Often as not they fail and find themselves inside a hail of bricks, bottles, and paving slabs; this would often be punctuated with gun fire from a sniper in a tower block or a hoodlum with a pistol down on the corner. Public buses are in flames, burning tyres let off a miasma of oily black smoke.

I have travelled here to cover the funerals of three IRA men killed by the SAS in Gibraltar. The funeral takes place in the Milltown Cemetery, just off the Falls Road. It is my first experience photographing the 'Troubles', which had been raging for 20 years by then. Of course, I had seen them on television, but walking into the reality was quite another thing. It was as surreal an experience as I had ever undergone. The funeral itself descends into a debacle of chaos and carnage when a man called Michael Stone attacks the mourners with hand grenades and a pistol, killing three and injuring sixty more. In the cemetery, as explosions and gunfire rocket around, it seems half the people run for cover while the other half charge the man with the weapons.

I just stand there and take as many photographs as I can; it is what I am there for - I am part of the media circus which has descended on Belfast to cover this event, and the predatory nature of my work is not lost on me, along with the shallowness of the justifications used to cover up this essentially voyeuristic activity I'm trying to make my profession. A strange dissonance is taking place in my brain: on the one hand, a cold professional joy the event has now become 'newsworthy' and I will able to sell my photographs (which I do, making the front page of The Observer); but at the same time, I have a feeling of horror at what is taking place all around me. The riots carry on for days, afterwards culminating in the execution of two British soldiers in nearby Casement Park. My film of this event is taken from me by ominous local men – who may or may not be IRA members. I make my way back to the hotel and, after phoning the paper to arrange pick up of my surviving film, I leave Belfast.

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In revisiting this early part of my practice with the benefit of hindsight, as well as a better understanding of my own impairments, I am led to a fresh interpretation of what I was attempting to achieve. I have used auto-ethnographic writing - a form of autobiography which explores the researcher's personal experience, and then connects the personal story to wider cultural, political, and social meanings and understandings (Maréchal 2010), as one way in which to elucidate and understand better these past experiences. Here I emphasise three themes - silence, resistance and disability identity - to help me structure and articulate how my practice has developed. Shakespeare (2014a) notes that some disabled people reject a disability identity, preferring to become assimilated to mainstream society instead. For me this is a complex proposition as I came to embrace a disability identity only after an *apparent* assimilation, one that involved internal and external silence and an unshaped, inarticulable resistance.

Silence & Resistance

'Silences exist in the historical record of the disability community. These silences are also evident within the everyday lived experiences of people with disabilities...' (Yoshida 2015, p. 433).

After Belfast it became harder for me to reconcile my profession with the brutal reality I was observing around me. I speculated that I should write as well as take photos, so that I could tell people about what I was witnessing in my work, but this was not allowed; in the strictly hierarchical world of the press, snappers, as we were derogatorily referred to, could not write; nobody did both. For us, only the image could 'speak'. But this silence was repeated by the fact of my presence, as an impaired person, in such settings. I was very uneasy about this but I did not have the right words to articulate what was wrong for me. It is only in retrospect that I can see why - I was there trying to forge a path considered unrealistic for anyone with a disability. I had a physical impairment, as well as undiagnosed autism. Nobody spoke with me about this - there was silence, mine and that of others in relation to my disability. It is a shame I did not have a mentor or someone, anyone, to help me see that my impairments were significant in what I was endeavouring to do - for example, there was no autofocus function, all cameras were manual and designed to be operated with two functioning hands, and I had to overcome difficult physical barriers in the handling of cameras and darkroom equipment. I wish there'd been someone to point out to me that I was a disabled person taking on a macho world that makes no room for me or for others like me.

In my profession I took many risks because I felt I had to prove myself, that I might never be good enough and that I could not afford to put a foot wrong. One might say I had become assimilated to mainstream society - but I came to realise this was in a problematic way. I did not feel I was anywhere near on equal terms with people around me; I did not feel validated, empowered or supported - rather, I felt ignored. To a degree this was what came with the job. As a freelance photographer I was not allowed to write about the truth of what I witnessed, having to let absent journalists write the story I'd been present at. But the silence I carried within added to the feeling of being insignificant and unimportant. My undiagnosed autism meant I became obsessed with my work, I had tunnel vision and I did not connect my disability with my obsession to be a photojournalist.

I'd been brought up to ignore my difference to others, despite my visible impairment. I'd received no special treatment even though my parents had problems with me because of my impairment. I had been continuously bullied at school for being a cripple and fought back as best I could, mostly by being absent for long periods. When the time came to take exams, the school would not enter me for any. So, I entered myself and managed to walk away with a handful of certificates – mainly just to spite the school. My resistance against and challenge to the established order was not fully conscious - at the time I was unaware this was what I was like. I did not have the words. This attitude was reinforced when I attended a Further Education college in London, to undertake an Art Foundation course. During my second month there I was called into the office by the head of the course, who told me I was banned from using all the equipment in the 3D and Ceramics studios. Together with my course tutor, he also me told that, had the college authorities known beforehand that I was disabled, they would not have accepted me onto the course in the first place. This was baldly stated in a way that could never happen now. I was an insurance risk at the very least. I managed to negotiate permission to use the darkroom, as I really only wanted to paint and take photographs. But my acquiescence now astonishes me, I was silent and did not protest or make a fuss, it never occurred to me to do so. I could not articulate - to myself or to others - how these people were using their prejudices about disability against me, nor anything of the complex way this made me feel. I struggled with the education system and with social interactions in general. This became easier to understand much later, when I was diagnosed as autistic. But at the same time, I can also see that I was fuelled by an angry, inchoate resistance; I expected no support from authority figures; I could sense they were against me, that I needed to make my own way in the world, that authority was something to be resisted.

Identity

These memories help me to untangle my past life and they form part, in a convoluted way, of the reasons that led to me to undertake this study. I think it was important for me to develop a consciousness of the role my impairments played in my personal and social/professional disablement, so that I could get beyond this silence and resistance. As noted above, for some disabled people, assimilation is precisely what they want and they reject a disabled identity; similarly, many disabled people identify as disabled in fluid, strategic ways, rather than allowing 'their health condition, or responses to it, to dominate their lives' (Shakespeare 2014a, p. 99). But, for me, assimilation was only at the surface level, sustained by silence, and I needed to understand this properly.

Watermeyer (2022, 2017, 2014) has adapted Cheng's concept of 'racial melancholia' to explain this phenomenon. He argues that disabled people rightly resist demeaning cultural representations of themselves as tragic figures but that, in doing so, they become alienated from themselves because they need to be able to grieve for their losses - which is what *any* human needs to be able to do. Disabled people though, find themselves in a no-win situation because they are 'positioned in ...(a) regime of failures' (Watermeyer 2017, n.p.). An example of this 'regime' is examined by Watermeyer in his 2014 paper, where he tells us about how charitable organisations rely on portrayals of 'disabled people as infantile, dependent and frail' in order to obtain donations, and he notes Longmore's 1997 critique of the US disability telethon that reflects 'the "conspicuous consumption" of the world's richest economy (that) requires rituals of equally "conspicuous benevolence", transforming the norm of social hostility towards disabled people into a spectacle of public virtue' (Watermeyer 2014, p. 101). Here, those who make donations can feel 'both powerful and virtuous' and at the same time, the telethon can generate '...a denial of the uncomfortable reality of a society shot through with injustice' (ibid.). Such constraining burdens result in 'block(ing) the conscious expression of both group-based and personal griefs associated with life in a ...disablist society' (Watermeyer 2017, n.p.).

It is important to disentangle this in order to heal. Shakespeare mentions Paulo Freire's concept of 'conscientisation', which is the act of becoming critically aware of one's cultural and social reality. In the case of disability this involves becoming conscious of, *inter alia*, these unhealthy regimes of failure that act as traps, imposed upon disabled people. In becoming critically aware of these, disabled people can also become more able to free themselves '... to name disability as social oppression (which naming) is not the defeated wailings of victims, but the clarion call of social change agents' (Charlton 1998, in Shakespeare 2014a, p. 93).

This problem of silence and melancholia that disabled people face can be further analysed using the concept of 'hermeneutical injustice', a form of epistemic injustice, a concept that has been much discussed in philosophy by Fricker and others. This concept refers to how a 'significant area of one's social experience (is)... obscured from collective understanding owing to a structural prejudice in the collective hermeneutical resource' (Fricker 2006, p. 100, in Scully 2018, p.108). Power differentials result in marginal groups' knowledge being left out of the shared epistemic resources, which is the source of language and concepts I would need to be able to break the silence in and around me, and to become more critically aware of my social and cultural situation as a disabled person. For me to be able to articulate what it means to be a disabled person in an ableist society, I needed to have the right epistemic resources. Such resources are 'internalized early in life, but they originate externally in the shared community knowledge that reflects... the collective (which)... is inevitably skewed by power relations' (ibid. p. 109). As '... privileged groups ...have understandings of *their* experiences readily to hand, because their lives are socially normative... the marginalization of other social groups means that the concepts, vocabulary, and narratives that are particularly salient to making sense of *their* lives are pushed aside' (ibid. p. 109). If the knowledge disabled people have about their own embodied, social and cultural lived experiences is excluded from the collective, due to prejudice against them, then, as well as silence prevailing in their lives, disability is left to the non-disabled to define, explain and represent so that such epistemic resources that *do* exist perpetuate the subordination of disabled people in relation to the non-disabled. (The concept of epistemic injustice is particularly pertinent in this thesis and I return to it in subsequent sections and chapters)[3].

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[3] For example, below I describe how, as well as 'hermeneutical injustice', the concept of epistemic injustice encompasses 'testimonial injustice', which is the situation in which a (disabled) person's statements are treated as less credible than those of other, more powerful parties. Again, in chapter four I examine hermeneutical injustice, in relation to documentary films about disability.

Looking at the social make up of the UK in the late 1970s and through the 1980s, it is not surprising I had not heard of, for example, the Disability Action Network or any other effective disability rights activism. There was no Disability Discrimination Act or Equality Act and I had not come across the 'social model', which existed as an academic theory but had not filtered through to me[4]. It was only when I started working as a documentary maker that I began to read about these important developments and networks/organisations, and to evaluate and recognise the impact that my disabilities had taken on my life. The early noughties were a moment in time when disablement was beginning to be accepted as a legitimate way of being and I found myself valued by others as I created work about being disabled and about what that meant for us and the rest of society.

To seek assimilation thus needs to be qualified by the question: what kind of assimilation? If it is one that involves blinding oneself to problems one really ought to be aware of and deal with, then that is problematic. Whilst a disabled identity might not be all about pride and celebration, it might not always be healthy to refuse to identify with a label just because it is socially stigmatised. After all, the values of mainstream society leave a lot to be desired. One social change Siebers advocated for was that disability's 'strange symbolism' (Siebers 2008, p. 6) be exposed and recognised, and he proposes 'purposefully interpreting disability as itself' (ibid.) as a means to achieve this. Becoming critically conscious of disability as an identity helped me to understand better the bullying and other forms of discrimination I had experienced, and thus to understand the consequences of this for me - both internally (in relation to my feelings of

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[4] An example of how academic theories can fail to reach beyond the academy is provided by Bone, when she notes how the aims of crip theory - to be politically generative and to challenge the norm - remain unrealised even to the extent of not reaching the wider activist movement (Bone 2017, p. 1310).

anger, shame etc.) and socially (lack of social support, lack of diagnosis re: autism etc.). Finding out about disability activism and disability studies enabled me to feel less isolated, to experience solidarity, and to create work that was no longer wholly from an alienated place of disconnection but instead that was more meaningful to me. I am grateful that there is a political place for disabled people, that there have been and are theorists and activists who keep this place open so that others like me may find it and be able to use it to improve their lives. I hope to contribute to defending that place.

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Part two - Practice

I have included films I have made for commercial broadcast during this period of study as 'my practice'. These are works I have originated, developed, and had commissioned. In a symbiotic relationship, they are directly influenced by my study as well as directly informing it[5]. They are examples of both my practice and my research and below I discuss how they contribute to this degree. Each of these works were very difficult to get commissioned and I struggled to retain control of the narrative in each case (whilst remaining cognisant of the diktats of mainstream broadcasting). They represent my various skill sets and my depth of understanding of the situation of the disabled. In the text I indicate when the examiners should watch these films. Alongside this written work and these films, I have also made a non-commercial film

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[5] Trimingham characterises this two-way relationship as a kind of 'hermeneutical spiral', capturing how, over time, one accumulates knowledge by to'ing and fro'ing between practice and theoretical materials, so that, as one 'constantly returns to our original point of entry' (Trimingham 2002, p. 56), one brings our renewed understandings. This affects the work as a whole, which can thus develop in such a way as to bring the more chaotic aspects of creative practice together with the theoretical materials one uses.

specifically for this PhD. This is less accessible than the commercial work and relates to the writing, sometimes directly and, more often, obliquely. It is also worth pointing out that I maintain a practice as an artist alongside my film-making, and this, like all my work, is intertwined with my research. I provide examples of this, along with links to my websites where they are exhibited, in Appendix one.

As a working documentary filmmaker there are two strands to my job. There is the work-for-hire – when a production company or broadcaster ask me to produce a film they have already had commissioned. These jobs I do infrequently and they are not included in this PaR. The other and more predominant kind of work is where I pitch an idea I have originated and developed myself which, if it gets commissioned, I then make. My roles are that of producer, director, and sometimes on-screen presenter. Some of these films are included in my submission as part of my practice. Alongside the original research and development there is a high level of what is called in broadcasting 'compliance', which is the equivalent to ethics committees in the academy, and involves legal and duty of care protocols and permissions. For example, all facts included in the film must have two discrete references attached to them. Television (especially current affairs) is subject to a statutory code of conduct managed by Ofcom[6]. There are many other films which I have made (including some that I refer to in this dissertation), but I do not submit them specifically for the PaR, as they were made prior to the start date of this degree. Although they show my thinking and progression, they are not as 'worked out 'or as pointedly related to this text as the films I am submitting.

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[6] see Ofcom's broadcasting code at: https://www.ofcom.org.uk/tv-radio-and-on-demand/broadcast-codes/broadcast-code

Representation

I have discussed some of the effects of my impairments - a withered left arm and autism & ADHD - elsewhere in the text, but here I provide a brief outline, in order to explain how I experience my impairments in everyday life. In relation to the first, my limb difference was caused by contracting Poliomyelitis at six months old. This has meant I have been unable to use my left arm since childhood, with all the commensurate difficulties contained therein. Over the years I have developed a great deal of back pain because of the weakness caused by polio and how crooked my body has become as a result of this impairment. There has also been a social stigma attached to my deformity. This stigma was at its most intense during my teens and early adult years; it has diminished (or I am less bothered by it) as I have become older.

Regarding my neurodiversity, I was diagnosed with both autism and ADHD in late adulthood. The effect of these conditions on my life, as I look back on it, were drastic - my inability to understand social cues and conventions and my intolerance of dissembling and diplomacy impeded my progress in any area of work or education. My late realisation that being ND (neurodivergence) is a feature of my embodiment has shifted my understanding (of how I have functioned in life thus far) in a positive way, giving me the chance to re-evaluate my existence and escape from self-blame (to some extent), and I have engaged with the world in a more effective way.

In the films I submit and also in this dissertation I use a broad, inclusive definition of disability such as Oliver's, which is made up of three elements: 1. having an impairment; 2. experiencing externally imposed restrictions; and 3. self-identification as a disabled person (Oliver 1996, in Shakespeare 2014a, p.94). I include myself in this definition of disability. An important reason why this definition is pertinent is captured by Wendell, who explains that, 'although 'the disabled' is a category of 'the other' to the able-bodied, for that very reason it is also a politically useful and socially meaningful category to those who are in it. Disabled people share forms of social oppression...' (Wendell 1989, p. 108).

On the other hand, it is also important to recognise the non-binary nature of disability because '...social oppression may be the only thing disabled people have in common...our struggles with our bodies are extremely diverse.' (ibid.). So, although I use this broad and inclusive definition, I am also mindful of problems surrounding the use of the binary disabled/non-disabled, in particular in relation to representation. Within Disability Studies, Corbett observes that 'we typically use the shorthand of disabled-non-disabled even while acknowledging the severe limitations of the binary' (Corbett 2013, n.p.). By way of contrast with Disability Studies, she gives us an example of an activist meeting she attended in the 1980s where, 'when asked to join either a disabled or non-disabled group, over one third of the participants chose to create a group called "not sure"' even though these participants had 'significant impairments' (ibid.). Shakespeare notes that '(i)mpairments ...vary greatly in the nature and extent of their impact on a person. Consequently, the disability experience is very varied and disability, as an aggregate of different health conditions or impairments, is yet more contingent as a category' (Shakespeare 2014a, p. 63). Contrary to activists' ease with the expectation of transparency over their disability status, Corbett found that Disability Studies scholars were reluctant to provide public disclosure of their disability status, which is confounding. Perhaps there is a problem of systemic ableism within the academy[7].

As Fraser (2016) notes: 'We should not overlook the way disability has been harnessed for exploitation by narratives – filmic, literary or otherwise – that reaffirm the denigrating discourse of disability as lack from the perspective of a medical model or as a product of an ableist imaginary. Nor should we ignore that disability has been systematically differentiated from a socially and politically constructed able-bodied or neurotypical norm' (Fraser 2016, p.6). Whilst this is to state the obvious, it is accurate. However, it is also referring to fiction films rather than documentary, and fiction is the purview of most film theory. The main difference in my view, between fiction and documentary is that the characters in fiction do not have agency in the real world. As I work almost exclusively with real people, an engagement with film theory takes me away from the thrust of this thesis, which is lived experience.

Corbett also reflects on the usefulness of locating oneself more precisely in relation to the lived disability experience as it 'shapes how people receive (a)... presenter's information' (Corbett 2013, n.p.). For example, one might be a parent of a deaf child, one might be blind, one might be a non-disabled scholar too - each of these perspectives can offer 'valuable yet... different glimpses' (ibid.). Questions surrounding representativeness can occur even when a disabled film-maker explores issues in relation to people with impairments that are different to their own. In a review of a film I made in 2018 (*Dwarves in Art: A New Perspective*, BBC4, 60mins), Wilde and Pritchard raised the question of my own status - I am of average height - in

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[7] For more on ableism in the academy, see Brown (2020) *Ableism in Academia*, for example.

representing people of restricted growth in my film. In this instance Wilde and Pritchard argued that my own disability and 'disposition towards aesthetics' positioned me as 'an ally to people with dwarfism' and did not disqualify me from 'telling authentic tales of "disability"' (Wilde 2018, n.p.). As Wilde and Pritchard allude to, acknowledging one's relationship to disability when representing people with impairments in one's work seems of profound importance in an artistic and aesthetic field.

The issue is perhaps of even greater import in an academic setting, when non-disabled scholars make claims about disability. Tom Shakespeare, a man with painful and disabling impairments, was uncomfortable being told by non-disabled researchers that 'impairment does not exist or is only the product of discourse' (Shakespeare 2014a, p. 66) and, 'challenging the ontological basis of the category' (of disability) is not any excuse. Some of those who deny or downplay the 'reality' of disability are seeking to challenge an ideologically normative concept of truth but this political move can appear to be using disability as a means to an end. A particularly compelling example of this can be found in crip theorist Robert McRuer's practice of 'coming out crip'. McRuer tells the reader how, in certain contexts, he publicly identified himself as HIV+ when he was not. He claimed to have done this in the name of solidarity (McRuer 2006, p. 57). Given how disability shares with other minority identities, the problem of oppression, this might make sense. But at the same time, crip theory, according to Bone for example, 'authorizes anyone to speak on behalf of the disabled rather than prioritizing actual disabled voices' (Bone 2017, p. 1308). If a 'crip' is not an impaired person then disabled people are further erased and made invisible and inaudible, the particular issues their impairments raise for them, not considered politically important. Especially in light of my own experience of the distorting effects of silence, and considering the problem of epistemic injustice, I think it is important for disabled people to explore their own epistemic landscape and bring to light their own narratives[8].

Another example of the non-disabled representing disability is addressed by Gruson-Wood in her critique of Siebers' 2006 paper on disability aesthetics. This example is about McCarthy, a performance artist who, in real life has no impairments, but who enacts mental and cognitive disability on stage (which he labels 'idiocy') as a cultural critique, in order to displace the values of intelligence and genius in normative society. The reception of McCarthy's work (his status as an artist is unquestioned) is contrasted with that of Judith Scott's who worked as a sculptor. Her impairment (she was classified as having Down syndrome), was felt (by art theorist John MacGregor) to disqualify her as an artist. As Gruson-Wood notes, 'Performing idiocy and living under the classification of idiocy are two very different things' (Gruson-Wood 2009, pp. 5 - 7).

With these qualifications, I use the binary disabled/non-disabled as it is still meaningful to me. I agree with Linton's inclusive argument that it would not be right to 'eras(e) the line between disabled and non-disabled people, as long as disabled people are devalued and discriminated against...' (Linton, 1998, p. 13). Unfortunately, my experience has shown me that disabled people are indeed still devalued and discriminated against, and I am a witness to this as a

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[8] Gianni Infantino, president of FIFA, famously 'came out crip' - albeit very briefly - when he claimed '"Today I feel Qatari. Today I feel Arabic. Today I feel African. Today I feel gay. Today I feel disabled. Today I feel (like) a migrant worker' just before the World Cup 2022 started. He was angry that there had been so much criticism of Qatar's poor record of respecting the rights of the migrant workers, some of whom had died as they built the stadiums for the World Cup, as well as LGBTQ+ rights. This may not be the most legitimate example to use, but I think it does show how anyone, with any motivations, can 'come out crip'.

disabled person as well as in my role as film-maker. This 'finding' of mine is not unique. Scully explains that, especially since the financial crash of 2008, 'progress towards equality for disabled people is stalling, or even actively regressing' (Scully 2018, p. 118), which is evident in 'an increasing number of policies that disproportionately harm disabled people... (as well as in) a documented rise in reports of hate crimes targeting disabled people' which suggests 'the trajectory of slow but steady movement towards the goal of the inclusion and equality of disabled people may not be as inevitable as we have wanted to believe' (ibid.).

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The films

The films I am submitting as part of my Practice as Research degree address specific factors around being disabled, and each covers a particular aspect of disability. I also intend them to address, in their subtext, a wider theme of how disability is perceived in society. As Dohmen, discussing testimonial injustice, notes: injustice against disabled people comes from how they are perceived (Dohmen 2016, p. 672). Hahn (1988, see also 1996) compares two US 'models' of disability - the 'functional limitations' and the 'minority group' models. In relation to the first, he argues people experience existential anxiety about disabled people because they identify with a disabled individual and imagine themselves suffering a lack of autonomy and freedom which they imagine a disabled person suffers. The second model, on the other hand, addresses how 'many persons with disabilities ...feel their problems stem primarily from prejudice and discrimination rather than from their functional impairments' (Hahn 1988, p. 39). Disabled people have characteristics - evident in physical or behavioural 'cues', 'that permit them to be differentiated from the rest of the population' (ibid. p. 42) and which cause anxieties in 'non-disabled observers about their own appearance or autonomy' (ibid.). The minority group model thus acknowledges an aesthetic anxiety, which is a term that describes the 'fears engendered by persons whose appearance deviates markedly from the usual human form or includes physical traits regarded as unappealing' (ibid. p. 41). It is reflected in how disabled people are shunned as well as in the 'extraordinary stress ...devoted to (the) quest for supernatural standards of bodily perfection' (ibid.).

According to Hahn, the functional limitations model has hidden from view the issues of aesthetic anxiety that inform the minority group model. He worries that, given how there has historically been such an emphasis on the functional limitations model, 'relatively few non-disabled people may be prepared to understand disability as a problem that revolves largely around aesthetic considerations' (Hahn 1988, p. 45). Some theorists have since argued that, with consumerism, the aestheticisation of society has resulted in an '...aesthetic stratification as powerful as class, gender or ethnic stratification' (Synnott 1993 in Hughes 2000, p. 560), such that Hahn's discussion of US experiences can be generalised more universally, it seems. As Johanssen and Garrisi argue: 'The bodies that we encounter in newspapers, on television and in our social media feeds are often made to appear perfect in order to conform to racialized, ableist and heteronormative ideals of what it means to be beautiful and normal in contemporary capitalist societies' (Johanssen & Garrisi, 2020, p.7).

Hahn suggests researchers could usefully attempt to 'disentangle the existential and aesthetic elements of attitudes towards disabled people' (ibid.). At the conceptual level it may well be necessary to disentangle these elements - for example, insofar as conceptual clarity can inform legislation. But, one can also speculate that the entanglement of functional limitation and minority group models might be caused by how the imagined freedom and autonomy associated with functionality may also be part of what constitutes ideas of beauty and aesthetic acceptance (I discuss aesthetics in more detail in chapter three). The decline of industrial society and subsequent rise of consumer society may help us to understand why the functional limitation model was historically dominant. But the idea of a 'model' is maybe less useful as well, maintaining distinctions where, in practical terms, they are all of a piece.

I submit five films for this PaR. The last one listed here was specifically made for this degree. The four (commercial/professional) films I have made over the duration of this study and which I am submitting as part of the PaR degree are:

The Disordered Eye. BBC4, 2020, 60 mins

Targeted. The Truth about Disability Hate Crime. BBC2, 2021, 60 mins

The Truth about Disability Benefits. C4, 2021, 30 mins.

Locked Away: Our Autism Scandal. C4, 2023, 30 mins.

The films can be watched in any order or at any point, however, to assist the reader I suggest points at which watching them will be most pertinent.

The Disordered Eye **(2020)**

Figure two.

This film is a one-hour arts documentary for BBC4, the second in what was meant to be a series of four films looking at art and the canon from the perspective of disability - that of the artists themselves and the art they created - and how disability informs such works. It is also an attempt to engage with Siebers' observation that disability is central to 'the canon', informing it in a myriad of ways. Unfortunately, after this film was made the BBC decided to stop commissioning original content for BBC4 and the remaining treatments languish, probably never to be made.

The film is framed by the rhetorical question of whether one needs excellent vision to produce good art. It addresses a 'hermeneutical injustice', a lacuna in our collective epistemic resources caused by how the contribution of disability has been overlooked in the canon. In the film I view both the canon and contemporary visually impaired artists to argue that their impairments have added, intentionally or not, a great deal of significance to art, and that this is downplayed by the art establishment, which sees disability as tragic loss. Examining art from this perspective adds to our collective epistemic resources by showing that disabled people have actively influenced and contributed to the canon. In doing this, I seek to unsettle and contribute to reconfiguring the representation of disabled people as unproductive, and their impairment as loss. For some of the artists, losing their sight gave them courage to paint, sculpt, photograph

and draw in a way being sighted would have precluded them from doing, which suggests visual impairment itself, as well as being common in the works of many across the canon, has also contributed to art. I talk with both academics, such as neuroscientist Anil Seth and professor of literature at University of California at Berkeley, Georgina Kleege, and contemporary artists Keith Salmon, Sally Booth, the family of the late Sargy Mann, sculptor Aaron McPeake and cyborg artist Neil Harbisson, all of whom use their disabilities in creative and innovative ways. This work argues that any kind of disability changes our perception of the world, whether we want it to or not; it both alters and adds a fresh dimension to an artist's work.

Targeted. The Truth about Disability Hate Crime **(2021)**

A one-hour film for BBC2. In this exposé I use the testimony of disabled people from around England and Northern Ireland, who have all been subjected to violent attacks, directed against them merely because they are disabled.

What was important for me was to create a space where the disabled contributors could define and represent what happened to them on their

Figure three.

own terms. To this end, one tactic I used was to depart from the usual format of presenter and narration, retaining only the testimony in the words of the disabled contributors themselves (and their friends, family and advocates), and some cards to display relevant facts and statistics. I also declined to interview any experts, police, CPS or other official bodies because I felt the insertion of outside voices would distract from the strength of the contributors' own words and images and dilute the intensity of their message. I used an autistic composer for the music, and the members of the production team were all disabled; this gave me another way to keep the ownership of the narrative in disabled people's hands. All the interviews were shot straight down the lens, with only occasional off-camera questions from me, to show articulate, well-balanced, problem-solving human beings rather than the tragic victims disabled people are often imagined to be. The film opens with a critique about non-disabled perceptions of and ignorance about disability that result in social exclusion and non-belonging, and shows a joyful, laughing individual, which contradicts the commonly held idea that disability is all about suffering - instead, disabled people can talk back.

The various locations used for filming, as well as details in the stories these people tell - for example, about work, home, nightclubs, the police, their neighbours and neighbourhoods - help to link their personal testimonies to the social world in which the attacks took place and from where the misrepresentation of disability arises. In showing disabled people as ordinary people going about their business in mundane settings, I tried to disrupt the representations of disabled people as confined, restricted and inhibited by their impairments. But, as Hannah and Ailsa (and her advocate) tell us, non-disabled people have the notion that this must mean they are 'fake' and gaining unfair advantages, and in this way, they become victims of testimonial injustice. This denial of their truth is used to justify targeting disabled people and attacking them, which shows another aspect of life for disabled people - that they have to do battle each day, to just be able to go about their ordinary lives. It is not their impairments that impede them so much as the disrespect and casual hatred they encounter in the social world around them.

__The Truth about Disability Benefits__ **(2021).**

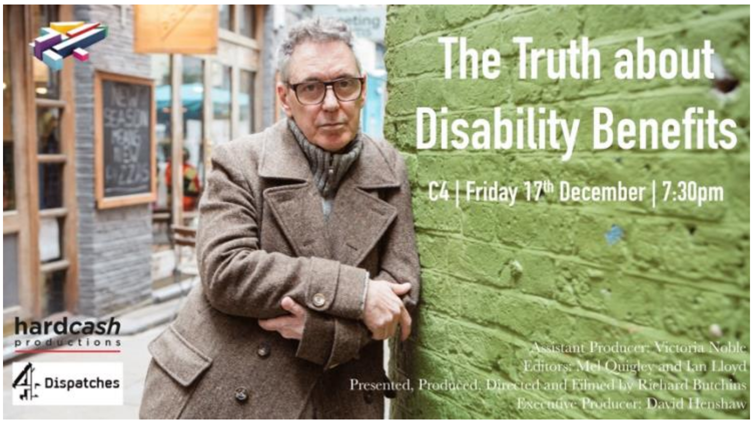

Figure four.

A half hour film for Channel Four’s Dispatches strand. This film reveals both state and community failure as it focusses on the stories of four people who died as a result of bureaucratic harm. The film aims to expose how these deaths were caused by interacting with the Department for Work and Pensions, a government department responsible for, among other things, the administration of all the state benefits payable to disabled people. The process people have to undergo to prove their eligibility for these benefits is arduous and complicated and there are repeated assessments and reassessments and paper-based reviews, which must be completed to gain and retain one’s eligibility for these state payments, but which make people feel (in the words of a relative of one of the victims) 'worthless, ill and fractured'. These processes frequently and repeatedly fail, leading to poverty, isolation and loneliness, malnutrition and in some cases, death. There is a lack of accountability for all this as, 'even when some of these injustices are exposed by coroners, the media or Parliamentary committees' (Duffy 2021, n.p.) - which is rare enough - the system of benefits does not change.

The film also examined the results of an original piece of quantitative research I commissioned in line with my academic study. An online questionnaire was designed in conjunction with the Centre for Welfare Reform (now called Citizen Network), to evaluate the impact on disabled people of interacting with the DWP. Dr. Simon Duffy and his associates helped with the structure and wording of the questions (which are included as Appendix two)[9]. I disseminated the questionnaire to over 80,000 disabled benefit claimants and received responses from over 5,000 (3,500 when corrected statistically). These were evaluated by academics Dr Anna Gkiouleka from Cambridge University, Dr Anna Ruddock from Kings College London, and Dr Anna Carin from Stockholm University, who agreed the results (within their limitations) were valid. We used the headline results in the film, illustrated with graphics and presented on camera by me. The key headline findings from this research were:

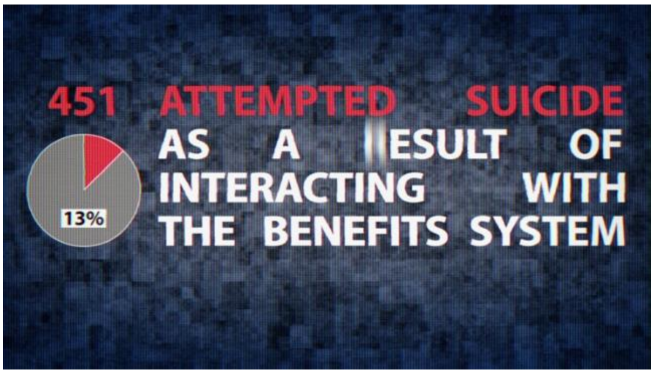

Figure five. Graphic from the film.

- 451 people (13%) said they had attempted suicide as a result of interacting with the DWP.
- 1,154 people (32%) said the DWP system had caused them to plan suicide.
- 2,158 people (61%) said the way the system worked had caused them to have suicidal thoughts.

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[9] https://citizen-network.org/library/disability-benefits-and-suicide.html - this is a link to Simon Duffy's article on this. I have also copied and pasted it into Appendix 3

- 3,331 people (93%) said the process of claiming benefits had made their mental health worse.
- 96% found the preparation for their assessment distressing.
- 3,180 people (89%) said the system had aggravated their pre-existing conditions.
- 79% said the system had made their physical health worse.
- 2,187 people (61%) said the system had caused them new health problems.
- 89% of respondents said the DWP is not “an ally" to disabled people.

For further details and analysis of this research see Appendix 3

The film seeks to counter the 'misappropriations of cause and effect' (Mika 2020, p. 1) by the DWP, by politicians, the media and other parties, all of whom hold that there is a need for a brutal system of benefits because claimants are scroungers and cheats, when the truth is that privatisation and outsourcing in the name of profit and in order to reduce expenditure on benefits as part of austerity policies, is where the responsibility lies[10]. As Duffy notes, '...the political leadership within the DWP has created a culture which encourages a negative view of disabled people, encourages bad and dangerous policy-making and hides from any accountability for the harm it has caused' (Duffy 2021, n.p.).

This film won me an award at the British Journalism Awards (2022) and as the SCOPE disability journalist of the year 2022.

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[10] In relation to this, see also Ryan's 2019 book *Crippled: Austerity and the Demonisation of Disabled People* in which she gives many examples of how disabled people in the UK have, since the rise of austerity policies, been scapegoated by the government and media, in particular, and characterised as a 'lazy and deceitful' underclass, becoming much poorer whilst also subject to a rise in hate crimes against them.

Locked Away: Our Autism Scandal (2023).

Figure six.

This Channel 4 film came about as a result of a personal mental health crisis, one that caused me to have to intermit my PhD studies for three months. At this time, I decided not to seek help from mental health professionals due to the inherent risk involved of getting trapped in the mental health system, and I wanted to explore this on film. Testimonial injustice, which occurs when people have prejudice against a 'speaker' and, as a result, refuse to believe them (Fricker 2006), is a key reason why people often become trapped in the mental health system. In this film there is testimony about a young woman (Lauren) who referred herself to a mental health ward on a voluntary basis but, when she wished to leave, was sectioned and thus trapped within the system for many years before finally taking her own life. The program shows that she and her mother were not listened to or taken seriously at any stage. Testimonial injustice considerably worsens what are already very disempowering and inadequate places. Furthermore, contributory injustice compounds the problem as the health professionals concerned showed bad faith and failed to even engage with Lauren's or her mother's words.

This film lets members of the general public hear from autistic people who are stuck inside this inhumane system, as they film and record themselves on their digital devices. I made contact with several people and they agreed to send me video diaries of their experiences to use for the program. This is another method of involving disabled participants in the making of films for mainstream television and thus of illuminating their perspectives and showing their contribution. It also gives them a real presence, when they would generally be kept faceless in films of this kind. This is important because such anonymity in undercover films means the participants risk only being seen as objects, as pitiful subjects of poor care and abuse, rather than as real people.

The film exacted a high emotional toll on me. The combination of my powerlessness to change or effectively aid the contributors combined with frustration in dealing with a broadcaster who had little understanding of the subject (and autism more generally) or any willingness to let me be free to make the film I wanted to make, was both distressing and exhausting. In terms of exposing a previously unknown narrative to the public, the film could be deemed a success as, within the constrained arena of public broadcasting, it did manage to achieve this. A positive impact of the film was that one of the units I featured was promptly shut down by regulators, whilst another was subjected to an investigation; and the film initiated a debate in the House of Commons. Nevertheless, the personal situation of two of the contributors remains much the same. (For further details and links see Appendix 6).

The practical work (Untitled)

The fifth film I am submitting here is the practical work I made specifically for this degree. In it I combine participant self-observation and interviews with people who have, to varying degrees, a ‘public ’profile. The film plays on the public/private divide. As noted above, the public/private divide disabled people live out is one that seems widespread and is part of the problem of silencing disabled people. It is characterised by the work disabled people do to protect the non-disabled from feeling uncomfortable about them. In his examination of the concept of 'melancholia', Watermeyer provides various examples - French (1993) was 'drawn into publicly denying her experience of disability in order to protect those around her' (Watermeyer 2022, p. 3); Murphy's 1987 book discusses how 'cultural and relational forces positioned discussion of his disability as strictly out of bounds' (ibid.) and he notes as well that no-one ever asked him about his disability, which is the same as my experience in my early work as a photojournalist. This echoes Corbett's experience of being taken aside and told not to ask scholars to publicly disclose their relationship to disability (Corbett 2013, n.p.). The divide is important because, in this labour to protect the non-disabled, disabled people are silenced and/or unable to begin to articulate their own perspectives, and it results in an experience of alienation both from themselves and from others, as they are 'by turns with others who need... protection and afford... guilt or (are) left alone with no one to rely on or to show ... (their) pain to' which 'seems like the worst of both worlds, leaving pain lodged underground' and thus, one might add, unarticulated and inexpressible (Watermeyer

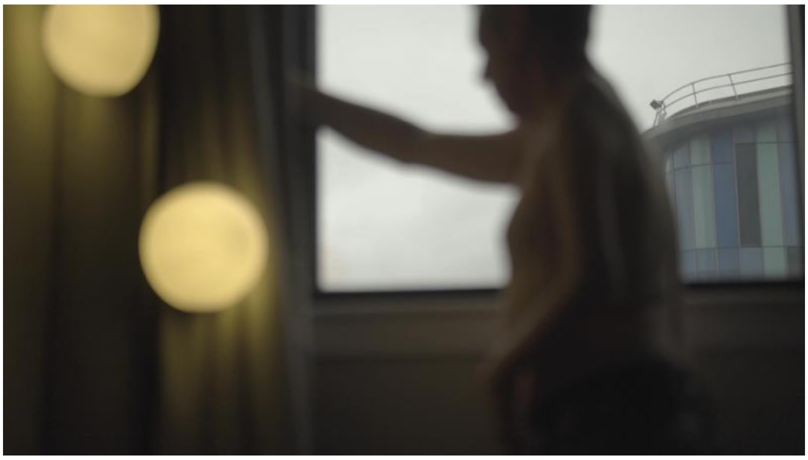

Figure seven.

2022, p. 5). But, importantly, it matters a great deal because of how this local, private labour sustains an ableist public life, which contains the denial of its own mortality and frailty, and makes being fully human impossible for everyone, disabled or otherwise.

Returning to silence - Narrative as dream sequence and unreal reality

The film purposefully dislocates the public/private divide, using the uncertainty of dream logic to permit the failure of linear narrative. It starts out, on first impressions, as a standard documentary narrative format. The subject (me) goes about his business and leaves the house to go somewhere. But I manipulate the conventions and assumptions of the documentary form so that it is highly personal and contains a whole range of unconventional, less public, meanings. In this way, I seek to disable the non-disabled audience, asking them to work harder to understand what is going on, letting them feel left out of the conversation in some way. For example, as a late-diagnosed autistic person, just the act of filming, the process of creating a piece of work in the moment, is a self-soothing activity - a 'stim', if you like (see Bascom 2011 for more on positive aspects of stimming) - because creating images results in a simple joy inside me, the calming of an otherwise ever-present anxiety which I feel in all situations. But this calm is not directly visible in the film, which speaks of my silence, but in a less negative way than in my earlier life, because I am 'articulating' it; it is part of my disability and that of the film.

There are multiple cues in the practical work which a non-disabled viewer may well miss, but that a disabled person is invited to notice. For example, there is a section in the film where I am travelling on a train. During this sequence I can often be seen wearing headphones. An autistic viewer is likely to spot the reasons I am wearing them - not so as to listen to music or some other audio entertainment but instead, as a defence against sensory overload. I listen to nothing, I seek silence, and the headphones are a particularly effective pair of noise-cancelling headphones I use, to escape the wearying clatter of everyday train travel and the cacophony of streets and cities. There is a clue to this in the sound design but it is not at all certain that a non-autistic person will catch on to this. Another, perhaps more accessible example, is the scene where I am making a cup of coffee. In this sequence I am screwing the top onto a coffee percolator and it falls over. The result is me shouting out a loud curse – seemingly an overreaction, but anyone with a physical disability will understand the frustration that occurs from the many years of failing to do simple physical tasks.

The film has an appearance of contiguousness but this is undermined by personal meanings attached to the elements that appear and cut into the 'real time' mode, generating a contrast between the dream of a past and the 'real' world in which it is filmed in the present. For example, the miniature railway in Hastings, where I live has been there for decades but it has private meanings for me as a remnant of my childhood. As a small child I visited Hastings to see my grandparents and the miniature railway was the high point of those occasions. I would cajole and nag my parents to let me ride on it and, if I was lucky, I was gifted the chance. I was surprised to find it still there, some fifty years later, so I took a ride. It was a much smaller and

Figure eight.

shorter ride then I remember. The present reality lacked the dreamy magic of those childhood trips round the small circular route. So, I incorporated it in the form of both present and past. An unreal reality existing both in the present and the past. The train journey has no destination, it is mere sequence which, again, expresses a failure of the logic of 'reality'. This sequence also illustrates a sense of being out of place, as I am an adult on a miniature train, as is the driver. The scale is all wrong, it is topsy turvy. This highlights a strong sense of not ‘fitting in’. Furthermore, I am clearly very miserable, which is inconvenient for the trope of a jolly fairground-esque train ride. The scene is imbued with a feeling of melancholy and yet portrays a resolute determination to make it to the end (although the end is, of course, the same place from where I started - something I am all too familiar with as a disabled person grappling with an unenlightened environment). It is also an oblique reference to the trope around autistics loving trains, which is echoed later in the film (in the clip from “The Autistic Gardener”).

The next section reiterates the idea of the dream sequence by being obviously a continuation from my being asleep in the first shot. In it I shave, make coffee, go out. But, despite an appearance of sequentiality, the shaving was filmed during an afternoon and entirely separately to the coming downstairs and making coffee scenes. It is fiction, but presented as a continuous reality, which subverts the assumption that the documentary is a truthful representation of linear time as we experience it. The coffee scene (as likewise the kitchen scene later) also references Mel Baggs' self-made videos (listed in the bibliography under 'silentmeow'). Baggs' videos are seminal user-created works about being autistic. Mx. Baggs at no time intellectualises the experience; the videos just show them being them and only sometimes explain this to the audience. I find this form of first-person testimony to be a very powerful expression of what it means to be disabled in our world and consequently I use it in the film

In an ableist society, to be disabled can mean the non-disabled have no expectations of one so that, to prove oneself in any way competent can generate a cognitive dissonance in the non-disabled. In chapter three I examine the issue of stereotypes in more detail but here it is worth noting how, after Baggs posted a video called '*In My Language*' (2007) they appeared on CNN and a backlash quickly started. They were accused of being a fake. Some said if Baggs was disabled they could not have possibly made the videos; others, that Mx. Baggs was okay in high school, so they must be faking their disability;[11] none of these accusations have been properly substantiated. What is interesting is that disabled people have to conform to non-disabled ideas of what being disabled constitutes, or risk being seen as a 'fake' of some kind. Unless we are Stephen Hawking it would appear we are not allowed to be both impaired and intelligent, to both drool and be brilliant, to be simultaneously low and high functioning. Baggs' work is, in my view, wonderful; their hypnotic narrative about the act of nothing becoming something is delightful.

Whilst I am uneasy about possibly being taken in by a 'fake', I have come down on Mx. Baggs' side, partly because the contrast between Baggs and McRuer seems instructive: while Baggs' enactment of disability - which is an unseen disability but is still visible in their behaviour - on camera and in public, causes their work to be questioned, able-bodied McRuer can, if you like,

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[11] For more on this story see Genzlinger 2020. There are various blogs in which these accusations are made. I have listed the example from an unknown poster on 'Facing Autism in New Brunswick' blog but there are others.

help himself to some disability in an instrumental way, his able-bodied 'appearance' placing him within a powerful rather than marginal position. This instantiates testimonial injustice, for McRuer's more powerful position means his credibility is not questioned, whereas disabled Baggs' is.

I, like Baggs, have involuntary periods of inaction; times when I cannot physically or mentally get anything done – the simplest act is rendered impossible. Of course, nobody witnesses these moments. I cannot film them but sometimes they encompass entire days (mostly they last for several hours) where I do nothing. In attempting to communicate something of this in the practical work, I filmed a period of semi-inactivity. Sensing this may happen, I set up the cameras so all I had to do was turn them on before sinking into a torpor. When Baggs says boiling a kettle can take four hours, it really can - in my case, there was an occasion when getting from the chair to the door in a hotel room took six hours. To a certain extent these scenes are 'fabricated', for the use of a video camera suggests some degree of cognisant control over the situation. But I don't think this matters - from the position of user-generated video, it is inevitable.

It is the fact that people assume the impaired are not able to function effectively and also be disabled which is revealing - it leads to testimonial injustice.

Figure nine.

Sometimes I can and sometimes I cannot do things. I am often told that I don't seem disabled or that I hide my autism well - again the implicit assumption is that if I am really disabled then I wouldn't be able to do what I do and therefore I must not be disabled. This is particularly a problem for people with unseen impairments[12]. A medical diagnosis lends them credibility and might also lead to access to medical or other forms of support. Thus, in the face of such testimonial injustice, medical authority can be a valuable support, despite its shortcomings (Shakespeare 2014a, pp. 95 -96).

An association between disability and creativity, although not proven, is well established (Fung 2009, p. 775). Fung examined the case study of the composer Erik Satie, whose music I chose to use in this film. Fung is persuaded that Satie almost certainly was on the autistic spectrum and, although the allocation of posthumous diagnoses to past creative artists is fraught, this is relevant to discussions over whether the work of people such as Satie is diminished by qualifying it as a result (at least in part) of a 'condition'. My thoughts on embodiment and aesthetics (see in particular, chapter three) are that it is impossible (and undesirable in the case of impairment) to separate the creative output of any human being from their corporeal existence.

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[12] I use the term 'unseen' rather than 'invisible' because these disabilities quickly become apparent when interactions occur.

Satie's use of free time, lack of key signatures and partial melodic formations make his music very compatible with this film. Satie was an iconoclast and an absurdist in both his music and his writing. He was also one of the first composers to make film music and to create ambient music – music not meant to be listened to. In this way he preceded the idea of the music soundtrack, which is often subservient to the narrative and visual imagery in a film work. I have taken his work to accompany the images in my film, using both well-known pieces and more obscure works. The more famous works, such as Gymnopedies and Gnossienne, have become linked in the public imagination with trite and sentimental advertisements and films, belying the revolutionary nature of his compositions and the structural disinhibitions which he used. The use of work by an established artist who is not universally acknowledged to have been on the spectrum is a reference to society's reluctance to accept that impairment can and does inform the cultural landscape of our world to a significant degree.

It is also worth noting that Satie had an incomplete and unsuccessful musical education: 'Satie's musical education was incomplete… (he) created a method equipped with just the things he knew' (Fung 2009, p. 778). He was noted, by Latour, as being in the position of 'a man who knows only 13 letters of the alphabet and decides to create a new literature using only these, rather than admit his own insufficiency…he made it a point of honour to succeed with his system' (ibid.) I am inclined to feel some affinity for the composer as I too suffered from an incomplete education where I was impeded and reviled to a degree.

It is difficult to intellectualise a piece of work which has been created intuitively. Disability is threaded through the entire fabric of my existence. Years of living disability, thinking disability and existing in this embodied state means there is not a moment of my film that is not about disability. For example, the section where I am arranging flowers to make a still life photograph is also about disability. For me, cut flowers are nothing other than disabled plants. I find it strange that we give dying plant matter in bunches, to people in hospital who may also be dying, so they can watch them die. Mutilation of a living entity in the name of beauty strikes me as an extremely human-centric thing to do. So, during lockdown I initiated a project called Floracide where I used cut flowers and references to Vanitas painting in the canon as a metaphor for disability (see Appendix one). This has become an important part of my self-therapy – a way to keep sane - as well as a way of commenting on the insanity of my everyday life. I was also aware that one of my interviewees (who is known as the Autistic Gardner from his 2015 Channel 4 series "The Autistic Gardner") has a special interest and love for plants and flowers, one that I, to an extent share.

The interviews in the work are self-explanatory. In each one the respondent gives the viewer their perspectives about their relationship to disability. The interviews are unstructured, with the exception of the final one, for which I prepared the questions in advance so the interviewee, who is non-verbal could write the answers for his computer voice. Each interviewee has a public profile and is or was a performer in the public eye. Again, this part of the film touches on the public/private divide. I was curious about the meeting points and tangents that the public and personal performances induce as I am very aware of the public/private differences in my own presentation. In the film I do not identify the interviewees, I use no strapline or introduction. This is deliberate as I wish the viewer not to be influenced by the identity or any knowledge they may have about the person talking so that they can be listened to in their own words.

The process of my professional/commercial practice also features in the work given how it is an integral part of my practice. I have inserted occasional clips of myself in the process of making these productions. These are momentary incursions revealing the process and breaking what is known as 'the fourth wall'. The choice not to add a narration, and for me to not talk in the film, is to intensify and complicate the viewer's relationship to the narrative. It requires the viewer to take a critical position and to attempt to interpret the visual and audio information so as to untangle what may be meant by it. This differs from a conventional approach where the explicit information is given to the viewer such that a comfortable resolution (in narrative terms) for the viewer may be attained.

Trains feature heavily in the work. This was not a conscious decision; it seems to have just turned out this way. However, it speaks to a commonly held idea that autistic people (males in particular) love trains. I think we do love machines of all kinds and clearly the use of train journeys is a way of creating a forward motion for the narrative of the film – even if that narrative is going nowhere. If the viewer expects a traditional narrative, the image of a person travelling on a train suggests they are going somewhere, to do something - like a narrative is meant to. But here, in a counterintuitive way, the film does not deliver narrative resolution - at least not in the traditional sense. In the film, the editing process is used to dislocate the points in time of the journeys, and the film has been cut to reverse and interrupt the flow of time, but this would not be immediately apparent. For the viewer, the journey appears contiguous and only careful watching will reveal the deliberate disjunctures that indicate the fractures in the timeline. In fact, the sequence on the train was shot over four separate days and edited into one, apparently continuous event. This technique appears elsewhere in the film as well: where the flowers are sitting on the table, careful viewing reveals the water is dropping upwards into the flowers and not down as gravity requires. There are many moments of this kind - in fact there is no timeline.

CONCLUSION

In this chapter I have examined my personal experiences as a disabled and impaired person, so as to contextualise this dissertation and show the reader how I am 'vested' in the task of developing my understanding and conceptual toolkit. I explained how, although I appeared to have achieved assimilation into 'normal' society - principally through working as a photojournalist - I carried a silence and an inexpressible resistance within me. I argued that my inability to articulate my identity as a disabled person was related to how disability is perceived in society, which is a source of discrimination and disadvantage for disabled people. This disadvantage was not something I knew how to face, which means I was doomed to feeling alienated from myself and others. One form this disadvantage took can be called 'hermeneutical injustice' - I did not have the epistemological tools needed to openly acknowledge and profoundly understand the role my impairments were playing in my life. On one hand, I had not yet received a medical diagnosis for my unseen impairments, so I did not know how, on top of my physical impairment, my personal mental experiences also formed part of my difference; on the other hand, I did not know about disability politics, the activism and the academic studies that over time, have yielded resources drawn from a much bigger collective of disabled people, which would have provided me with more access to the words, concepts and narratives I needed.

Noting that academic theories had failed to filter through to me leads me to believe that hermeneutical injustice persists partly because disabled people's epistemic resources are to be found dispersed inconsistently across unconnected groups of people - the academy in particular seems removed from the everyday practical issues of inequality and injustice disabled people experience. However, from the academy, Siebers has argued that disability symbolises human frailty, dependence and mortality and that this may explain why its importance is denied and silence about it sustained by everyone. Hermeneutical injustice is apparent in how disabled people's perspectives are not fully integrated into the greater, more widespread collective, so that they can inform the practices of not only disabled people but also the non-disabled.

The importance of this question is given expression in the second part of the chapter where I introduced the films I am submitting as part of my PaR degree. As my own work on disability has sprung from my becoming more conscious of my disabled identity, it has increasingly come to matter to me that there should be disabled ownership of the narrative, and staying true to this ideal has meant keeping the process of making these films in disabled hands too, wherever possible. The Disordered Eye seeks to show the extensive contribution disabled artists and disability itself make to the canon, which is not widely known about, due to hermeneutical injustice, but that seems full of promise for the subversive possibility of disability as a value, a theme this dissertation seeks to explore further, especially in chapter four. The other commissioned films I made are about disability as disadvantage. These films in particular seek to expose and critique how perceptions of disabled people, perceptions that bring about existential and aesthetic anxiety in the non-disabled, lead to very serious practical problems that include hate crimes (Targeted), the power of the state and the media turned against disabled people (Disability Benefits) as well as testimonial injustice leading to autistic people getting stuck in the inadequate system of mental health (Locked Away). The fifth film (Untitled) I made specifically for this degree, is more experimental, and in it I explore the idea of a film that is itself somewhat disabled. In playing with the public/private divide that can be so detrimental to disabled people, I seek a return to silence, but this time, on my terms. I seek to show aspects of disability to the non-disabled viewer, from a disabled person's perspective, which results in a playing with what is visible and known to them and what is invisible and needs to be thought about a little more, but that other disabled people might perhaps recognise more easily.

The untitled film reflects my deeper engagement that has developed as a result of undertaking this academic study, with the related issue of legitimacy when it comes to the representation of disabled people and the question of who owns the narrative. In passing, I noted the difference between the reception of Mx. Baggs' work and that of McRuer, a respected and popular academic, and I brought up a problem with crip theory: if a crip does not have to be impaired, then the representation of disability can be made by the non-disabled and our impaired bodies cast aside and excluded again. In this respect, it seems to me that the subversive potential of disability is lost. I should point out that it is my deliberate decision not to title the film, to not have any credits at the end nor to put name straps under the interviewees. All this aims to remove the conventional devices used to make watching a film a passive intellectual experience, and to create a subversive piece of work. However, the process of making the untitled film has shown me that disabled people's perspectives are under-explored and underdeveloped in cultural productions. In order to truly understand what the subversive, disruptive and destabilising potential of disability is, there need to be more artistic and other cultural productions that explore and develop these disabled perspectives and these need to be owned by disabled people themselves. Thus, the impaired body needs to be centre stage, right at the heart of what it means to be disabled.

Chapter two: Are We Missing Something…? Academic approaches to disability

Introduction

In chapter one I examined how important a political identity of disability has been for me, enabling me to find creative ways of grasping my agency as a disabled person in my work as a film maker (and as an artist) as well as in my personal life. I argued that it was through silence, mine and that of others, that my own agency as a disabled person was underdeveloped until much later in life. I introduced the reader to the films I am submitting as part of this degree. In the process of making them I have prioritised the idea that disabled people must own the narrative, as agency is a key aspect of claiming and living with a disabled identity in a healthy, positive way. At the same time, the commissioned films show how disabled people face a real struggle as they are negatively judged in society, and this struggle also forms a part of the meaning of disability. At the start of this chapter I use auto-ethnography as a means to examine disabled children's agency. Whereas obtaining a medical diagnosis, in 2018, for my unseen impairments helped me a great deal, as a child my encounter with a medicalised approach to disability was largely negative, forming part of a pattern of silence and resistance that took a long time to overcome.

My use of the term 'disabled' is inclusive but, in chapter one, I discuss the limitation that, as non-disabled people are not grappling with impairments, they are not in a position to make uncontested claims about what it means to be disabled. An impaired body (which I take to include the mind, and thus to include both visible and unseen impairments) has important effects in ones lived experience - both in how a disabled person navigates the world as/with their body and in how a disabled person experiences other people, both directly and through representations of disabled people. I argued that, in leaving out the impaired body as central to what it means to be disabled (as for example, McRuer [2006] does), there is the risk that disabled people's agency will be undermined as their presence gets erased and their disability represented by non-disabled people. The theoretical underpinning that permits scholars of disability to ignore impaired bodies is social constructivism, a perspective that, in seeking to be critical of ideological normativity, focuses on representation and social meanings, to the exclusion of bodily realities. In this chapter I seek to elucidate this constructivism further.

A long time ago…

The car jolted along tiny country roads. I think mum was driving, but it might have been dad. I spent my time staring at the brown seat cover or pressing my nose against the window, watching the passing countryside. It took hours and hours to get to the Hospital. We were going to the country branch of the hospital, not the vast red brick one in London I sometimes went to. That one had a huge metal statue of Peter Pan in the reception. It was made of some kind of brown black metal. The half boy half creature frowned down on me every time I walked in. It was a frightening apparition to be confronted with in a place where I knew they were going to cut me up while I was asleep. The ward I stayed on in that hospital had a balcony running along the length of the ward which sometimes I was allowed out onto if a nurse was available to mind me. It was fenced in with chicken wire to stop the children from leaping off, I supposed. I wanted to fly away like Peter, but the chicken wire prevented me.

I was in an office on a metal chair, my feet swinging back and forth. The man behind the massive wooden desk wore a white coat. This meant he was a doctor or a surgeon. He was talking to me, but I wasn't listening. I was staring at the jar of jelly babies on his desk, it was full. All the jelly children were jammed inside the jar; yellow, red, black and orange. Orange was my favourite. The lid was screwed shut. I thought the jelly babies must be uncomfortable - that was my primary thought, alongside a desire to eat as many as I could get. I wondered why the grown-ups who made sweets thought children eating jelly versions of themselves was a good idea, but they were tasty and I wanted one.

Dad told me to pay attention to the man. I looked at him. He was an old man and had an enormous face with a jolly grin and deep blue eyes. He told me they had to operate on me to fix my arm in a better position and move some muscles around. I pretended to pay attention. He exuded warmth in exactly the opposite way that my parents did – well, they didn't and he did. After a long time of him talking, he spotted me eyeing the baby sweet prison and opened the jar and pulled one out and gave it to me. All my efforts had paid off. I didn't take in the surgeon's name but in my head, he was known as Mr. Lloyd George. My dad was saying expansive thank yous and goodbyes. I slid my hand across the desk and whipped a couple more jelly children into my pocket for later.

The version of the hospital hidden in the country was a series of 1920's low buildings connected by wooden walkways open to the elements with slatted roofs, deep in the Surrey countryside in I-don't-know-where land - I might as well have been on Pluto. Each ward had massive glass doors that opened to the outside. They were frequently open even in the cold weather. There were slides and swings outside on the grass although no children from my ward could ever use them. I was the only one on the ward that could walk and I was in bed like all the rest of them. The sheets over the bed were crisp and white. The nurses' aprons were the same - starched to perfection. Even the nurses inside the costumes seemed to be starched. I knew only one by name: the ward sister, Sister Moon. I have no idea if that was her real name but that was what I called her. She was a dark blue monster with pointed horn-rimmed glasses and a stiff white cap. She was my sworn enemy. Sister Moon wasn't always on duty and the mood of the ward lightened if she was not present. I had a bed next to the nursing station, presumably so the Sister could keep an eye on me. I would run about the ward until I was told to go to the playroom. Being the only child able to get out of bed and move around caused the staff headaches, but it also meant I could raid the toy cupboard and supply illicit toys to the other kids in their beds. The toy store was down some steps in a

Figure ten. Tadworth hospital exterior 1960's.

cellar. The door wasn't locked and I rummaged around inside and scooped up toys and sneaked them onto the ward. After my second toy raid the door was mysteriously locked.

All the days rolled into one and when the time came for me to be operated on it was Sister Moon who was to give me the pre-med injection. I hated injections. I ran down the ward and hid under a bed in the separate little alcove ward at the end of the main ward. I grabbed a pillow from the bed, and, as she strode into the alcove carrying a metal, kidney-shaped tray containing the dreaded hypodermic needle, I laid into her with the pillow, yelling and bellowing at her to leave me alone. Her spectacles flew off with the first thwack of the pillow and the second reverse hit knocked off her starched white cap. She marched off and I slumped on the bed as tears strolled across my face. I was alone and about to be dissected. I was an unhappy child. Some minutes later my favourite Doctor poked his head around the alcove.

"Hello, seems you are a touch unhappy about things."

He was also carrying the metal dish with the injection jangling inside like a demented sleigh bell.

"We have to give you this injection so we can fix your arm; it will hurt but not that much".

I liked the doctor and would listen to him. He sat next to me for ages, talking until I was calm enough to let him stick the needle in my right arm. He told me I would get drowsy and that when I woke up, I should say sorry to Sister Moon because I had upset her. I told him I would and descended into a grey fog of drowsiness.

I came to lying in a bed. My left arm was encased in plaster of Paris and I hurt. My head and my arm ached. I was thirsty and the nurse sitting next to me by the bed handed me a glass of water. I took a sip - it tasted wonderful. I wanted to gulp it all down but the nurse told me not to and only to sip it gently. My head was full of cotton wool and pain. They had moved me to a bed right next to the nurse's office so they could keep an even closer eye on me.

It made no difference. After a day or so I had recovered from the anaesthetic and was able to walk about again. I was discouraged by the nurses, but how do you keep a 6-year-old in bed against his will? The answer is, with great difficulty. They took to letting me have free access to the playroom to keep me occupied. I was planning to escape. There was a boy called Sean in the next bed to me and we had become fast friends. He was a thalidomide baby, but not a baby anymore. He was seven and had a normal sized head, but a small body and two flippers-like-arms and disjointed shortened legs. He had a funny smell - not unpleasant, just strong and specific. I liked the smell and I liked Sean. I would push him around the ward propped up in a pram. It had four wheels with spokes and a boat shaped carriage with a fold-up hood. It was cream and blue and had a foot brake to stop it rolling away. I would push the pram up to the side of the bed and he would tumble over and half climb, half fall out of the bed into the pram and scurry around until he was sitting up. We would hurtle along the wards and corridors pushing the device with my one working arm, scattering nurses and doctors as we went. The careening inevitably stopped when I crashed the pram into a wall or some chairs and tables, and Sean would tumble out of the perambulator chuckling and laughing, and we would be gathered up by nurses and deposited back to our ward with chastisement and scolding. I planned to push him in his pram right out of the hospital. I never did.

One day in the morning, after my usual cornflakes breakfast - I don't recall ever eating cornflakes or anything at all while I was there, but I loved cornflakes and I suppose they must have fed me or I would have died - I ambled out of the huge glass sliding doors that covered the sides of the ward and strolled along the walkway and across the field towards the hospital main entrance. As usual my intention was to escape the hospital. I had no plans further than getting out of the main gate, when the pigs caught my attention. These pigs lived in a brick structure and were part of the hospital staff. I had intended to leave the hospital, but first I wanted to get to know the pigs. The huge creatures enraptured me. The largest was a Gloucester old spot. Its large envelope-like ears falling forward and covering its beady eyes. It had big mottled black spots over the rear of its body; the rest was covered in white hair through which its pink coloured skin could be spied. I could only see it through the bars of the wooden gate because I was too small to see over the wall. I could only see the one pig as it snuffled through the straw of its enclosure, but I could hear others, out of sight, grunting and squealing somewhere behind the wall.

"Hello Pig" I said.

It didn't answer and carried on rooting around in the straw covering its pen. I shook the gate to get its attention. It carried on as if I didn't exist, which I suppose in pig world I didn't. I was still entranced and so I didn't notice the nurse as she swept up behind my fixated body and scooped me up in her huge flabby arms.

"What you doing out here little boy?" The nurse shouted.

It was uncomfortable in her bear hug of a grip, although I still had time to wonder why she shouted, given I was enclosed in her arms and very close to her. I kicked and struggled, yelling for her to release me and put me down. She ignored my threats and pleas with equanimity and, with me secured under her arm, strode away back to the ward. The only plus was, as she strode off, I could see over the wall. Another massive pig and three piglets were in the pen. They all smiled at me as I was hauled away.

I jolted along inside the car - one of my parents driving, the other talking at me. I paid no attention. I was delighted to be out of the Hospital. I could not wait to return to my home. To my room with its yellow bed cover and blue circus truck full of animals. My arm was wrapped in plaster and inside it itched and hurt. I didn't care; I was going home.

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These auto-ethnographic notes highlight a facet of disability, until recently seldom commented upon, which is the fact that disabled children often do not consider themselves to be disabled. It is others that create this condition and position it as a problem. As Sajid notes, 'many disabled people are not necessarily sick…' (Sajid 2009, p.8). My impairment was a problem for my parents and one that my father and the doctors, true to the tradition of the medical model, felt they had to fix. This assertion is supported by a study published in 2011 - over four decades after my personal experience (Barnes, Priestley & Shakespeare 2011). It shows a remarkably similar situation exists now as did then. The researchers found that designating children as disabled formed part of the adult view of the world, which restrained children's experiences. This designation made disability the dominant identifier, while other differences were muted or not attended to, and everything related to a disabled child was explained in the context of their impairment (ibid. p. 3). However, the children themselves were ambivalent about the description. For example, one respondent found wheelchair basketball 'equalised social relationships' so that, in situations such as these, she did not regard herself as disabled (ibid. p. 19). On other occasions, claiming to be disabled had certain benefits (privilege and exemption in school settings), and yet again, impairment could result in a child being left out (ibid.). This demonstrates a fluidity in whether or not children claimed disability as an identity, resisting the description in various situations (ibid. pp. 3 - 4). Such fluidity calls into question the notion of a fixed identity and shows the importance of respecting children's agency as they grapple with their identities.

This study was of 11 - 16-year-olds but, as my own experiences show, such perceptions of disability in the 5 to 7-year-old range could be even more ambivalent. Kelly's study of children and disability shows they made no reference to feelings of loss or of having being dealt a bad hand. Most of them expressed desires '... expected from children in general...', such as parties, money, toys, friends and animals (Kelly 2005, p. 269). It seemed that having an impairment was 'not a big deal ’in their lives. Indeed, the researcher states: 'Involving children throughout this research process underlines their competency as active "experiencers"...' (ibid., p. 272). This literature shows that children possess their own unique and embodied perspective on their own lives, which for the authors, is an exciting and novel finding one hopes will be taken into account in future studies of childhood and disability.

The idea that childhood - as opposed to biological immaturity - is a social construction, accompanied by the usual features of class, gender, ethnicity and so forth, has more recently been promoted in the field of sociology of childhood (Connor & Stalker 2007, p.20). In research, children are now starting to be recognised more fully as active agents, playing an important role in creating their childhoods, and attempts are now recommended and made (see for example, Barnes, Priestly & Shakespeare 2011 and Kelly 2005), to study disabled childhood from children's perspectives (Connor & Stalker 2007, pp. 20 - 21). Much of the existing research is embedded in medical rather than social models of disability where children are treated in a passive role and are viewed as dependent recipients, perhaps as 'adults in training' (ibid. p. 20). This is particularly important for disabled children because, denying their voices and how they construct their self-identities can lead to self-hatred and embarrassment (Thomas 1998 in Kelly 2005, p. 271), and, for disabled people more generally, a loss of dignity (Sajid 2009, p.9) and control over their lives (ibid.), and feelings of self-pity (Shakespeare 2014b, p. 217). Searching the literature shows disabled children have received scant attention under the social model of disability, and theorists argue that its useful and informative explanations about childhood experiences are under-explored (Connors & Stalker 2007, p.19).

Medical and Social 'model' approaches to disability

The medical approach to my disability not only ran roughshod over my own agency, inhibiting me from even articulating my perceptions, but it situated the 'problem' of my disability in me (see for example, Sajid 2009 on disability 'models'). *I* was the one needing a cure, needing care, needing to be segregated (albeit temporarily) for this to take place - for me to be 'fixed' (which ultimately, I wasn't). My mother's inability to see, even in retrospect, that my unhappiness - leading to my attempts to run away - came from adults trying to 'fix' me, speaks of her entrenchment in the authoritative ideology of the medical model and wider paradigm of medical paternalism (as opposed to patient autonomy).[13] That my parents and other adults focused so much on my visible impairment also meant, importantly, that my neurodiversity was not uncovered or addressed and it was not until very late into adult life that my odd perspective on the world was named as atypical autism. As I navigated my way through life these less 'visible' differences became increasingly problematic for me, while also becoming less so for others as the process of becoming an adult firmly placed the responsibility and ownership of disability with me. It is, however worth noting that my formal medical diagnosis of both ADHD and autism in 2018 did, in this case, assist me in dealing with and ‘naming’ my ‘condition’ and it legitimised it in the eyes of other people.

The social model (a term coined by Mike Oliver in 1983 [Shakespeare 2014b, p. 214]) introduced a social construction to how disability is viewed, through the making of a dichotomy between impairment and disability. The bodily reality of impairment was relegated to the private sphere of individuals and in itself not given political import. Disability, on the other hand, was politicised because, in redirecting focus away from the body and the medicalised approach to bodily impairment, the barriers that prevent disabled people from fully participating in society could be brought into view (ibid.). Hitherto, disabled people were excluded from society and many were sent to live in institutions. Whilst the medical approach to disability defined it in terms of individual impairment, counting its instances and reducing its complexity to issues of medical prevention, cure or rehabilitation (ibid. p. 215), the social model regards disabled people as an oppressed group, and disability as 'a relationship between people

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[13] For more on the important role of families in enacting this ideology, see for example, Weiss 1994, see also Pearce 2006

with impairments and society' (ibid. p. 216), which is built into the barriers that exclude and isolate them. The features of such barriers include lack of access (to buildings, for example), inadequate transport, unsuitable housing and interior features (such as out of reach switches, for example), rigid work routines and lack of updated aids and equipment (ibid. p. 215) but also ignorance, prejudice and negative attitudes (Sajid 2009, p. 13). Violence against disabled people is a case in point; it is an instance in which the disabled body is targeted because it deviates from the norm, as this transcript from an interview with Andrea, a 55-year-old woman with Achondroplasia [a form of dwarfism] shows[14]:

Figure eleven. Andrea.

13:06:07 I was taking my dog out for a walk. It was around 6:30 in the evening, it were light outside, it were quite quiet because of Covid-19, and I was walking across the road from the apartment where I live. I didn’t notice anyone on either side of the road other than it was me and – and the dog.

13:06:52 And then I just heard someone say, "I dare you to go and kick that midget in the head". It’s a word I really hate, it’s a word that has followed me all my life, where it’s... I find it very derogatory, very ignorant…

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[14] These words come from a transcript taken from the original interview with Andrea, but the entire interview is not completely reproduced in the film.

13:07:36 So I looked over the road to where – where it had come from, but as I looked over, the person that had... A man aged around 20 year old appeared in front... of me, and he kicked me in the head, in the face, and then ran off. I stumbled; I didn’t fall. On CCTV you can see that I look down, and I think I must have been looking, I don’t know, but I think I may have been looking to make sure I’d still got the dog.

13:08:21 And I went home, I just went home. And looking back now, I think I was in shock, because all I did was, I went home, and I just sat on the sofa for the rest of the evening. I didn’t speak to anyone, I didn’t tell anyone, I didn’t do anything, I think I was in shock and when I got up the next day my eye had closed, it was black, bruised.

13:09:06 ...my partner came in and he asked me what’d happened and I told him, and he said "and what did the police say?" So, I said, "I’ve not rang the police". So, he said, "why?" So, I said, "well, I – I don’t think they’ll be do anything, to be honest". He said, "Don’t be silly, ring the police or I’m going to ring them". So, I did, I reported it to the police. The police took a statement over the phone and asked if Andrew would send photographs of my injuries, and suggested that I went to A&E to get it checked out, which is what I did... When I went to A&E, they did various X-rays and a CT scan, and as a result of the incident I’d got a perforated ear drum and a fractured skull...

Later in the interview Andrea talked about how she felt people with dwarfism are viewed by society at large:

14:19:50 ...I mean people are marching at the moment because of what happened in America to that young gentleman [George Floyd] which was horrendous and I wouldn’t ever want to take anything away from that, but I’d be interested to see what would happen *if – if we got thousands of people with dwarfism marching down the street, what would happen then? We'd all get laughed at.*

14:20:25 ...They'd probably tell us all to go home, "just go home, stop being stupid, you're a dwarf, accept it". Why? why should we? We really shouldn't have to. But society makes you feel you do. You feel you've got a constant battle. Every day when you get dressed you don't just have to put your clothes on, you've got to put your wrestling tights on because when you go out there that's what… You've got to prepare for a battle... Like I said earlier, you have to choose whether you're going to take that battle on that day or whether you're just going to leave your wrestling tights at home and just have a day off …Those two men that did that to me obviously thought it was okay to do that. And am I supposed to just accept that? Do I? Am I supposed to just think well, it's my fault because I'm disabled? No, I'm not. I shouldn't have to adapt for society, society should adapt for me, not just me, anyone with a disability... Society should adapt for them, not… not – not the other way round. If you've got a disability, that's hard enough; having a disability without having to try and adapt for the expectation of society. And also, to be made to feel that you've got to accept people name calling, pushing you about, pointing, laughing, staring. Because if it's not good enough… if it's not acceptable for other differences why should it be acceptable for people with a disability?

It is testament to the power of the social model that Andrea, who left school in 1981 at 18, is fully aware of the predicament her difference places her in and that it is society's responsibility to accommodate her needs - the fundamental tenet of the social model.

Again, in the film (*Targeted: The Truth About Disability Hate Crime*) the social model, with its focus on structural factors is relevant and is applied in explaining Ailsa's eventual homelessness in particular, by her advocate. In relation to the housing problems Alisa experienced, one can reflect on Shakespeare's observation that violence against disabled people may be more common on deprived housing estates. He speculates that this may be motivated by the boredom and anomie of life on the margins, and resentment of disabled people, who are perceived to be getting access to better welfare benefits (Shakespeare 2014a, p. 234). He goes on to speculate that disempowered people who feel insecure or devalued may well be more likely to commit such crimes (ibid. p. 235), so that such an act may 'strengthen... their own sense of self as individuals or boost... their status in their wider peer group' (ibid.). It is, after all, always easier to punch down than up.

Politicising disability was a crucial, positive move we can attribute to the social model. It enabled disabled people to allocate moral and legal responsibility to society (which, for example, led to the 1995 Disability Discrimination Act[15]). But it is arguable the degree to which keeping impairment private has helped disabled people to live better, to have improved self-esteem and a sense of collective identity (see for example, Shakespeare 2014b, p. 217). Given the aesthetic emplacement of disabled people in our society (see Hughes 2000, for example), attacks such as those upon Andrea highlight a key limitation of the social model in regarding impairment as a private, individual affair - disabled people's bodies are public and social at the very least in how they are aesthetically judged. 'The problems of living with a disability are not private problems... separate from the rest of life and the rest of society.' (Wendell [1989] in Abrams 2015, p.10).

Lived experience, impairments and the body

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[15] The 1995 DDA was not an unqualified success, though. See Oliver 2017 and 2019

Shakespeare argues that the social model 'evolved into a rigid ideology claiming that disability was everything to do with social barriers, and nothing to do with individual impairment' (Shakespeare 2014a, p. 14). This relegation of impairment to the private, individual world is problematic because '... people with impairments are disabled by society *as well as by their bodies*...' (emphasis mine, Shakespeare 2014b, p. 218). The social model does not permit for a bodily understanding of disability when, for disabled people, the body is particularly pertinent: '... The impaired body is a "lived body". Disabled people experience impairment, as well as disability ... as part of a complex interpenetration of oppression and affliction.' (Hughes & Patterson 1997, pp. 334 - 335).

As Patterson & Hughes argue, as well as the physical pain many disabled people experience, impairment also involves conditions that are not biologically painful but that are problematic nonetheless (Patterson & Hughes 1999, p. 602) because '... the disablist and disabling socio-spatial environment produces a vivid, but unwanted consciousness of one's impaired body' (ibid. p. 603). This 'vivid... consciousness' occurs by virtue of having to constantly negotiate a hostile and/or difficult environment. For me, this engagement is riddled with difficult propositions that I must solve, e.g. How do I open that door with all these parcels under my one functioning arm? But steering through a difficult world is not limited to the physical - it includes other issues of a non-corporeal nature; for example, for the neurodivergent mind there are endless hurdles and traps in their navigation of social situations, and their behaviour may signal their disability to the non-disabled. A non-disabled[16] lived body

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[16] "Non-disabled" is used here to mean unmarked, and there are a variety of alternative terms one could use - for example,'TAB' (Temporarily Able Bodied [that takes into account human mortality, so that everyone will eventually be deprived of their able-bodiedness]) or for example, 'normate' - both of these options feel too jargon-like to me (and 'normate' has extra meanings of seeking to disrupt the taken-for-granted meaning of normativity). On the other hand, 'able-bodied' does not make that impression. I

can perhaps be more taken-for-granted. It is when one's body has challenges and/or problems that one becomes conscious of it; when one fails to socially navigate a situation, that one realises there are problems, for example, chronic pain which though invisible, '... re-arranges our lived space and time, our relations with others and ourselves' (ibid. p. 603).

In relation to this, Patterson & Hughes examine Leder's 1990 discussion of the term 'dysappearance'. 'Dysappearance' is what happens to disabled people when their experience of pain (physical or otherwise) makes them extra conscious of their body. The taken-for-grantedness non-disabled people enjoy rests, they argue, on norms that 'largely reflect the carnal information of non-disabled people' (Patterson & Hughes 1999, p. 603) which leave disabled people at a disadvantage. They use the example of speech impairment: 'Exclusion from and disruption to communication is not... a matter of the ability of an impaired person to communicate, but about conventions and norms of communication which are (*a priori*) hostile to non-conforming forms of physicality' (ibid.). If embodiment creates one’s perspective of being in the world, then impairments clearly cannot be excluded from what we mean when we discuss disability. There is something real and true about impairments that must not be lost if we are to take disabled people's perspectives seriously.

Critical Disability Studies

The social constructivist principle gained traction in disability theory and helped politicise disability issues by using positive representations of disabled people as empowered, their

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prefer 'non-disabled' because able-bodied implies that disabled people are not able to 'use their bodies well' (see guidance for language use by the National Centre on Disability and Journalism - https://ncdj.org/2015/09/terms-to-avoid-when-writing-about-disability/#:~:text=Able%2Dbodied%3A%20Refers%20to%20a,to%20use%20their%20bodies%20well).

disabilities as sites of resistance. The social model has been a crucial conceptual and political move because it 'countered the traditional assumption that disability is the direct result of an individual deficit or incapacity' (Anders 2016, n.p.), and it has enabled a mode of resistance to the social majority's pejorative constructs and received forms of knowledge that insist on disability exclusively as a medical condition or fact of the body – although it is also that, which must never be lost sight of. The point is that '...disability, as an effect of social oppression, is naturalized through medical and popular discourse as the "symptom" of individual attributes... of impairments' (ibid.).

Whilst theorising about disability has something to offer, insofar as it can tease out some of the sociocultural structures that contribute to the exclusion and adversity disabled people face, the actual lived experience of disabled people is frequently neglected, especially by scholars in Critical Disability Studies (see for example, the post-structuralist and post-modern work of Shildrick (1997), Goodley (2011), Tremain (2002), McRuer (2006)[Shakespeare 2014a]. Shakespeare uses the term 'cultural disability studies' to encompass the theoretical approaches taken by these and other scholars). This neglect can yield a situation where academic studies become irrelevant, as Wendell notes when she argues 'much, probably most, of the truth about disability is not to be found in academic writing' (Wendell 1996, p. 7).

In chapter one I argued that McRuer's crip theory was problematic because of how, in merging all minority groups together as 'crips', disabled people are inevitably going to be made invisible and erased once again as other, non-disabled people 'come out crip'. Whilst the constructivism of the social model has enabled disability to become politicised in a way that is helpful to disabled people, it is a matter of some consternation that in the writings of post-structuralist scholars constructivism has been taken too far, and these writings do not chime with the lived experience of disabled people in the world (see for example, Siebers 2001). Not entirely unlike medicalised approaches to disability, with the need to classify and group disabled people, Critical Disability Studies scholars reduce disability to a semiotic object, a 'class' of all things disabled. As Siebers argues, ‘social constructionism, as an argument, 1) limits the political possibilities of people with disabilities and other minorities, 2) refuses to allow that disabled identity possesses verifiable knowledge about the world, and 3) discounts the disabled body, limiting the importance of its appearance and feelings’ (Siebers & Bieling 2014, n. p.). Such social constructivist approaches have impact on methodologies by reducing the material and biological body to a theoretical construct far removed from the actual experience of disability.

Siebers critically comments on the post-structuralist idea that representation governs the body, by positing the argument that disabled bodies affect and alter how processes of representation themselves take place: ‘… Deaf eyes listen to television… Feet wash the breakfast dishes. Mouths sign autographs ’(Siebers, 2001, p. 738). Reducing disability to some kind of representational object means neglecting the potential contained in this bodily power disabled people have to affect and alter, and thus it silences and evades disabled people's agency, inhibiting possible developments in how they can contribute to society. The differences disabled bodies make ‘…require and create new modes of representation ’(ibid.), which both weak and strong versions of social constructionism have blunted and failed to address, but which in principle, seem promising.

Social constructivism is important because it is through representation that normalisation serves, ideologically, to marginalise disabled bodies and thereby causes oppression. This social constructivist principle rightly gained traction in critical disability theory. However, this was accomplished by omitting any real engagement with the often difficult and painful physical realities of disabled people. The social constructivist idea that culture determines meaning is important, and a disabled person is not outside culture. But the body is also a lived reality, a physical truth. One might say post-structuralists are happy to 'replace... truth with discourse' (Goodley 2011, in Shakespeare 2014a, p. 52) by viewing 'language as the agent... (whilst treating) the body ...as a language effect rather than as a causal agent' (Siebers 2008, p. 2). See for example, Shildrick's statement that she understands 'all bodies to be discursively constructed rather than given... all bodies are in some sense phantasmatic' (Shildrick 2002, p.4).

A pertinent instance of this failure to consider impairment as true and real, concerns the use of Foucault's notion of biopower to interpret the act of diagnosis. Foucault's concept of biopower does not engage directly with physical reality but instead with how knowledge, enacted by powerful agents (such as authoritative doctors, for example) who 'impose their standards of normality and deviance' (Shakespeare 2014a, p. 63), constructs bodily reality as it is. Shakespeare discusses various examples of how some cultural discourse analysts have used the concept to reduce impairment to diagnosis: '... impairments understood as the traits associated with disabilities seem little more than diagnoses' (Areheart 2011 in Shakespeare 2014a, p. 63). But for Shakespeare, diagnosis is not really the problem, 'and nor is the label which you give to my skeletal dysplasia/restricted growth/dwarfism/achondroplasia, let alone my spinal cord injury and consequent neuropathic pain. My problem is my physical embodiment and my experience of negative symptoms arising from impairment' (ibid. p. 66 - 67). My personal experiences are mixed. Obtaining a diagnosis for my autism and ADHD was very useful as it helped me to understand my life better. On the other hand, the medicalisation of my withered arm at a very young age, was an unhappy additional layer upon my own unexamined self-understanding as a 'normal' kid.

Despite the advantages of diagnoses for obtaining various kinds of social support, practices of diagnosis are imperfect and must be criticised because they have undoubtedly contributed to the suffering of disabled people. The critique contained in the concept of biopower is useful as it can be used to, for example, 'expose and criticise failures of diagnosis and of professional response to diagnosis' (ibid. p. 58). Shakespeare notes how 'within medicine and psychology, actually existing diagnosis may sometimes be mistaken and even oppressive. The treatments - electroshock therapy, hypnosis, Ritalin - may be crude, may be over-prescribed, and may have damaging side effects' (Shakespeare 2014a, p. 64)[17]. But none of this takes away from the fact that impairment is the ontological or material reality (Shakespeare 2014a, p. 65) disabled people live with, and it cannot be treated as only discursive power/knowledge. As Wendell says: '... in most postmodern cultural theorizing about the body, there is no recognition of – and, as far as I can see, no room for recognising – the hard physical realities that are faced by people with disabilities…' (Wendell 1996, p. 45).

Restoring the body to the social - disability as itself

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[17] A famous example of this is the pathologisation of homosexuality.

Siebers wishes to examine the proposition that disabled identity has the potential to 'transform critical and cultural theory' in the field of minority identity (Siebers 2008, p. 3). The disabled identity functions to violently and unnecessarily exclude impaired people from society, but it also functions as a symbol that marks *any* '... difference that secures inferior, marginal, or minority status' (ibid. p. 6). It is a foundational symbol that informs discrimination against other minority groups - being of the wrong gender or sex; looking and behaving in ways that mark the wrong class; being of the wrong race, etc. - as well as shaping negative attitudes towards human conditions of vulnerability such as poverty, childhood, old age, etc.. That its presence as a marker is not recognised but instead 'serves as an unacknowledged symbol of otherness' (ibid.), raises the question of what would happen if we were to insist on 'its presence and reality' (ibid.) by restoring the impaired body to centre stage.

For Siebers it is worth paying attention to similarities between different minority identities because, insofar as minority groups are excluded and marginalised, they are able to make common cause, sharing a solidarity that is based on the critical potential their situated knowledge offers in relation to mainstream values (such as ableism). For McRuer's crip theory, this solidarity justifies claiming a 'crip' identity whether or not a person has impairments, which is suggestive of a kind of merger of minority identities, under the generalised rubric of 'crip'. In this sense, social constructivism seems to have been taken too far, as what it means to be disabled is taken in a symbolic sense and the lived reality of impairments is left out. Whether or not a disabled person shares with the non-disabled the feeling that disability is a symbol for what it means to be fully human, they are not just a symbol but a fully embodied person.

Siebers though, does not put aside the impaired body, suggesting instead that social constructivism can be taken 'in the direction of realism' (ibid. p. 30) by acknowledging the complex embodiment of disability. He argues that theory should describe 'reality as a mediation ...between representation and its social objects' (ibid.). I take this to mean that disabled people, living with impaired bodies as well as with what it means to be an embodiment of a key social symbol, have a very specific perspective on the world. At the same time, it also means we should be critically conscious of the role representations play in situating disabled people as excluded.

CONCLUSION

In this chapter I have argued that, in Disability Studies, we must take descriptions of lived experience seriously. To seek them out as a way of exploring the embodiment of varied human form and use this to attempt to inform others that the difference of disabled people is not so uncommon as they may imagine (or have been told) nor is it something to fear or strive to destroy. The chapter aimed to add to views that reinstitute the importance of the body itself without reverting to the medical model.

In examining an auto-ethnographic example of a medical approach to disability in childhood, I have raised the issue of children's agency, in particular the importance of listening to disabled children's perspectives on their lives and their disabilities. To an extent, such perspectives show there are social factors which cause a person to come to see themselves as 'disabled' and which simultaneously disempower disabled people, even internally, in how they see themselves. The social approach to disability is undeniably powerful in providing insights into what it means to be disabled.

On the other hand, despite the political strength we gain from examining disability as socially constructed, unless we include the impaired body - with all its pain, inconvenience, problematic 'lack of fit' with what is 'normal' - there is the risk that academic theorising will be irrelevant and will not contribute to improving the lot of disabled people, an aim Oliver brought to disability studies (in his ideas about 'emancipatory research') and one that critical disability studies scholars also subscribe to. Whilst a medical approach to disability can make an important, positive difference to a person's life, the bodily reality of the impaired body cannot be limited to the individual at the mercy of medical expertise but must be examined further, in the context of the lived, social experience. This experience involves confronting on a continual basis, the negative attitudes arising from ableism, which are perpetuated through derogatory, patronising or exploitative cultural representations that stand in for the fear and denial of human frailty, disease and mortality. My approach, which emphasises disabled people's agency in telling their own stories and challenges epistemological oppression, seems necessary.

It may be that disabled people, as a result of their 'situated knowledge' (which, as Siebers points out 'adheres in embodiment' [ibid. p. 23]), which is specific to them and which is not the same as or reducible to the situated knowledge of other minority identities, can themselves offer a way forward because, intriguingly, their very impairments challenge conventional processes of representation. This possibility is one I explore further in chapter four. Before that though, I examine aesthetics, in chapter three, because of the important way in which representations come to embody prejudices against disabled people despite how, as Siebers argues, disability seems to inform art and culture in a fundamental way.

Chapter three: Are you sitting uncomfortably? Disability and social problems

Introduction

In the previous chapter I examined academic approaches to disability and how impairment matters and cannot be excluded from discussions because '... the body is at the heart of social life, and... its constitution is both biological and cultural' (Hughes 2000, p. 556). People with impairments are disabled by both society and their bodies. In focusing on the impaired body, it becomes possible to consider disability not just as a symbol of what it means to be fully human, but as itself - as a real and lived experience of bodily and/or mental impairment.

This issue is also important because, in insisting on the need to fully include the impaired body in our understanding of disability studies and disabled people, it becomes possible to properly address the problem of negative aesthetic judgements. In this chapter I examine aesthetics in more detail - as they are embodied in the everyday - by providing practical examples of how these judgements play out in the social problems disabled people face and thus, the meaning disability has for the non-disabled - as a reminder of human frailty and mortality - can be examined in a critical way.

The aestheticisation of contemporary life that has accompanied consumerist society (see for example, Featherstone 1991 in Hughes 2000) has, as I noted above, led to an '...aesthetic stratification as powerful as class, gender or ethnic stratification' (Synnott 1993 in Hughes 2000) and suggests there is a need to examine the aesthetic aspects of disability. Whilst negative judgements about disabled people are numerous, they are also aesthetically informed, as aesthetics, in a semi-/unconscious way, inhabit the body and the everyday. In the next chapter I return to this issue of aesthetics in relation to how disabled people are represented and I comparatively examine three films. Whilst, in these reviews, I examine aesthetic dimensions from a non-everyday perspective, here I would like to explore problems disabled people experience in a more everyday sense.

Embodied aesthetics

The term aesthetics is most commonly connected to notions surrounding art objects and other productions of high culture, and it is often used interchangeably with the idea of beauty: 'When people in general speak of "aesthetic objects" what they really mean is "pretty objects" or the equivalent' (Mandoki 2010, p.6). However, the etymological origin of the word aesthetic comes from Greek *aisthetikos*, which means "of or perceptible to the senses". This original meaning, then, 'extend[s] to the entire realm of sensuous apprehension' (Begam 2006, p. 43) and, in this vein, Baumgarten argued that aesthetics concerned the sensations some bodies feel in the presence of other bodies (Siebers 2010, p. 1).

It was Kant who, building upon Baumgarten's ideas, reformulated the meaning of the word, 'transforming the immediacy of its experience into the abstraction of thought' (Begam 2006, p. 43), making it 'philosophically respectable' (ibid.) by converting 'sense' into 'sensibility' (ibid.) and 'cordoning off aesthetics from the physical and empirical world... dematerialis[ing] it ... [and] cut[ting] it off from its vital source in the human body' (ibid.). An example of the effects this 'cutting' had can be found in the ideal of 'disinterestedness'. This terms refers to how the viewer is meant to evaluate a work of art in an objective way, with no physical or emotional reactivity; it is a denial of the reality of embodiment and it exemplifies how 'the underlying corporeality of aesthetics ... (was replaced) with idealist and disembodied conceptions of art' (Siebers 2010, p. 1), resulting in a devaluation of the role of the body as well as a limitation of the definition of art (ibid.).

This sensory connection is important because of how it permits us to restore the concept of aesthetics as grounded in the body and the existential condition of human life, (which includes the sociocultural but which might even include the biological[18]). In other words, the realm of the aesthetic does not have to be restricted to art objects and high culture, or to 'pretty things', but instead it pervades the whole of human life and is an embodied experience whether we are responding to high culture and art objects or to everyday experiences. For example, in her interview with Sinclair, Gill argues that it makes sense to use the term 'beauty industrial complex' to characterise how there has been a 'blurring' of the cosmetic, pharmaceutical and surgical industries in the development and promotion of beauty procedures. This focus on one's image, as part of an aesthetic labour expected of one, has affected the workplace to such an extent that it has become normal to have a cosmetic surgical procedure during one's lunch break (Sinclair 2017, n.p.).

Everyday aesthetics - appearance and behaviour

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[18] see for example, discussions about neuroaesthetics - Brielmann & Pelli, Chatterjee et al - and the findings that suggest the possibility that some aesthetic responses are a phenomena of the brain and thus may well be cross-cultural and universal

Disabled people, with visible and/or unseen impairments, experience oppression in their everyday lives, whether because of their visual appearance or because of their non-conformist behaviours. Naukkarinen has done interesting and illuminating work on what has become known as 'everyday aesthetics' (see, for example, Naukkarinen 2017 & 2013. See also, Melchionne 2013, Mandoki 2010). Naukkarinen examines what he terms 'my everyday now'. Included in this idea of the 'everyday' are objects, activities and events (and linked attitudes and relations), which form part of our normal, routine, habitual life, often experienced in our work, home, and hobbies (Naukkarinen 2013, n.p.). Again, Melchionne (2013) lists five key areas of everyday life in which aesthetics of this kind can be considered: food, wardrobe, dwelling, conviviality, and going out (in Naukkarinen 2013). In fact, for Naukkarinen (2017), everyday behaviour is one of the most significant areas of everyday aesthetics.

One important difference between the aesthetics of art and everyday aesthetics is that art objects and/or high culture are not experienced as routine, but instead, as exceptional, strange experiences - as ruptures to the normal - whereas the idea of everyday aesthetics, precisely because of how it is about the safe, comfortable and normal, tends towards a kind of conservatism (Naukkarinen 2017). Thus, when thinking of aesthetics as embodied, a disjuncture emerges between art and the everyday, which Siebers has not taken into account: '…disability aesthetics does not have to be limited to works of art... It can also play a significant role in… (designing) a society in which the buildings, household objects, automobiles, tools, computers, jewelry, furniture — all these things and more not only accommodate the disabled body but also reflect the aesthetic values of disability' (Siebers & Bieling 2014, n. p.). In how he moves from art to fields of the everyday, Siebers does not acknowledge this disjuncture.

In the everyday, people expect what they feel are 'normal' appearances and behaviours (although of course, what is deemed normal and routine varies across different cultures). This idea of 'normal' is one that infuses our lives, starting from childhood: '... the first context in which we encounter and learn aesthetic values, practices, and requirements is our normal, daily life. From a very early age, we are repeatedly guided to... behave nicely... Such demands... are aesthetic guidelines for our social life. They tell us what kind of behaviour is expected and how it looks, sounds and feels' (ibid. n.p.). This infusing leads us to take our notion of normal for granted, to such an extent that it disappears into the semi- or unconscious. As Berleant notes, 'occasions of aesthetic value ... do not lie at the surface of conscious perception in everyday life for most people' (Berleant 2011, p.75) and Naukkarinen notes that we rarely 'verbalize our aesthetic evaluations' in everyday life, so that the 'aesthetic character of a given situation can remain implicit from other people's perspective' (Naukkarinen 2017, n.p.).

The everyday and high culture are intertwined

I have drawn a contrast between aesthetics that is about art objects and high culture and aesthetics that concern the everyday. A defining characteristic of everyday aesthetics is how they are naturalised, embodied as the way things are, and thus are not at the surface of our consciousness. Their power is precisely that of seeming 'normal', affecting our social interactions in an unquestioned manner. Particularly problematic for disabled people is that a taken-for-granted sense of the normal is deemed the way things are and *are meant to be*: 'the aesthetic fuses with the moral' (ibid.) because 'aesthetic feelings of pleasure and disgust are not easy to separate from political feelings of acceptance and rejection...' (Siebers 2010, p.2). Thus, 'normal' means how things are when things are 'right'.

Everyday aesthetics concerns everyday, ordinary spaces - our homes, the streets and other ordinary public spaces. But art objects and high culture are, if you like, 'framed' - they are separated away in special places that are meant for them, which spaces signify that they are supposed to be remarkable in a way that the everyday is not. In this sense, there is a certain opposition to the normal, a license to art that is not necessarily encountered in the aesthetics of everyday experiences. Gruson-Wood has argued that 'in art, the beautiful is that which disrupts normal reactions, normal perception, normal life, where normal life is about keeping things normal' (Gruson-Wood 2009, p. 16). However, this distinction is also somewhat theoretical as these spheres seem indistinguishable in certain contexts outside of the framing architecture and settings of galleries, theatres, and other spaces given over to art, where the aesthetics of art is positively valued.

Drawing on Shakespeare (and the anthropological materials he uses, i.e. Victor Turner's theories about the social spaces of ritual), one can argue that disabled people are liminal, anomalous, ambiguous; they are 'betwixt and between' (Turner in Shakespeare 1994, p. 296) and fit simultaneously into both aspects of aesthetics - having features from both sides; they occupy normality and everyday life but they also seem to rupture everyday aesthetics; they both belong and do not belong. In my film *Targeted: The Truth about Disability Hate Crime*, Andrea told us about a violent attack she suffered. Here I return to this crime to argue that it was informed by a negative aesthetic judgement. Going out for a walk (Andrea) and hanging about (the youths who attacked her) are both very everyday kinds of scenarios. At the same time, though, their encounter instantiated a rupture to the aesthetic expectations of normality the youths held, which, I contend, was a key factor that led to their violence upon her. The liminal position of disabled people in everyday life does not make the non-disabled view them as 'beautiful' but instead renders them vulnerable to attack.

As Garland-Thomson notes, '...in this economy of visual difference, those bodies deemed inferior become spectacles of otherness while the unmarked are sheltered in the neutral space of normalcy' (Garland-Thomson 1997, p.8). As well as physically attacking Andrea, the youths filmed their act on a mobile phone - presumably to disseminate - before running away laughing. This additional act shows another, rather ambivalent, way that the spheres of the everyday and of 'creating' get mixed in together, here into a form of 'reality tv'[19]. The youths got sadistic thrills - 'We crave aesthetically promising configurations for the pleasure or thrill we can derive from them' (Mandoki 2010, n.p.). Mandoki is discussing aesthetics in relation to art. But Gravell, who discusses abuse and crimes against people with learning disabilities, states '...perpetrators experience a perverse and sadistic pleasure from their acts of cruelty - from seeing others hurt, humiliated, embarrassed, demonstrated as weak and helpless' (Gravell 2012, p. 20). Given the rise of worldwide electronically connected generations, the cross fertilisation of ideas about how to respond to disability and disabled people increases, but whether this leads to more positive outcomes and a more universal acceptance of the ubiquitous nature of disability remains to be seen. Judging by this instance, the prospects for disabled people do not

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[19] It is of some interest that reality tv could be considered to be a modern iteration of the old freak show - see Woolf 2019

seem promising. This violent instance, rendered digital and spread online, is, as Johanssen and Garrisi explain, an example of how ‘collective anxieties of non-disabled people, projected onto disabled people, create and perpetuate harmful representations online’ (Johanssen & Garrisi 2020, p. 12).

This discussion about aesthetics is important because 'the oppression and alterity of disabled people is closely connected to the negative perceptual constitution of impairment in ...visual culture' (Hughes 2000, p. 557). For example, in 1973 in Chicago, Illinois' disability rights activists succeeded in getting a city ordinance repealed. The measure was originally enacted in 1939, and banned from public places anyone: 'who is diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object' (Schweik 2009, p. 279). The ordinance demonstrated 'the persistent nexus of disability and poverty at the heart of the ‘ugly law(s)’, as well as illustrating the complex interweaving of economic interest, social policy, and cultural (including aesthetic) imagination at work' (ibid. p. 24). The Unsightly Beggar Ordinances, now more commonly referred to as the 'Ugly Laws' (Burgdorf & Burgdorf 1975), were not an exceptional case of one city banning the disabled from being able to go about in public. In the late 19th and early 20th century many US cities passed similar ordinances. They were unequivocal in taking aim at the aesthetically displeasing sight of cripples and invalids on city streets.

The appearance of disability disturbs the non-disabled, upsetting their already threatened and fragile sense of self and reminding them of their own frangibleness. Shakespeare argues that disabled people are scapegoats, so that, in how non-disabled people '... are perpetually anxious to deny their own mortality and physicality, ...disabled people are the group onto whom these difficult feelings are projected' (Shakespeare 1994, p. 297). He goes on to argue that '... it is not *our* impairment which frightens people... it is non-disabled people's own embodiment which is the issue...' (ibid. emphasis mine). Whilst it may be true to say that disabled people are a symbol of what it means to be fully human, this renders them vulnerable to attack and negative aesthetic judgements, so it is a major problem for us.

Representation and the media

The advent of mass and digital media has assisted and accelerated the propagation of negative stereotypes about disability, many of which have been identified and discussed since the 1960's. For example, Barnes tells us about eleven 'commonly recurring media stereotypes' (Barnes 1992, n.p.), such as the disabled person as pitiable or as sinister or as a burden, and so forth. Such stereotypes contribute to epistemological injustice and oppression, as they provide an easy way to unquestioningly dismiss a disabled person; they also provide images upon which the difficult feelings Shakespeare refers to can be projected.

A recent phenomenon illustrative of this was a trend on TikTok. Between May 2020 and February 2021, a meme developed denying the existence of Helen Keller[20] and the facts of her life. Not only was it being claimed that she was a fraud and that her teacher, Anne Sullivan, perpetrated a hoax, in some cases it was being claimed she never even existed. The main basis for this particular conspiracy theory appears to be the ableist notion that it is impossible for a

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[20] Cosslett 2021 and Kunka 2021 claim this meme may have started as a 'joke' but then was taken as truth due to the incredulity of TikTok users about disabled people being capable of doing things, a classic example of testimonial injustice

deaf blind person to achieve the things Helen Keller did, which is clearly based on negative stereotypes of a deaf blind person as 'pitiable and pathetic' or as 'an object of ridicule' (ibid. n.p.). The video that sparked this off racked up 600,000 views and, according to Newsweek (Morris 2021, n.p.) there are dozens, if not hundreds, of videos questioning Keller's existence or mocking her deafness and blindness on TikTok. The hashtag #helenkeller has more than 70 million views, #helenkellerisfake has 3.7 million views and #helenkellerhateclub has 2 million views (ibid.).[21]

As Barnes notes, '...media distortions of the experience of disability contribute significantly to the discrimination... (and institutional discrimination)…process' (Barnes 1992, n.p.). It is through the everyday media that citizens add to their understandings of what disability is and what it means, including disabled people themselves, as they also gain information about disabled people’s position and relevance in society. The media is a powerful institution and it can magnify the impact of any given story and be instrumental in causing real damage to disabled people. An example of this is how 'media speculation and simplistic reporting' fuels 'popular curiosity' about big science, such as the Human Genome Project, and can inflate and distort announcements by scientists (Shakespeare 1995, p. 23), leading to beliefs that human

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[21] The inability of people to accept that Keller could possibly communicate, think and have ideas of her own, because she was deaf blind, is not new. Ozick (2003) recounts how Keller was first accused of artifice when she was only eleven years old, and was investigated by staff at the Perkins School for the Blind where she was a student, for apparently plagiarising a fairy story she wrote, called 'The Frost King'. Keller was put on trial in front of several staff from the school after some felt there were similarities between a piece by a published author and Keller s story, and the head of the School called her 'a living lie' (Ozik 2003, n.p.). The experience was distressing for Keller and proved to her early on how easy it was for people who put her on a pedestal to turn on her. In her autobiography she wrote of the incident: 'As I lay in my bed that night, I wept as I hope few children have wept...' (Keller in Ozick 2003, n.p.). Again, when Keller s autobiography came out, in 1903, she was accused of inauthenticity, with interviewers and reviewers accusing her of writing about things that she could never really know about. ('All her knowledge is hearsay knowledge', wrote a reviewer in the Nation [Ozik 2003, n.p.].)

traits such as intelligence or homosexuality or aggression and so forth are caused by genes (ibid.). Given the 'close relationship of medicine to the media' (ibid.), such misrepresentations can benefit the discourses of science and strengthen the case for biological determinism and the medical model, which cannot accept the 'authenticity of impaired life forms' (ibid.).

Biological normality, disabled people and ableism

Grue & Heiberg have examined how polices for and care of disabled people are dominated by a notion of what is normal (an 'empirical norm') (Grue & Heiberg 2006, p. 232) which leads to the structural reproduction of inequality and social exclusion for disabled people because the body and the behaviours that form the empirical norm are those against which disabled people are measured as different, abnormal and other (ibid.). What a normal person should be is not written down, it is knowledge instilled into us from the day we are born, and this ‘knowing’, implicit as it is, uses primarily aesthetic considerations when these judgements are formed. If the body perceived does not get close enough to the 'normal' it is outcast. Garland-Thomson coined the term 'normate' to describe an idealised position that possesses dominance and authority in society (Garland-Thomson 1997, p. 8). The normate is an imaginary everyman whose self-determination, independence, rational thinking ability, and physical sturdiness define our society’s ideals. Garland-Thomson suggests the normate is created through contact with unconventional bodies of all types; for example, people with severe congenital disabilities serve as 'icons upon whom people discharge their anxieties, convictions, and fantasies' and reify their own sense of ordinariness (ibid., p. 56).

Eugenics - the social as the biological

In seeking to explore 'the historical basis for assessing some people as less valuable than ...the normal' (Grue & Heiburg 2006, p. 244), the authors examine Galton's innovations in statistics that enabled him to order human traits not as neutral characteristics but rather in terms of desirability ('rank-ordering'). Galton was 'driven by a strong belief in the blessings of racial hygiene, i.e. eugenics' (ibid. p. 236). He posited that humans inherently differ from each other with respect to character, disposition, energy, intellect, and so on, and that humans inherited the ‘talents’ they would have throughout their lives - this was how the civic or genetic worth of people could be ranked. In 1883 Galton coined the term eugenics, from the Greek for ‘well bred’. The eugenic movement he thus initiated was based on this notion of inheritance - the belief that mental characteristics such as intelligence and diligence pass across generations in the same way as physical traits such as blue eyes do. Most early statisticians were eugenicists, the authors note, and social policies of the early half of the twentieth century were dominated by their views, which valued people largely according to how productive they could be in an industrialising and modernising world (this point relates to Hahn's 'functional model' which I discussed in chapter one).

Eugenics was a highly influential theory at that time and eugenic societies were established in most western countries, their views - 'of limiting the number of "the genetically inferior" in the population' (ibid. p. 237) - very publicly propounded by all kinds of agencies, intellectuals and lay people (Grue 2009, p. 1). Such 'limiting' found expression in sterilisation (forceful or not) laws and practices across western countries, but included more extreme discussions - public and private - about 'eliminating' impaired children at birth (Grue & Heiburg 2006, p. 237) and euthanising disabled people. For example, in 1908 D. H. Lawrence wrote, in a letter to his friend: 'If I had it my way, I would build a lethal chamber big as the Crystal Palace, with a military band playing softly, and a Cinematograph working brightly; then I'd go out in the back streets and main streets and bring them in, all the sick, the halt and the maimed; I would lead them gently, and they would smile me a weary thanks; and the band would softly bubble out the "Hallelujah Chorus"' (Carey 1992 in Grue 2009, p. 2). The incarceration of disabled people in large institutions, and programmes sterilising the mentally deficient were enacted across Europe and in America, (where immigrants from Southern Europe were also seen as 'feeble-minded' and thus whose numbers were restricted in the Immigration Restriction Act of 1924, because they did not perform well in IQ tests due to their lack of fluency in English [Hubbard 2014, pp. 76 - 77]). It is worthy of note that poverty, criminality, alcoholism, prostitution and other social problems were also regarded as biologically inherited (ibid. p. 77) and, in concert with these ideas, came the industrialisation of charity, often run by eugenicists, whose imagery and practices contributed to recreating the old tropes of the deserving and undeserving.

This ideology of eugenics reached its ‘ne plus ultra’ in the Nazi Aktion T4 euthanasia programme and its unofficial counterpart, which involved gassing sick and disabled people, mostly children, or poisoning them or starving them to death (Grue & Heiburg 2006, p. 240), prior to the development of the extermination camps where Jews, gypsies, communists, homosexuals and other 'undesirables' were selected and eradicated for being deemed 'diseased', 'their presence... an infection or a cancer in the body of the *Volk*.' (Hubbard 2014, p. 81).

Gene technology – “Newgenics" for the twenty first century

Whilst Nazis' eugenic practices have been widely condemned, Grue & Heiburg argue that the more widespread pernicious notion of normality they were rooted in persists and can be found in a range of practices and policies concerning disabled people, for example, in ideas of 'rehabilitation', 'prosthetics', 'normalisation' and 'integration'. Furthermore, modern public health, genetics and biomedicine are more strongly linked to old eugenics than we might wish to acknowledge, according to Grue (2009, p. 7), especially because 'combating disease supplies the perfect moral justification for pursuing a gentler "eugenics quest" than in the first half of the twentieth century' (ibid.).

Prenatal testing is seen by some disability scholars (for just a few examples, see Shakespeare 1995, Hubbard 2014, Thomas & Rothman 2016) as a form of eugenics, because 'scientists and physicians... are once more engaged in developing the means to decide what lives are worth living' (Hubbard 2014, p. 82) in their use of gene technology. Once again, though differently, 'gene location is the means for a strategy of eugenics by limiting defective fetuses' (Shakespeare 1995, p. 31) with one difference being that nowadays 'pregnant women themselves have to make the decisions, euphemistically called choices' (Hubbard 2014, p.82) over whether or not to abort. Such a choice may not really be a choice at all if the only alternative is more 'dreadful' (Morris 1991, n.p.). Women know 'that society does not provide adequate resources for disabled people' (ibid.) and they also know, and may even share in, ignorance and prejudices about disability (ibid.). As well, the encounter between doctors and patients, the situation in which women or parents make these 'choices', is a 'specific context of power' (Shakespeare 1995, p. 26) and cannot be unquestionably accepted as non-directive and neutral but rather must be understood as part of 'oppressive social relations... which allow... no value or viability to disabled people's quality of life' (ibid.).

Abortion

A person's quality of life cannot be predicted through genetic testing and other forms of prenatal screening and diagnoses, and yet discrimination against disabled people is enshrined in British law in the form of the 1967 Abortion Act where it is legal to abort a foetus up to and including at term if the foetus is disabled, but only up to 24 weeks when the foetus is 'normal'. The act was amended in 1990 but the provision remains, abortion is permitted if: '(d) ...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' (legislation.gov.uk, n.p.). The rules are different for the non-disabled but the potentially disabled child is not afforded legal protection. There is also a complete lack of definition in the legislation as to what constitutes ‘seriously handicapped’. However, there are no grounds for this discrepancy as 'people with impairments are fully human, deserving of equal rights...(as) everyone has a part to play and a contribution to make' (Shakespeare 1995, p. 27). Morris argues that predefining the potential quality of life for any person is to make a subjective judgement about the worth of a life, which judgement here takes place in 'the context of a society which is generally hostile towards disabled people' (Morris 1991, n.p.). It is also worth noting, as Morris does, that such judgements are usually made by non-disabled people when it is disabled people who must 'define the negative things about (their) experience - and not the medical profession, health and social services professionals, parents or other non-disabled people' (ibid., n.p.).

Post-natal disabled babies

Ignorance and prejudices towards the impaired body are dramatically apparent in the rejection of deformity in new-born babies. Israeli anthropologist Meria Weiss carried out a quantitive research study into the rejection of appearance-impaired babies by their parents. Her 1994 research demonstrates the significance given to ‘body image ’and how aesthetic judgements determine the future of a child. Weiss collected data on parents' behaviour towards 1,450 children across three major hospitals in Israel over a period of six years. She found that 68.4% of the parents in the study abandoned a child with a visible deformity regardless of the severity or long-term prognosis for the child; but in the case of a non-visible disability (for example, a heart condition) the number abandoning the child dropped to 7%. The appearance of the child was paramount in the parents ’acceptance’ of him or her as a family member. This also held true for children who later became visibly disabled. Weiss offers a fascinating analysis of the bio-politics of falling in love (or not, in the majority of cases) with one’s physically imperfect child, referred to as 'appearance-impaired'. She shows how a child’s appearance determines the parents' terms of affection, and explores practices of abandonment, dehumanisation, territorial seclusion and abuse to which parents will subject their appearance-impaired child.

The social and the biological

It is important to note that only a small proportion of disabled people are congenitally impaired and most impairment is caused by ageing, degenerative disease, lifestyle/consumption patterns and traumatic accidents (Shakespeare 1995, p. 32). A medical approach to disability is 'based on the disabling extrapolation that bio-physical "maladaptation" ...leads to social maladaptation'

(Hughes 2000, p. 555). Biological/genetic determinism claims to explain the social, reducing the social to the biological. Biomedicine in this respect then, provides us with an example of ableism[22].

A sociological approach to disability and impairment permits us to reject such biological determinism and see disability as socially determined, rooted in how disabled people are regarded and treated as inferior. As well as arguing that it is 'easy' to imagine a world not dominated by the principle of normality (Grue & Heiburg 2006, p. 233), Grue and Heiburg want us to challenge our concept of normality because it is not supported by biological facts. Instead, they examine how our unique genetic variations mean 'we are all "mutants"' (ibid. p. 243). The principle of normality is based on similarity, a genetic similarity between humans; but for these authors, variation is what should really 'represent the "norm"' (ibid.). A similar argument is made by Shakespeare (1995) who examines how genetic variation helps us to see how complex and non-reducible impairments are. He focuses on how everyone is impaired - physicality involves impairment (and ultimately death) - so that a view of human life which embraced that fact would be healthier' (Shakespeare 1995, p. 28 - 29).

A 'no-win' kind of social inclusion

Whilst we can argue against biological determinism, this does not mean social life has become truly inclusive and egalitarian. Instead, disabled people's lives are still in thrall to inequality and exclusion even if these shift around the social system, as Shakespeare notes. He argues that,

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[22] It also shows us how powerful ableism is, for example, in how the Human Genome Project's 'rhetorical impact' (Shakespeare 1995, p. 23) spreads through media speculation and simplistic reporting, fuelling popular curiosity (ibid.), ignorance and prejudice.

'while it may once have been true to say that to be disabled was to be poor and excluded, that judgment now has to be qualified' (Shakespeare 2015, p. 65) because, despite the gains in civil rights that have been won by the disability movement, there are significant, though under-researched, variations of the impact of inequality between impairment groups (ibid., p. 63), particularly across social class, where differences are notable between the lives of working class and middle class people with impairments. He uses the example of the knowledge economy to explain how those with physical or sensory impairments will 'enter the mainstream and enjoy better quality of life' whilst the same cannot be said of 'those with intellectual impairments... mental health conditions... or speech or communication difficulties' who consequently will 'remain excluded from the labour market and disproportionately poor' (ibid. p. 65). Thus, as 'some disabled people are moving ahead in the race, ...others remain at the starting gate' (ibid.). What Shakespeare wants is a 'more radical social philosophy' (ibid.) that could lead to the emancipation of all disabled people.

Oliver identifies two phases in disability history. The first, dating from the 1970s to 1997, is characterised by 'disability politics, activism and pride', whereas the second, heralding changes from when New Labour was elected, has not yet come to an end and is characterised as 'disability corporatism, managerialism and special pleading' (Oliver 2019, p. 1028). He tells us that New Labour, in seeking to manage capitalism better than previous governments, wanted to reduce the welfare bill and embarked on an ideological battle 'by raising issues around fraud and scrounging in the benefits system, the bureaucratic nature of the health service and the dependency-creating nature of state welfare generally' (ibid. pp. 1030 - 1031). Insidious and deceptive changes in state provision followed, which were then continued by subsequent governments, while 'protests became much more muted and reliant on special pleading... Privatisation and the contract culture benefitted the big non-disabled led charities more than the organisations of disabled people who often found themselves short of funds and forced to close' (ibid. p.1031). Both my films, *Targeted: The Truth about Disability Hate Crime* and *The Truth about Disability Benefits* are pertinent here, as they show how beliefs that disabled people are scroungers and cheats lead people in the social worlds of disabled people to target and attack them. On the other side, such beliefs help obscure how the system of benefits has been partly privatised and outsourced for purposes that have nothing to do with benefitting disabled people.

Historically, disabled people's scope for social participation has been limited by segregation and by problems of access to the public domain, for example, to mainstream education, transport and the labour market (Hughes 2000, p. 556) so it is unsurprising to still find that many disabled people are poor. As Hughes notes, 'while care and rehabilitation did much for the reputation of the medical profession, for disabled people, such practices served, primarily, to sustain the myth that they were sick and dependent' (ibid., p. 556). Disabled people have often had to find unconventional ways to make ends meet. For example, the use of “Ugly laws” in the USA meant disabled people were not able to earn money on the streets. This led to the development of mendicant literature and photo-cards, alongside the freak show, as alternative ways to make a living. Interestingly, these were also a means disabled people created, to control their own narrative[23]. In an era when state aid did not exist for the disabled nor could they work, the freak show was a viable form of income and, to a degree, independence.

For those disabled people who are poor, to receive support for their disability is determined by the state in the form of bureaucratic assessments and clerical regime (here it is pertinent to watch the film I have submitted as part of this degree, listed in chapter one, *The Truth about Disability Benefits*). The way disability benefits are administered in the UK (and many Western countries) is a clear example of 'biopower': '... techniques of power... essentially centred on the body, on the individual body. They include... all devices... used to ensure the spatial distribution of individuals' bodies (their separation, their alignment, their serialisation, and their surveillance) and the organisation, around those individuals, of a whole field of visibility. They were also techniques that could be used to take control over bodies...' (Foucault 2003, p.242).

Although Foucault was referring to all bodies rather than, specifically, disabled bodies, how the disabled are 'managed 'currently is apposite. In the system of government support, the disabled are measured against a theoretical norm – what a normal person is capable of doing in a repeated manner, in a reasonable timeframe, and safely. None of the terms are defined in any detail. As a disabled person though, it may take me anywhere between three minutes to three hours to make a sandwich (or I may not make it at all) depending on what is going on inside my embodied state at any given moment. This is normal, albeit sometimes infuriating, for me.

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[23] The freak show itself is the subject of a great deal of controversy and discussion. The issue of exploitation and objectification associated with Freak Shows, of course, is true (see for example, Shakespeare 1994, p. 287, who discusses how freak shows were about disabled people being objectified as non-human and treated like exhibits in what for him, amounts to a kind of museum/zoo). However, there is another, more liberating side to them, but it is not the purpose of this dissertation to delve directly into the nature of freak shows. I return to this issue in chapter four.

Amanda Baggs' video "*How to boil water the easy way*" (silentmiaow 2007) shows us how it can take her five hours or longer to boil a kettle of water. But the way disabled people are assessed and measured is pre-determined and

Figure twelve. Amanda Baggs.

clear-cut with no sensitivity for how a person's disability is experienced in their own lives, and only a cursory attempt is made to cater for fluctuations. Applicants are forced to try to average out the effects of a disability. For example, were I to make (or attempt to make) a sandwich everyday – how long does it take me on average to make a sandwich? If, over a week, I make a sandwich on 5 days but do not succeed in making a sandwich on days 6 & 7, my calculations would look like this: day 1 took 10 mins; day 2 took 5 mins; day 3 took 60 mins; day 4 took 30 mins; day 5 took 15mins. Adding these figures together gives me 120 mins which, divided by 7 equals 17.15 mins to make a sandwich. But, as I did not make one on days 6 and 7, because my disability was active enough to preclude sandwich making, the answer is skewed unfavourably against me. But, if I had made them: taking say 30 minutes each time, my average would be 25 mins a sandwich – so, in fact, I am penalised for being *too disabled* to make a sandwich on days 6 and 7.

Our current system is infested with these kinds of traps. My point here is not to declaim on the welfare system but rather it is to illustrate that the disabled are measured, evaluated, questioned and examined before they are considered disabled enough to be eligible to receive the minimal financial assistance available – we are compared against what a ‘normal ’person could do. As with the concept of a 'reasonable person' in UK law, there is no actual definition of a normal person, which complicates matters. If you are not disabled you will not come into contact with this method of defining you as a disabled person - it is demeaning, humiliating and defines one as an object, to be personally looked at as a burden on the state’s resources. The impact this has on disabled people is not on the whole, positive.

In employment, disabled people are also often at a disadvantage. Shakespeare posits the existence of a 'glass staircase', finding that jobs disabled people do have are often 'concentrated in lower occupational roles' (Shakespeare 2015, p. 63) but also that it is not uncommon for disabled people to not get, or seek, promotion (ibid.). For him, disabled people may prefer 'to stay in a role or a workplace where they fit in, are accepted, and can manage, rather than risking promotion to another situation where they may be rejected or fail to cope' (ibid.). Thus, to be a 'successful' disabled person can also be problematic, entailing worries about risk-taking other people may not experience, which demonstrates how disability can be turned inward, and made into a matter of individual self-blame.

In thinking about this self-blame, it is pertinent to also see the public images against which disabled people can measure how they are being measured. For example, Silva & Howe use the idea of an 'achievement syndrome' to describe the patronising attitude that 'the impaired are successful *in spite* of their disability' (Silva & Howe 2012, p. 174). Drawing on Kama (2004) and others, they examine the deceptively positive narratives that heroise disabled people who achieve anything at all. Kama, who focusses on media representations of disabled people, distinguishes between the 'regular' and the 'glorified' 'supercrip'. A 'regular supercrip' is a disabled person who lives their life, including doing mundane, ordinary tasks. That they do so is treated as a great accomplishment, and they are seen as having unusual gifts in managing to perform such minor feats (Kama 2004, p. 450). This attitude attests to how 'all disabled people are not actually expected to perform at all' (ibid). The 'glorified supercrip' is someone who performs extraordinary feats such as climbing a mountain or sailing the ocean, for example. The message conveyed in this second narrative, according to Kama, is twofold: first, that disability is a physical impairment that can and ought to be overcome through resolute dedication, so that, secondly, it must be that all disabled people who cannot 'perform well in their daily endeavours… (must) lack willpower and self-discipline' (ibid.). This stereotype has also been described by Oliver (2017) as 'the Douglas Bader syndrome' (Oliver 2017, n.p.). He also finds that '(m)ost disabled people... will have been told to "man up" by well-meaning relatives, friends or even passing strangers saying, "look what Douglas Bader did or Beethoven or Helen Keller and on"' (ibid.). Oliver gives us a more recent example - of how inspiring disabled people are meant to be - in the Shaw Trust's list of Britain's 100 most powerful disabled people, arguing that, whilst putting this brochure together involved 'an awful lot of corporate schmoozing and public relations effort', it did not benefit disabled people (most of whom never see the 'glossy publication') but did benefit the Shaw Trust. He was not inspired by all this and, although he was on the list too, he did not feel powerful but, rather, he felt powerless to 'put a stop to such nonsense' (ibid.).

Disabled people are caught up in a no-win situation. On the one hand, to even begin to be socially accepted in for example, the workplace, they may have to accept being regarded as heroic supercrips who triumph over 'adversity' (i.e. 'overcome' their impairment); they may have to be 'inspirational' and an example to other disabled people; but on the other hand, they must simultaneously be tragic, sufficiently feeble (to qualify for governmental support) as to fail under the weight of the same adversity, whilst being viewed with suspicion for failing to be 'superhuman'. It is difficult, if not impossible, to do all of these things.

Is inclusion 'lip service'?

These problems are not going away. A timely and personal example of disability's semi-visible position in society's awareness is my experience of a compulsory module for all students at the University of Kent. The module, called 'Expect Respect', was designed to inform students on how to deal with marginalised groups and minorities within the campus. Primarily, it deals with race and issues around sexual consent, but unfortunately it makes no mention of disability. This lack of inclusion shows how disability is not regarded as an important or structural issue. When I raised the issue, I was told this omission was an 'unfortunate oversight', but it does seem to be indicative of how the disabled are rarely thought of as in need of recognition. I decided to confront the matter and fired off emails to the appropriate parties (see appendix four), who responded and set up a zoom meeting, at which I requested that the ‘oversight ’be publicly acknowledged and some kind of investigation be carried out into how the module could have been signed off with such a glaring gap. At the time of writing, I am still waiting for an explanation and for some kind of resolution to this situation. I admit to being saddened that an institution apparently committed to an equitable university culture and community, where discrimination and violence is intolerable in any form, is capable of missing out an entire protected characteristic - it does not inspire hope. Added to this is the delicious irony that the institution where this happened is the same one in which Mike Oliver initiated the Social Model of Disability.

This picture repeats itself in other UK universities. Chen (2022) tells us about Freshers' Week in London universities, where even access, which some people might assume one can take for granted after all these years, was made impossible for disabled students who '... "practically had to act out a limp to provide a visible impairment" ' in order to gain access to the Fair. UCL Autism Society were laughed at, pointed at and then ignored by the Student's Union Sabbatical Officer, who went around all the other tables to see if other, non-disabled students, were okay. Likewise, the KCL Neurodiversity and Mental Health Society stall was placed near a speaker, which was 'incredibly loud and very, very overwhelming' (Chen 2022, n.p.), posing real problems for students with sensory needs.

Conclusion

In this chapter I have examined a range of practical problems of inequality and injustice that disabled people face in society. These problems relate to the low worth society places on disabled people's quality of life - problems of accessibility, income disparities, epistemological injustices, and the general way disabled people are targeted for unfair and sometimes criminal treatment. Disabled people are also confronted, through both laws and biomedical research and practices, with the idea that their lives are not even worth living. In failing to be 'normal', disabled people are made vulnerable to countless injustices and inequalities so, while it may sound positive that disability symbolises what it means to be fully human, in practical terms, this is not generally acknowledged and this renders disabled people highly vulnerable to non-disabled people's projections of fears and hatred onto them.

I have used the idea of an embodied aesthetics so as to be able to relate the impaired body of disabled people to the negative effects of the 'strange symbolism' of disabled people as fully human (Siebers 2008, p. 6). This is in keeping with the previous chapter, in which I examined Siebers' argument that disability is not only a symbol, albeit a fundamental one, but also is a real, lived experience people with impaired bodies have of this world, and embodied aesthetics is a way of thinking about relationships between human bodies encountering each other. I also built on Hahn's notion of aesthetic anxiety (which, in chapter one, I collapsed with his other notion, existential anxiety, to do with functionality), in examining aesthetics as an everyday embodied experience. However, the contrast between the everyday and the space of art (be it the gallery or the picture frame, the theatre or street art on the mural) brings up a crucial problem. Art is always framed in some way, whereas the everyday is a conservative realm where what is normal is considered 'right'. Art has the licence to disturb and disrupt whereas the everyday is where people expect normality. In seeking to explain further how negative aesthetic judgements arise, I argued that disabled people are 'liminal' in that they cross both spheres - the extraordinary (that art represents) and the ordinary, which is where we all co-exist together.

Siebers arguments about disability aesthetics, in keeping with his ideas in his earlier 2008 book Disability Theory, again promote the idea of disability as fundamental; here, not only in relation to what it means to be human (which is particularly promising in relation to analysing other minority identities), but also in relation to art, in its broadest sense. However, the spaces of the everyday and those of art and cultural productions are not the same - in real life disability is devalued whereas in art there is value placed on the unusual and disruptive - and this problem is what chapter four will address.

Chapter 4 Are you seeing what you are believing?

'We have to do it for ourselves' (Mike Oliver)

The societal drive to homogenisation is framed in terms of 'medical innovation', 'diversity and inclusion', and 'empowerment and respect'. As these discourses are enacted, practices develop that may alleviate problems disabled people have, through provisions such as rights in law, architectural access, technology, support etc. However, these do not challenge the fundamental discrimination against disabled people. They are, as Oliver said, '...easily incorporated into the agenda of governments without requiring them to change very much at all' (Oliver 2017, n.p.).

Oliver ends his 2017 lecture - about disabled people's history - with a major message: that disabled people's agency counts; He says: '... we cannot rely on the bleeding hearts brigade and parasite people to do it for us. We have to do it for ourselves. We have to insist that our personal troubles are public issues that need to be resolved' (ibid.). One problem though, is that the exclusion of disabled people's lived and social experiences means the words and concepts their perspectives provide are not valued and may not always be available - because they have been excluded. As Scully tells us, ‘Hermeneutical injustice' means that powerless people have significant areas of their 'social experience obscured from collective understanding' (Scully 2018, p. 5). Whilst the powerful 'are far more likely to have understandings of *their* experiences readily to hand, because their lives are socially normative', disabled people suffering from hermeneutical injustice may not have 'the concepts, vocabulary, and narratives that are particularly salient to making sense of *their* lives' (ibid. p. 6). This exclusion means the 'social experiences of ... (disabled people) are not properly integrated into collective understandings of the social world' (Fricker 1999, p. 208) and this means there are limits or distortions in collective social understandings more generally, such as, for example, in how disabled people are represented on film. Epistemic injustices rest on a kind of silence and, if Siebers and others are correct, part of this silence consists of a failure to acknowledge the centrality of disability to human social and cultural life.

I have argued that disability is perceived - in a normative, everyday sense - as a negative aesthetic such that disabled people are regarded as meant to be kept out of sight, are made to not belong and, when visible, are seen only in constrained circumstances - as tragic objects of pity to be gawped at, their impairments as something to be overcome or destroyed. Disabled people are expected to achieve nothing at all (and thus they are seen as a tragic burden) or to rise above their impairments and achieve normalcy (in the inspirational hero mode). One important reason why there is a negative aesthetic in relation to disabled people is that their impairments are a reminder to the non-disabled of their own mortality, frailty, and lack of utility, both personal and societal. I argue here that, insofar as disabled people remind the non-disabled of their own inevitable decrepitude, their representation ought to be regarded as symbolising what it is to be a fully human person. This is, as far as I can see, 'disability as a significant value'. And yet, in examining representations of disability, one may well find the opposite is true - most cultural representations of disabled people that are part of ordinary, everyday life, are in various ways deeply and offensively dehumanising.

In the previous chapter I called into question whether cultural productions that are in the secluded, framed places they are to be found as 'art' or 'high culture', can affect any transformation in normative ways of perceiving disabled people in everyday 'real life' (see Gruson-Wood 2009 on this). I argued that disabled people share with art objects, the feature of being 'framed' in some way, and of being regarded as not belonging in ordinary, everyday spaces. Siebers' vision of a disability aesthetics that can transform society's perception of, and attitudes towards, disability seems to be unsuccessful in this respect. The aesthetics he discusses and which meet his criteria of beauty and humanity are confined to culture and the art canon, which arenas perhaps contribute to keeping mainstream ableist values in place, rather than disrupting or transforming them. How can Siebers' characterisation of art as 'permeated, inspired, and engaged with representations of disability' (Gruson-Wood 2009, p. 5) generate change in how disabled people are regarded and, indeed, in how humans more generally see themselves? As Gruson-Wood pessimistically asks: 'Is there any connection between disability aesthetics and the re-evaluation of disabled embodiments in real-life social relations?' (ibid.)

There has never been a shortage of representations of disabled people. Take the cinema for example: 'mainstream filmmakers have constructed hundreds upon hundreds of cinematic portraits of disabled characters for predominantly able-bodied audiences since the earliest years of the medium' (Norden1994, p.ix). However, 'the body that becomes disabled in films is routinely devalued and degraded... A ...narrative process of negation for an impaired character appears in almost all films about disease, impairment, and disability, whatever date, diversity of style, genre, and production base' (Darke 2010, p. 98). Darke analyses the 1981 film '*Whose Life Is It Anyway?*', which is a critique of medicalisation, but which uses the impaired body to base its critique on. In their desire to demean medical technology that keeps certain people in hospitals alive, the film-makers treat the impaired body as a burden, not worthy of being kept alive (Darke 2010, pp. 97 - 98). The problem is that, in collective understandings of disability, the lived experiences of disabled people are excluded, due to a prejudice so widespread it encompasses individual prejudices and long-standing institutions and structures. In relation to representations of disabled people, this results in degrading distortions and untrue portrayals.

I have argued that there are two key problems Siebers has not adequately addressed: the first is the idea of the framing spaces of art, which divide cultural productions from the everyday and which may sustain the prejudices disabled people encounter; the second is the failure to recognise the importance and centrality of disability, whether in the everyday or in art, which is an important part of the silence that keeps epistemological injustices going. Oliver's insistence that disabled people must do it for themselves can be used to bolster the idea that disabled people themselves have a particular perspective on what it is to be disabled in a social and cultural world that excludes them. Fricker explains that, insofar as 'our collective understandings are... "structured" by the powerful... the powerless (are)... epistemologically oppressed' (Fricker 1999, p. 209) because their understandings are excluded from the collective. She set out to 'vindicate' the insight (which she derived from 'standpoint theory') that '... there is some kind of epistemic "privilege" in the position of the powerless' (ibid., pp. 209 - 210). Thus, one potential way forward is to examine the work disabled people themselves make. In this chapter I critically examine three documentary films about disability which involved disabled people in their making, and I locate my discussion within a 'disability aesthetics' that seeks to establish disability as a significant value.

A critical concept such as 'disability aesthetics' must provide ways to discern between aesthetic productions that make disability a value and those that, whilst being about disability, nevertheless succumb to dominant ideological frameworks that render disabled people as tragic losers/inspirational heroes, subordinate and inferior to the non-disabled. The simple presence of disability in a cultural representation is not enough. For disabled people, true equality can only be achieved by a 'form of life... that is informed by the social experiences of *everyone*' (Fricker,1999, p. 209 [emphasis mine]) and for this to happen, disabled people's narratives, concepts and words must find a place within the collective. Siebers argues disability is a fundamental social and aesthetic, critical value, one that has the potential to disrupt and transform society for the better, and that we should endeavour to bring this to light. This chapter's discussion of the three documentaries is informed by Siebers' argument and asks whether the selected films provide a privileged disabled perspective.

The three films

To begin with I provide summaries of the three films I will be examining. These will be followed by a comparative discussion in which I seek to provide an evaluation of the perspectives on disability contained in them. The three films I critically explore are: *Crip Camp* (LeBrecht & Neuman 2020) [CC], a Netflix film that can be thought of as mainstream, it is both commercially and critically successful; *Sayonara CP* (Kazuo Hara 1972) [SCP], a film that is complex and uncomfortable to watch. It exists on the fringes of the film world and is largely unknown to an English-speaking audience. It was neither a commercial nor critical success at the time of its release. Lastly, *The Last American Freak Show* (Butchins, 2009) [LAFS] is a film I made in the early years of my becoming more critically conscious of disability in society and more able to claim my own disabled identity. This film was considered 'unpalatable' by the media establishment (and BAFTA) at the time of release[24] (which I will discuss below).

For comments on the Bafta controversy, see Fraser 2008, 'Go ahead - take a good look' (https://www.theguardian.com/film/2008/feb/15/disability.baftas2008); see also, Gilbey 2009 'How the

Summaries

Crip Camp (2020).

A groundbreaking summer camp galvanizes a group of teens with disabilities to help build a movement, forging a new path toward greater equality.

Figure thirteen.

This feature-length film celebrates 30 years of the passing of the Americans with Disabilities Act, by telling the story of how attendees of Camp Jened, a summer school for young disabled people, in Catskills, New York state, became politicised about their disability and very influential in founding the Independent Living Centre, as organisers/attendees of protests, and as disability activists in a movement that eventually led the 1990 Act to be passed into law. The historical documentary is structured in two parts; the first part is about Camp Jened during its summer camp in the early 1970s, shown through archive footage and photographs. The camp, during the 1960s and 1970s, was influenced by the counterculture hippie movement and at that time, served as a site in which disabled people could experience a fairly freewheeling, non-segregated, non-isolated 'normal' life (smoking, being cool, making out, having dates, playing music, and so forth). The camp was a site where bodily impairments were not scorned but rather, disabled people were able to

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'freaks' got their freak on' (https://www.theguardian.com/film/2009/mar/27/last-american-freak-show-disability) experience themselves as seen, known and accepted for who they were. Importantly, they could exchange ideas and discuss the problems they and others, as disabled people, faced in society. The second part of the film shows scenes from various disability activist protests, including the 1977 '504 sit-in', that some of those who attended the Camp participated in, occupying the Health, Education and Welfare offices of San Francisco. It charts how the experiences they'd had at Camp Jened led them to becoming disability activists and community organisers, agitating for accessibility and against discrimination. The film ends with a return to the site of Camp Jened, now an empty lot, and a reunion of some of the activists who featured in the archive footage. *Crip Camp* was distributed by Netflix, had a large budget and high production values. It was made by two directors, one of whom, Jim Lebrecht, is disabled and was a participant at Camp Jened at that time, and he leads the film onscreen. The executive producers included Barack and Michelle Obama and the film was nominated for an Oscar (for Best Documentary Feature).

***Sayonara CP* (1972).**

Figure fourteen.

This film was completed in 1972 by a non-disabled director (Kazuo Hara) who developed his ideas as a result of working for three years in a school for disabled teenagers. Although well known in Japan, the film's non

English language status prevented it from reaching US and UK disabled audiences at a time when the disability rights movement was nascent in both places (and indeed, in many other parts of the world, including Japan, which was in the grip of student demonstrations and political upheaval at that time). SCP follows the lives of members of a group called Aoi Shiba no Kan (The Green Grasses Movement), an organisation set up by people affected by cerebral palsy, a group of whom were living independently in Tokyo during the 1960s and 1970s, a time when to do so was radical action. The film is a collaboration between Aoi Shiba no Kan members and the director, whose unorthodox filmmaking method and challenging portrayal of the film participants is contentious. Kazuo Hara spent six months negotiating with the Aoi Shiba no Kan members before they agreed to make the film with him. The documentary focuses mainly on two members of Aoi Shiba no Kan, Hiroshi Yokota and Yoichi Yokotsuka, following their daily routines around public and private spaces - city streets, trains, stations and domestic spaces - as they confront society with their disability. It is 82 minutes long and shot in black and white, on 16mm film, with no synchronised sound, external comment or narration. Kazuo Hara had no editor, so put the film together himself. It was shot with 100ft rolls of film, giving him around 2:46 minutes of footage per roll. Parts of the film were shot on a spring-loaded camera that only allowed 38 seconds of filming before needing to be rewound. I do not speak Japanese, so I watched the subtitled version (although Hara refused to subtitle the original, maintaining that (Japanese) audiences should work to understand the contributors' words, given that they had no intellectual deficit - I return to this issue below). The film took 12 months to make and filming itself was conducted over 14 - 15 days. The budget was minimal, raised by both Hara himself and by members of Aoi Shiba no Kan, who took out loans. No funding was received or applied for and the budget was approximately $30,000. The film

Figure fifteen.

includes controversial scenes such as Hiroshi Yokota getting around without his wheelchair in various risky situations (such as getting off a train, crossing a road, for example), discussions about the members' sexual lives, a domestic row that became violent and in which a participant asks Hara to stop filming (which he does not do), and Hiroshi Yokota's naked body.

***Last American Freak Show* (2008).**

This film is a 75-minute road movie, shot during 2008, documenting a 3,500-mile journey, from Oregon to Austin, Texas. The journey is made by a group of disabled performers and their non-disabled colleagues down the west coast of the USA, in a yellow bluebird school bus (until it breaks down) powered by used vegetable oil. The performers are members of 'The 999 Eyes of Endless Dream', a self-proclaimed freak show. As they journey, they stop at various bars, nightclubs, parties and even a wedding, to perform their show and earn money. Various mishaps occur - mainly concerning the vehicle(s), that break down and need fixing/replacing - that place strains upon the group. The film was made by a disabled filmmaker (myself), who was embedded within the group and whose participation in the group together with his questions about what was happening, led him to a new understanding of both the group and his own disability. The embedded technique the filmmaker used, enabled him to share in the story of this journey as a participant as well as director. Importantly, this meant he could look at and be looked at, surrounded by a community of disabled people who took him into their group, giving him a sense of belonging. It was also through this 'doubled up' role (director and participant) that the story of the film is narrated. There were no broadcasters or distribution networks involved, which meant the work was free from executive and corporate oversight. It was made on a tiny budget and filmed solo, with a hand-held digital video camera, over the six weeks on the road; it was edited chronologically. The road movie engages with the American archetype of 'the road', and provides a perspective of 'the road' as a place outside the norms of mainstream life, made of marginal spaces (parking lots, highways, rest stops, diners, dumpsters, cheap motels etc.) found and used en-route. The participants are bohemian rebels who find a sense of community and family, albeit ambivalent and strained at times, in their conviviality and acceptance of each other. The film shows disabled people in both their 'work' mode - when they are performing in the freak show - and in more 'everyday' settings - as they travel, drink, repair vehicles and so forth. The troupe reject the idea of 'normality' and go about 'reclaiming' the freak, as they flaunt their impaired bodies, showing how they regard the freak show as a positive form of self-exploitation. Whilst the troupe earn money through their exhibitionism, they also interact with their audiences, encouraging them to feel comfortable touching and looking at different bodies, and asking about what it is like to be disabled in contemporary America, as the participants tell stories that reflect their social critique and a rejection of the need to be 'normal'.

Discussion

In chapter 3, I argued that everyday aesthetics contains an implicit assumption that disabled people do not belong in ableist society. Disabled people are 'framed' in everyday life, in such a way that positions them as on its edges and its outside, which is alienating and damaging to disabled people, who are the bearers of symbolic meanings the non-disabled seek to disavow. These three films arose from instances of disabled people coming together and taking action of some kind, attempting to forge an identity that places them in such a way that they are seen and recognised as human beings with value and as much more than merely failed bodies.

Collective space

In the films, the perspectives show instances of how social spaces can be used not only to enact the separating away of disabled people and their en-framing, but rather, they can be taken by collectives of disabled people and used as spaces from which to act against ableism. In CC the key space was Camp Jened. According to the story CC tells, it was in Camp Jened that disabled individuals found inspiration to become disability activists in USA and went on to challenge ableism in society in multiple ways that led to the Berkeley Centre for Independent Living, various protest actions and, ultimately, the 1990 Americans with Disabilities Act. Some of the protests also involved innovative, disabled uses of spaces - at the 504 sit-in in particular - but the viewer unfortunately was not shown enough about this aspect of the story. Camp Jened though, was an ableist space created for disabled people - of course, it was indeed a transformative place of wonder for the individuals featured in the film, but it may not have been for other campers before and after this period and the history of the camp is never discussed, questioned or challenged. The camp is treated as 'unique' when there were, in fact, many of these styles of summer camps during that period in the US; they were largely attended by white, middle-class, physically disabled adolescents ... (who were) offered a barrier-free environment and a sense of community that provided ... (them with) an escape from their everyday experiences of exclusion (Patterson 2012, p.474).

In SCP the director and the members collaborated to make a film that confronted the non-disabled, making their 'private' lives a matter of 'public' concern. In this case, Yokota Hiroshi and Yoichi Yokotsuka undertook various activities (reading poetry, taking photographs, getting out of the wheelchair, getting naked) and public spaces were notably used to enact this confrontation. Obviously, the mostly off-screen social spaces of the Aoi Shiba no Kan collective were very important and key decisions about the film, their roles in it as well as its funding, were made by this group. But the use of public spaces by the film's protagonists and director forced non-disabled passers-by - and thus also the viewer - to address the impaired body. Of particular note, in one section of the film, Yoichi Yokotsuka is filmed taking photographs of non-disabled members of the general public, in a reversal of the more conventional gaze, which is another way in which this confrontation occurred.

With LAFS the main collective spaces were the locations where the troupe set up their performances in which the raucous encounters between the disabled 'freaks' and the non-disabled audience members took place, and the challenge to ableism was most keenly expressed through the freaks' seizure of the 'frame' (in this case, the framing device of the circus sideshow). Again, collective social spaces - which included the troupe members living and social spaces, their vehicles (rundown, recycled, leftover), and the 'road' (which, in their case, was made up of all kinds of marginal spaces - Slab City, cheap motels, etc.) - were also important sites where discussions about a whole range of different matters took place (for example, the shows, new and returning members of the troupe, encounters between disabled and non-disabled people, etc.).

Critical approach

Because control over the production and distribution of CC was spread across various production companies as well as Netflix, the 'final cut' was subject to notes. 'Notes' is filmmaking term for editorial changes that the executive producers and commissioners want made to a film; notes are, in practice, mostly non-negotiable. LAFS was shown on More4 (a Channel 4 owned UK channel) and Channel 4 wanted it to be cut shorter by a few minutes. The director was happy to comply with this (the film needed tightening up anyway), but did not concede any editorial input to C4. As far as I can tell, SCP has never been shown on TV or had a general theatrical release. Like LAFS, the film was self-funded and complete editorial control retained by Kazuo Hara and the Aoi Shiba no Kan group.

On screening in Tokyo, it was panned by the press and there was a great deal of criticism, which Aoi Shiba no Kan dealt with effectively, and SCP has gone on to be considered an exemplar of Japanese documentary filmmaking. Before LAFS was shown on More4, it was rejected by BAFTA for a screening at the London Disability Film Festival as it was considered an inappropriate representation of disability and too 'raw' for their members/audience. It was felt that 'the aesthetic of the film was wrong, that it was too explicit, raised too many questions and was too demanding for the event in question' (Adams 2012, p. 420). Bafta's decision caused controversy and was condemned by disabled activists in the UK (see, for example, Fraser 2008, see also, Gilbey 2009). Whilst the film was refused a screening at the London Disability Film Festival (now defunct), it was shown at Moscow Disability Film Festival (where it won Best Director), and Superfest International Disability Film Festival (where it gained a merit award). On the subject of Disability film festivals, Mitchell and Snyder have argued, ' Disability film festivals enable a critical space that opens up disability to the true multiplicity of its expression across the species. Rather than being treated as exemplifying unviable lives, disability at the disability film festival records the messy networks of human materiality as they interact with technological spaces such as human-made environments, prosthetics, media-made contexts, and nature' (Mitchell & Snyder 2018, p. 149). Certainly, that was not my experience in London. Other festivals, including London Documentary Film Festival (that is not disability focused) did, to a certain extent, record this 'messy network of human materiality'. However, although enjoyable, these festivals have a very small audience and are mostly preaching to the choir, so to speak. It is my objective to get films on disability screened on mainstream channels so that my audience can be larger than those reached by disability film festivals. It is, perhaps, telling that CC caused no controversy at all. A film about disability that doesn't ruffle a few non-disabled feathers seems all wrong from a disabled perspective.

The premise of CC - a celebration of 30 years of the ADA 1990 as a result of disability activism - is rather triumphalist. It's self-congratulatory tone ('This camp changed the world' says LeBrecht), nostalgic footage and sunny imagery could fool the viewer into feeling that disabled people are lucky, seem to have become economically well-off, and to hold really interesting well-paid jobs; this imagery acts to confirm the success of ADA 1990 in the USA and disabled people's triumph over adversity. The ending of CC is rather ambivalent. In it the elder campers revisit the site of their youthful antics - it carries a degree of pathos, but it does not address disability at all. The optimistic message seems to be that the audience can now see people, rather than disabled objects. Although at twelve minutes before the ending there is acknowledgement of the need to keep up activism (when Denise Scherer Jacobson says that the ADA was only the tip of an iceberg and it's people's attitudes that need to change), the critique of society is almost entirely limited to the past, where it seems to be contained in a comfortable, safe, happy frame of hippie action, far removed in time. This strikes the disabled viewer as rather hubristic and complacent, whilst it may be comforting and reassuring to the non-disabled. The film was shot and edited in a conventional documentary style; it had a large cast and crew, including two directors, two editors, four producers and five executive producers. All of its archive materials will have needed to be cleared for worldwide rights and likewise, the music. In other words, although I cannot discover any detailed budgetary information, it was clearly well financed and staffed.

This retrospective perspective is in stark contrast with SCP which was made during the same period of protest and activism (the early 1970s) but stays focused on the harshness of life for disabled people in Japan. Here there is a confrontational, even angry and disillusioned tone.

The final scene sees Hiroshi Yokota naked on a bridge saying nothing. His body is fully revealed and, by implication, so are those of all disabled people. The image is a difficult one for the non-disabled to confront as it

Figure sixteen.

unflinchingly and unsentimentally shows the visible appearance of impairment. In the scene Hiroshi states that the process of making the film has shattered his hopes that he could ever be independent; he feels that he will always have to rely on the help of the able world, and this leaves him feeling 'totally empty'. It is a bleak and moving dénouement and explicitly announces to the world the position and predicament of disabled people. This disability is allowed to be apparent in the film-making process too - the over-exposed scene at the beginning, the out-of-synch sound in the head-shots scenes, the scene on the train when Hiroshi Yokota scrambles to get out of the train but Kazuo Hara runs out of film so the viewer can only hear the sound - lend the film itself a kind of disability.

LAFS is more contemporary. Its setting in the USA makes for an uncomfortable contrast with CC, as the disabled people who feature here do not appear to have benefitted from the celebrated ADA. The film notes how a low socio-economic position makes disabled people vulnerable to exploitation and self-exploitation in its recording of the tensions between the disabled and non-disabled members of the troupe. This situation was one I was not far from myself, at the time of making the film (which was useful in terms of becoming immersed in the experience alongside the film participants), and had certainly experienced before and after making the film. In the film there are also tensions between the disabled participants and the American general public. There are various scenes that show people in a shopping mall gawping and cringing as Ken Peg Leg goes by; the members of the troupe tell stories - both to the director and to the audiences of their shows - about their experiences of being bullied, misunderstood, their impairments mismanaged by the medical establishment and so forth. But, unlike SCP, the disabled people here are experimenting with how to set the terms of their engagement with the non-disabled and are willing to embrace a marginal and makeshift lifestyle in order to do so.

The impaired body

All three films are explicit in their imagery and discussions about the impaired body. These films' strong emphasis on the impaired bodies of their participants demonstrates bodies that are anything but contained, framed, or safe. However, the issue of 'audience' capture seems to inform how the impaired body is contextualised.

Neither SCP nor LAFS shy away from the impaired body but they also do not seem to present any narrative of 'triumph over adversity', rather, they present disability in a bitter, discomforting and blunt way. In SCP, by convincing Hiroshi Yokota to abandon the wheelchair, Kazuo Hara has removed the shield (a kind of 'frame') that makes drastic impaired physicality digestible to others. If a person is in a wheelchair, it is a kind of corral, their impairment is contained and there is nothing to be afraid of. But liberated from his wheelchair, Hiroshi Yokota's body is 'impossible' to deal with, not least by his wife and by Hiroshi Yokota himself. The challenges the participants of SCP had were akin to those faced by participants in LAFS - while society may have provided more ramps and lifts on subways, access is not the same as inclusion.

The contrast between useful and useless bodies can help us to make sense of differences in how these films approach the impaired body. In both SCP and LAFS there is no pandering to the idea that bodies should/could be functional and useful. It this sense, the films touch on one of the ways in which the negative aesthetics of disability are threatening to disabled people's lives, because, in having ‘useless’ bodies, they can be targeted and attacked. SCP is upfront about this - there is no hiding the 'useless' body and it is presented as a visceral challenge, as a means to confront the non-disabled about their ableist practices and world. LAFS is more exploratory. The context of the freak show as a means to reclaim being a 'freak' also involved the use of carnival-type tropes of 'fabulous', 'amazing', 'magic', 'imagination'. The troupe are explicit about seeking to make connections between disabled and non-disabled people, by encouraging audience members to touch their 'freaky' bodies and to ask about things. Lobster Boy tells the director about when he learnt to tie his shoelaces and how it was 'magic'. The suggestion is that, in making connections between non-disabled people and impaired bodies, 'magic' can happen, one can be 'amazed'. Because both films are seeking a confrontation with the non-disabled, there is a refusal of 'normality' and in this sense, a refusal of 'usefulness'. The participants are not seeking to fit in and become invisible members of normative society. In these ways, both films reclaim 'uselessness' too, which is rather subversive and may account for the rejection of both of these films, to some degree, by the media establishment.

CC, on the other hand, frames the problems of disabled bodies as those of access (mostly to work places, albeit rather nice workplaces). This issue of access is of course, an extremely important aspect of disability and has not been solved by any manner of means. We still hear stories of disabled people's difficulty of access to this day. But it's a safe issue, the demands are for acceptance within the status quo, which is not so challenging for the viewer. This strikes me as a missed opportunity to truly explore what it means to have an impaired body in an ableist society.

There seems to be no available neutral space - the logic in SCP and LAFS means the makers of the films cannot support the idea that normalcy is desirable for disabled people. The desire to capture a non-disabled audience and make the film comfortable for them, means CC is driven precisely by a logic of normalcy. But one must ask - what is it really protecting the non-disabled viewer from? And the answer is: From the idea that they may be prejudiced against disabled people. This is unsurprising. In a recent film I made, I ran into the same desire to protect the 'normal' audience from noticing their prejudices, when the executive producers pressured me to use the attractive young female contributor and her non-disabled companion at the top of the film (and elsewhere) so as to make the other, less visually appealing contributors and the film itself more palatable, even though the life experience and exposition by other contributors told the story more effectively. The pressure was ableist and, when challenged, was denied by the producers.

Involvement of non-disabled people - who owns the narrative?

All three films feature active and decisive participation in the filmmaking process by disabled people but, in some respects, all three films have an uneasy relationship between non-disabled and disabled people. For example, CC wishes to attract a non-disabled audience and this has important effects on the film itself. Co-director Nicole Newnham (a non-disabled person) stated 'How can we draw people [in] and make them feel comfortable? I'm talking about non-disabled people' (Lopez 2020 n.p.). Co-director Jim LeBretch is disabled as well as being a key contributor, telling his own story in his own way. Although in an interview I undertook with him (via zoom), he agrees he had considerable oversight, it is not clear whether he felt pressure or whether he just accepted the imposition of a non-disabled agenda onto the film's structure and content. He says: 'Nobody wants to make a documentary that feels like you're eating your vegetables… it was difficult, or was a challenge, let's say, to really find the right balance… It needed to be entertaining'.

That the film is a nostalgic reminiscence enables there to be a comforting distance from the events being recounted and the disabled people being portrayed, and the viewer is not discouraged from extrapolating that disabled people's lives are so much better now. The trope of telling people's personal stories keeps the mood cheery and attention drawn away from critical questions about contemporary discrimination and inequality for disabled people in America. In a very individualistic approach, there are many talking head interviews with various camp members and counsellors and there is a great deal of celebratory attention given over to Judy Heumann, who is treated as a leader in the field of disability activism. Again, this approach detracts attention away from the collective contributions made by many other individuals and groups.

Unlike Kazuo Hara, and in another effort to please the non-disabled viewer, the directors here choose to subtitle the spoken contributions of people with cerebral palsy, rather than asking the viewer to listen more carefully. I find this troubling. I had no difficulty in understanding for example, Denise Sherer when she speaks. It's also noticeable in one scene with camper Nancy

Rosenblum, who is verbal but very hard to comprehend, that her words are not subtitled but a fellow camper interprets what she is saying and his words are subtitled. Although the film benefits from a large budget, high production values and expert craft, it is watchable in a non-challenging, politically conservative way.

In LAFS the filmmaker is disabled and controls the production process but it becomes clear that there is a hierarchical structure within the freak show - it is run and organised by two non-disabled people, Sam and Dylan who, as a result, have power over the disabled 'freaks'. There is a noticeable difference in how the disabled participants talk about themselves when they are not in the presence of the non-disabled members of the troupe. Both the director and some of the 'freaks' express ambivalence about the freak show. Jackie ‘The amazing half woman’, for example, worries about playing to stereotypes and is unsure what to make of how, in certain respects, there is no particular difference between the work she undertakes for the freak show and the other jobs available to her in showbiz.

In SCP, the Aoi Shiba no Kan participants agreed to collaborate with the non-disabled director, and the participants co-funded the film and made critical choices about their roles in it. But the director challenged Yokota Hiroshi and Yoichi Yokotsuka to do things that they themselves had not thought of - such as photographing members of the general public, getting out of the wheelchair, getting totally naked on film. The film starts with an over-exposed scene (Hara accidentally over-exposed the film but as they had no money, he used it anyway) of an as yet unidentified woman walking away from camera saying 'I am leaving you'. We then join Yokota Hiroshi who is shuffling along the ground on his knees, swaying and quivering as he moves past

Figure seventeen.

playing children, who are ghostly due to the overexposure of the film. We are immediately aware that the man - clearly physically disabled - is not in a reassuringly normal context. For example, he is not in a wheelchair, a comforting signifier (to the non-disabled) of disability. Yokota Hiroshi says that this way of moving is faster than a wheelchair, so we suspect he wants to shows us he is choosing to move in this way. The film then shows him leaving his wheelchair and crossing a road, grasping his spectacles and shuffling as fast as possible across the pedestrian crossing, which strikes the viewer as very risky - we are unsure he will make it across. It is now clear this is a statement of some kind. But it is a co-created statement - Kazuo Hara challenged Yokota Hiroshi to do this. Perhaps that was precisely why the Aoi Shiba no Kan members accepted Kazuo Hara's confrontational approach - it was what they wanted. In a wheelchair Yokota Hiroshi's body can be comfortably compartmentalised but out of it, his body becomes a very difficult proposition. Kazuo Hara has a confrontational approach that his protagonists seem to relish. Hara said that in 'the dichotomy between “the healthy vs the disabled” ... our starting point was this antagonism between the two…I strongly felt that without this premise, anything I might depict would simply turn out to be a lie' (Hara 2009, p. 75).

One might think of the director as exploiting the participants due to his own radicalism - but, on the other hand, the Aoi Shiba no Kan members wanted to collaborate with the director (there is a scene in the film where they are having a meeting) - perhaps thinking the director's provocative ideas were the right medium for their own messages about disability. In SCP the willingness of the participants to take up Kazuo Hara's challenges involved 'reverting the gaze' - where Yokotsuka photographs members of the general public, making spectacles of *them*. Again, around 30 minutes in, Kazuo Hara switches to very tight head shots of the male members talking about their first sexual experiences. As this is not shot with synched sound, the disunity between the image and sound adds to the sense of disjointedness and otherness. It is in this scene that one of the interviewees tells of how he partook in a gang rape - which presents an intense and disturbing challenge to the preconceptions of how disabled people should behave - as asexual and infantilised.

A particularly perplexing scene comes later in the film when Hiroshi Yokota's wife (who had been against the film from the start) demands that the filming stop. Kazuo Hara lets the film run and a fight ensues. This scene is harrowing, all the more so when the children get involved. A meeting follows, which seems to be happening in the same scene, of Hiroshi Yokota's disabled colleagues discussing whether the film should continue. The other activists are telling Hiroshi Yokota that he cannot quit because they are all involved and they have put money into the making of the film. They argue he should not be told what to do by his wife. 'You shouldn't have married her', they say. 'You're the man in the family, you're the one to make the rules, no need to listen to her', they continue. This scene is disturbing for various reasons, not least in having the children present. Importantly, Kazuo Hara did not include perspectives of disabled women in the film, which is an omission on his part. But at the same time, the scene shows that, like all families, this family has tensions and fights; like all groups, whether families or activists, disabled or not, there are unities and divisions simultaneously. Perhaps more importantly, these challenging scenes humanise the participants - they are not simply strange impaired bodies, they are not simply cyphers or symbols but complex, fulsome human beings in their own right.

Another problem with CC's pandering to the non-disabled is that disability is treated in a po-faced way; despite 'in-house' jokes about personal hygiene matters, it is made humourless in a way that panders to middle-class 'pc' sensibilities, which is not the case in the other two films. In LAFS the words and actions of the film participants are marked by irony. For example, Erik, the seven-foot giant, innocently delivers the line: 'I had to grow up really fast as a kid'. The people in the film seem to be unaware of the absurdity and paradoxical nature of their activities - the show is sometimes chaotic, there is a late-night raid for used vegetable oil, at the back of a Chinese restaurant; there are nights spent sleeping out in the woods; some of the 'freaks' get drunk/take drugs and have hangovers, and the whole business has a shambolic feel about it. Whilst the problems and tensions encountered en-route are very real and important, the participants (disabled and non-disabled) tackle them with a sharp and mocking humour, but there is also a genuine willingness to laugh and make merry across the unequal and unfair disabled/non-disabled line - because they found a way to make what the non-disabled think not matter. An example of this occurs when they arrive in Los Angeles to work as extras in a horror movie being made by Andrew Getty (the multi-millionaire). He is trying to symbolise the 'stranger' and can only think of achieving this effect by using disabled people! Members of the troupe are conscious of this but don't really care, rather they treat it with humour, and comment that he is a 'funny shaped director' - which they find amusing, considering.

All three films have a degree of non-disabled involvement in how they have been made. CC in particular, does not have a radical agenda and is geared towards a non-disabled audience - which is fair enough, its story is interesting and it is good to have this slice of social history. It is not just a non-disabled film about disability - as noted above, the focus stays on disabled people, their actions, their thoughts, their protests. But the non-disabled agenda that comes with such a mainstream and well-financed production shows its intention is not to generate change through disabled people's agency - they do not 'own' the narrative. Both SCP and LAFS do have a radical agenda, and do seek to push forward disabled people's agency and thus are more successful in this particular sense.

Conclusion

I started this chapter asking whether or not these films provide a 'privileged' disability perspective. The comparative critical discussion shows us that the question hinges on the manner and degree to which the films challenge ableism and show disability in a new light. This is because there are two aspects I am seeking to bring out of Siebers' idea that disability is a 'critical value' - on one hand, the films need to be critical of ableism by exposing the way disability is used as a symbol for things the non-disabled wish to deny, silence and thus displace and project onto disabled people; and on the other, they need to show the lived reality of impaired bodies from the perspective of disabled people themselves. This lived reality cannot be taken out of the context of ableism, the impaired body is always within an ableist context and there is no outside of this context, so the two aspects run together.

In all three films there is critique. There is an acknowledgement of the need to struggle because ultimately, one's life is what is at stake. All three films acknowledge the importance of disabled people getting together and acting in a united way. They also all address ableism in various ways - lack of access, poverty, getting gawped at, being othered and made to feel one doesn't belong and so forth. It is useful to have a film like CC in some respects - its joyous exuberance enables the viewer to feel good about those disabled people back then, in the 'good old days'; it's a ‘feel good’ film. But, in framing the disability rights movement as 'inspiring', an important challenge is ducked. The disability rights movement was formed out of desperation and the need to have disabled people recognised not only as humans with needs, but also as bearers of a symbolic load that makes them vulnerable - at the individual and structural levels - to discrimination and other forms of violence, which society should address.

There is also 'disability as itself' (Siebers) in how all the films involve impaired bodies in a whole range of different ways. In CC we see many different bodies, gathered together in protests and at the camp. It is a pity that not more is made of this given '...the pertinence of disability to the human condition, ...the value of disability as a form of diversity, and ...the power of disability as a critical concept for thinking about human identity in general' (Siebers 2008, p. 3). More footage of how the 504 sit-in protestors actually, physically occupied the buildings where they held the sit-ins would have been good to see. The film does not bring out the antagonism between ableism and disabled people enough, and impaired bodies become incidental, which is counter-intuitive in such a film.

In SCP and LAFS the impaired body is given a stronger value. Kazuo Hara's challenges to Hiroshi Yokota and Yoichi Yokotsuka are also challenging to the viewer and put the impaired body at the centre of the film's focus, in a bleak and bitter way. Likewise, in LAFS the impaired body is centre stage - both literally, in their shows, and incidentally, in how the rest of the film works to show the troupe in their everyday activities. In both films, the impaired body 'steals the show' and offers the opportunity for non-disabled viewers to see differently. This does not mean the viewer will not gawp, but the impaired body goes beyond this gawping, doesn't care at all, and imposes itself on the viewer as a challenge - to abandon normality, to admit to ableism, and thus to encounter the human in its variety. Neither film seem to hold out much hope for this happening anytime soon, but the challenge is there.

Figure eighteen. Dame Demur and Lobster boy.

An important aspect I sought to address in discussing these films was that of collective spaces because, as I noted in chapter three, the spaces of art/cultural productions are framed in such a way as to encourage the appearance of the strange, the disturbing and the disruptive, whereas the spaces of the everyday are where what is normal dictates what is deemed acceptable. I noted various spaces - public spaces (across all the films); Camp Jened (CC) where disabled people can exchange ideas and get politicised; the collaborative spaces of the green grasses movement and Kazuo Hara (SCP) where important decisions about the film's production and content are discussed; the performance spaces of the freak show (LAFS) where the performers seize the frame of performance. In all three films disabled people claim spaces for themselves - through protest (CC), through confrontation (SCP), through performance (LAFS), making their impaired bodies centre-stage - the films all focus on disabled people's actions and on their agency.

Gruson-Wood's critique of Siebers is very pessimistic: 'Entertainment and art are "outs" in which the real and commonness of human variation are spectacularized, fetishized, and freaked... simultaneously adorned and gawked at through the voyeuristic gaze of ...high and low, cultural texts of the ...arts' (Gruson-Wood 2009, p. 26). However, she does not examine the degree to which the agency of disabled people - in their seizing, confronting, showing, reclaiming and owning the narrative - can transform this relationship between the spaces of the everyday and those of art and culture. It matters that these three films are produced by disabled people and are about disabled people, to varying degrees. The presence of disabled bodies alone does nothing to challenge the problems they face - instead disabled people need to own the narrative.

CONCLUSION

Disabled people have achieved a great deal of progress for themselves, especially since the 1970s, in ameliorating the practical problems of social inequality and injustice they face. It is worrying that these gains disabled activists have made could easily be lost, as we can see in austerity politics for example, or in the politics informing pandemic and post-pandemic economics. Such achievements are constantly undermined by the interests and actions of governments (seeking to reduce spending on the populace), charities (who become corporatised), and other parties, so progress for disabled people is always precarious. Facing and addressing these issues involves making exposés through writings, films and other means, using discrimination laws and regulations, campaigning, setting up disability-led organisations, and so forth; calling out bad and unethical policies and practices in an ongoing, piecemeal way is an important task activists engage with and face on a continual basis.

But these problems are deeply rooted in another problem: that of disability being made to stand as a symbol for what ableist society fears and denies - the suffering, dependence and mortality being human entails - which is projected upon disabled people as they go about their everyday life. While impaired bodies and/or minds are simply part of the variation of human life, in practice these differences are targeted, through aesthetic means, and impairment is turned into disadvantage as disabled people are treated as society's scapegoats. Furthermore, the category of disability also informs how other minority groups are similarly marginalised and targeted, which shows disability is a central concept. This is a deep, societal problem and it is not clear to me whether or not it can be solved. Medical technology is so advanced that congenitally disabled people risk being screened and aborted out of existence; although 'congenital impairment accounts for a small proportion of all disabled people' (Shakespeare 2015, p. 32), the impulse informing the desire to eliminate these people is suggestive of this deep-rooted rejection of difference. A rejection of difference involves not even acknowledging that disability is such a core category in our social practices. Such a failure to recognise and acknowledge this creates a silence around disabled people and perpetuates misunderstandings of disability. This leads to our exclusion from society, including from social epistemological resources, which undermines us and can lead to violence against us. For all I know, disabled people will always carry this symbolic weight, will always be denied, silenced, made invisible, misrepresented and erased. My investigation has not enlightened me about this possibility.

What it has shown me is that disabled people need to do it for themselves (Oliver 2017). Disability activism has opened up valuable social and political space that disabled people can use to seize and claim the agenda, taking charge of the narrative, and using their agency to combat the silence that surrounds how they are used to carry the symbolic weight of human vulnerability, even if it is not clear the degree to which disabled agency can permanently change the agenda. There is a lot we can do. We can witness previous disability activists, artists, and others, and the contributions they've made. We can learn from them and we can share what we know with other disabled people who struggle, as well as with any non-disabled people who may be interested, as this may help spread the recognition that impaired bodies are nothing to be worried by. That we can take action, even if we subsequently lose ground for various reasons, is itself progressive. Whilst losing control of the agenda can happen, regaining it can as well.

Summary

My exploration of disability in this Practice as Research degree was motivated by my personal and professional experiences as a disabled person. As I developed an increased awareness of the way I have been affected by my impairments, and how this affected my working life as a film-maker. I started to search for a clearer and deeper conceptual understanding of what it means to have an impaired body and mind in an ableist society. I was perplexed by how, despite significant social and political changes that have made a positive difference to disabled people, especially since the 1970s, there is still widespread discrimination against disabled people, which is expressed in multiple practical problems of social inequality and injustices.

Examining Siebers' ideas, I discovered that we can posit that disabled people are a symbol for what it means to be fully human. All humans are frail, dependent and mortal. I argued that disabled people carry this symbolic weight as a distinct disadvantage because non-disabled people do not celebrate this interesting and deep symbolic meaning of disability, but instead, project upon disabled people, their fears, grief, and fury about their own upcoming decrepitude, suffering, and death. The success of this ableist projection rests upon denial and silence. A failure to recognise and acknowledge what it really means to be fully human.

I associated Dotson's idea of an 'epistemic landscape of oppression', which builds on Fricker's concept of epistemological injustice, with this lack of recognition and acknowledgement, and I used this concept as a means to explore and to name both the practical examples of injustices and inequalities, and how they are rooted in epistemic injustices of various kinds. In both the text and in my films I explored three kinds of epistemic injustice. They were: testimonial injustice - which occurs in a background context of hermeneutical injustice between individual agents, is shown in *Targeted: The Truth About Disability Hate Crime*; hermeneutical injustice - which describes the structural failure to include marginal (in this case, disabled) people's perspectives in collective epistemological resources, I found particularly pertinent in describing how I and others were silent about my impairments and how I was at a loss for words until much later in life; and finally, contributory injustice, which involves agents who act in bad faith in the face of articulate disabled people and who therefore maintain structural hermeneutical injustice by refusing to take up the words, ideas and narratives that disabled people do develop. This form of epistemological injustice seemed to describe some of the events in *Locked Away: Our Autism Scandal* as well as in *The Truth about Disability Benefits*, for example (see Dotson 2012, see also Miller Tate 2019, for more on contributory injustice).

I sought to explore the value of subscribing to the more political identity of disability and argued that, whilst this act might have positive outcomes for disabled people - in our being able to celebrate disability and take pride in ourselves - it also involves disabled people facing up to the negative results of being the bearers of this 'strange symbolism' (Siebers 2008, p. 6) in an ableist world. A further pernicious outcome of ableist rejection of human vulnerability and mortality can be discerned in how the same symbolism of disability is used in relation to other marginal groups, as a means to mark them as being 'other'. This makes disability potentially a very subversive and central category, according to Siebers, because, in bringing about widespread recognition of this fact, disability can disrupt and destabilise these other categories as well.

A crucial 'move' at the theoretical level, towards recognising the centrality of disability, involves restoring the importance of the impaired body and treating disability 'as itself'. For the denial of human vulnerability is also the denial of the human body as it is lived in reality. Social constructivist approaches to disability undermined recognition of the impaired body; in Oliver's original approach (the 'social model') disability was separated from impairment and treated along the public versus private divide, making impairment a private issue. This relegation of the impaired body to the private realm took away its political import, by overlooking its aesthetic dimension, which is fundamentally public and interpersonal. This problem was extended further in post-structuralist critical disability studies, as the truth and reality of the body was treated as an ideological question of language and representation, when it is the reality of impaired bodies and minds that is precisely what makes disability so crucial in how differences between people can be dealt with better. In these ways, theory was made less pertinent for those disabled people whose bodies cannot be ignored and who also experience pain as a reality of lived experience.

Siebers goes further; he advocates that we bring to light the centrality of disability, not just to political and social life generally, but also to the art canon and aesthetic productions as a whole. For Siebers, disability has been at the core of modern art and culture, but in society generally, this presence has not been recognised as such. My film *The Disordered Eye* sought to show this presence of disability in the canon. This matters to critical theorists because they, Siebers included, see art as a space from which critiques about the dominant ideological structure of our social world can be made. In relation to this point, Gruson-Wood disagrees and argues instead that '... Art is situated in a paradoxical zone in which the gestures of transformation occur in the safety-net of image while temporarily escaping, but not disobeying, the hyper-real predictability of normate hegemony. Disability aesthetics does not challenge - rather it reinforces - the veracity in which the only acceptable aesthetic in real life is the norm' (Gruson-Wood 2009, p. 27).

Whilst the difference between the space of art, where disability is not necessarily a disadvantage, and that of the everyday, where it definitely is, suggests she is right, the pessimism of her argument can be countered by specifically focusing on the agency of disabled people and whether or not, and/or to what degree, they are able to seize the narrative, claiming it for themselves. Siebers argued that disabled people have a specific perspective that needs to be brought to light. This claim is in keeping with Fricker's desire to vindicate 'standpoint theory'. Both theorists are pointing to the situated nature of knowledge and how being marginal permits a perspective not available to powerful groups. In examining three films, I sought to explore this claim and found that, in keeping with the approach I adopted in making the films for this degree, the key difference that seemed to mark a more specifically disabled perspective, can be summarised as disabled people being the ones who own the narrative. In this ownership, it becomes possible to open up a space in which disabled people counter the ableist misrepresentations of them. In particular, by making the impaired body and the reality of disability 'as itself' (Siebers 2008) appear and affect how disabled films are made as well as viewed, one can see the possibility of this specific perspective disabled people can bring to light.

Limitations

I adopted an exploratory and experimental approach, and this permitted me to move between different concepts and theoretical approaches as I sought to sharpen my understanding and as I discovered new concepts and new ways of understanding, which informed the later written drafts. It was also conducive to the inclusion of my work in film-making, which explored the issues through image and sound. This approach permitted me to really deepen my understanding. On the other hand, the dissertation itself might have benefitted from a narrower focus (with a concomitant more evenly-paced analysis).

One aspect that would have been appropriate to examine in this thesis is society's need for scapegoats. Without disabled people, one can speculate that society would find another cohort of people to use in this way. It could be pertinent to examine further all the issues underlying such practices, which I have not done in this investigation because it would have detracted from the focus of this dissertation. Likewise, intersectionality seems very relevant, at the very least within academic theorising where it informs much of the critical disability studies' scholars work. Here it is only really touched on (particularly in the relationship between disability and class), but its inclusion might have permitted a more nuanced critique of, for example, McRuer's 'crip theory'. Again, addressing this complex issue would have diluted the thesis somewhat and I chose to leave it out.

One development in the study of epistemological injustice has been a pluralisation of what is meant by 'collective', as well as more conceptual work on 'wilful hermeneutical injustice' and 'contributory injustice'. More materials on these concepts might have opened up further areas of interest. Likewise, a closer examination of the complexity of impairments, including the 'hierarchy of disability' would have been useful in disrupting the binary disabled/non-disabled as well as in considering differences between visible and unseen disabilities. Furthermore, the lack of cross-cultural comparisons has had a rather narrowing effect on the dissertation but the word count and time limitations prohibited this.

Recommendations

Society needs a paradigm shift in relation to mortality - sickness, dependence, death - and its issues of denial that have such negative consequences for disabled people. Disabled people ought to be able to live as simply people with impaired bodies and/or minds the same as the non-disabled. Their difference should be a matter of neutrality. It is true that, like many other minority groups, disabled people can show us how varied the human condition is, but it is ethically unsound that they carry this symbolic weight arising from society's denial of its own mortality and vulnerability. This further work is outside of the remit of this research, but a paradigm shift of this kind would require multidisciplinary efforts, for example, in the fields of psychology, anthropology, medicine, counselling, perhaps even spirituality/religion.

Prioritising avenues to explore the agency of disabled people and how they can grab the initiative through making their own films, writings and other cultural representations, seems important to promote, so that disabled people's perspectives can be accepted and included in the general collective epistemic resources. This agency it seems, is necessarily critical - because of how disabled people carry the weight of being society's scapegoats; but it can also be revealing - of the human body and its differences, and it can also reveal that disability itself is very varied, which adds to the notion of physical and mental difference being a more accurate representation of what is to be human.

Original contribution

In linking Siebers' ideas, in particular about the lack of recognition of the centrality of disability, with Watermeyer's work on the damage silence creates for disabled people, and with Dotson's epistemic landscape of oppression, alongside my exposition of the importance of aesthetic judgments on the treatment, representation and attitudes to disability, I hope to have made an innovative contribution to knowledge.

The films I have submitted showcase the agency of disabled people. *The Disordered Eye* builds on Siebers' claim that disability informs and is central to aesthetics, while the untitled film I made seeks to reclaim silence, transforming its meaning by casting it in a disabled light; it also speaks of my disabled everyday life. The other three films - *Targeted: The Truth About Disability Hate Crime*, *The Truth About Disability Benefits*, and *Locked Away: Our Autism Scandal* - show disabled people being articulate and critical of the injustices and inequalities they are subject to. All my films have, insofar as is possible, involved disabled people in their making. They have in some cases resulted in direct positive impact for disabled people and at the very least exposed issues known mostly only to disabled people to a mainstream audience.

Figure nineteen.

END

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Appendix 1

Cover page for Floracide Art Booklet

Appendix 2

Cover page for : Channel 4 Survey for Disability Benefit Claimants

Appendix 3

- Disability Benefits And Suicide

Disability Benefits And Suicide

Author: Simon Duffy

Channel 4 recently produced a powerful and moving documentary about the failings of the DWP's disability benefit system and the multiple harms caused to disabled people in the UK. The documentary, produced by Richard Butchins, was fair and measured and explained how the DWP's systems, particularly since 2008, have led to increased poverty, malnutrition, unnecessary deaths and many suicides.

You can watch the documentary here:

https://www.channel4.com/programmes/truth-about-disability-benefits-dispatches

Before beginning I want to say to anyone reading this article who is thinking about suicide - don't do it. Talk to someone, to the Samaritans, to your friends, family, advocacy organisations or mental health services. If you are having problems with your benefits then this is something hundreds of thousands of people have also experienced; but there are some solutions and there is help out there. The benefit system is not fair; but there are good people out there who are willing to help. Reach out. Your life is precious. Please don't let your bad experience of a bureaucratic system cause you to lose hope.

Real life stories

At the heart of the documentary were four heart-breaking stories, describing how the DWP had played a lead role in someone's death.

Phillipa Day took her own life after losing her benefits, falling into debt and being punished for being unable to attend a DWP assessment (run by the private business, Capita). The

DWP lost important information, but cut her benefits anyway. She was even threatened with sanctions as she lay dying in a coma.

The coroner wrote a damning report which stated:

"…problems in the handling of her benefits claim was, in my finding, the predominant factor and the only acute factor, which led to her decision to take an overdose."

Similarly Jody Whiting took her own life after her benefits were incorrectly stopped. Errol Graham starved to death in his own flat when his benefits were cut off. Roy Curtis, a young man with autism, took his own life after his benefits were cut off. He had attempted suicide after previous dealings with the DWP, but this didn't stop the DWP from continuing to send him threatening letters, and it was these that triggered his final suicide. He lay dead in his apartment for nine months before his death was discovered.

The benefit system causes direct harm by not giving people enough money to live on. But it also causes harm because of the way it treats people. If you need disability benefits the system you face is complex, unfair, incompetent and often absurd:

- The DWP loses your paperwork; but you are made to suffer and you are not given the money you need.
- Medical experts agree that you cannot possibly attend an DWP appointment; but you still lose your money because you didn't attend an interview you couldn't attend.
- People who don't know you or your situation ignore you and independent expert advice and tell you that you are fit to work when you are plainly not.
- You get no help to challenge unfair decisions; you are presumed guilty, even though the DWP's decisions are frequently overturned by the courts and independent reviewers.
- There is no care, no human connection, no flexibility and no human rights.

Even when some of these injustices are exposed by coroners, the media or Parliamentary committees the injustice continues. Promises of change are made, but there is no accountability and no transparency. The DWP is a profoundly harmful institution. And as a whistle-blower from within the DWP explained, these problems start from the politicians and civil servants at the very top of the system.

The statistics

To support the programme the Centre for Welfare Reform (now called Citizen Network Research) provided technical assistance with the development of the questionnaire. Once the survey was completed we also helped provide an analysis of this new data on the disability benefit system. 3,500 people, a large number, completed the online survey, which found:

- 451 people (13%) said they had attempted suicide as a result of interacting with the DWP.
- 1,154 people (32%) said the DWP system had caused them to plan suicide.

- 2,158 people (61%) said the way the system worked had caused them to have suicidal thoughts.
- 3,331 people (93%) said the process of claiming benefits had made their mental health worse.
- 96% found the preparation for their assessment distressing.
- 3,180 people (89%) said the system had aggravated their pre-existing conditions.
- 79% said the system had made their physical health worse.
- 2,187 people (61%) said the system had caused them new health problems.
- 89% of respondents said the DWP is not “an ally to disabled people.”

It is impossible from this data to make an accurate calculation of the total number of extra suicides caused by the DWP and their systems. Obviously people who have taken their lives do not fill out questionnaires. Also the number of people completing the survey (3,500) is less than one thousandth of the total number of people who have received disability benefits during the ‘welfare reform ’period (from 2008 onward). We cannot simply multiply these figures by 1,000; we do not know enough about the people and the relevant timescales.

However we can be confident that the total figure of suicides and attempted suicides is very high indeed and we know that our data closely corresponds with the findings of other research in this field:

'First, do no harm', independent academic research, found that between 2010 and 2013 the WCA disability reassessment process had caused 590 suicides (Barr et al. 2015).

Assessing the Assessors (n = 884) found that 95% of people experienced the assessment process as damaging to their health, 29% severely so (Burgess et al. 2014).

Fulfilling Potential? (n=445) found that for 61% of people the work programme had worsened their health or impairment (Hale, 2014)

Counting the Cuts found that disabled people in poverty had been targeted with cuts to income and support four times greater than the average person (Duffy, 2014).

It is also useful to examine this important analysis by Dr Jessica Saffer, who spent time trying to understand the details of people’s experience of the disability benefit system (Saffer, 2017). She summarises her findings here:

“*The research to date suggests that disabled people on benefits experience significantly worse health than the general population. It is reported that changes in benefits have reduced household finances, which has affected the ability to buy food, fuel and clothes. Efforts involved in* ‘*getting by* ’*on benefits were often time consuming and emotionally draining. For many, the precarious nature of benefits contributed to a sense of insecurity. Claimants reported that they found the benefits system difficult to navigate, with long forms and lack of transparency and poor communication about processes. This has been found to cause considerable stress, fear and anxiety. In particular, the WCA has been found to* *be humiliating, degrading and inaccurate. The associated emotional and financial stress has been found to have a negative impact on both physical health and mental health.*

“*Furthermore, disabled people on benefits felt that their lives have been placed under increased scrutiny due to the political rhetoric and media coverage of poverty. They reported feelings of stigma and shame when relying on benefits. Many reported feeling angry about these perceptions and attempted to distance themselves by* ‘*othering* ’*those deemed less deserving, concealing their claimant identity or attempting to validate their illness. However, it was reported that many also internalised self-loathing. The stigma appeared to affect welfare recipients negatively in ways that are largely absent from public discourse, and there seemed to be a mismatch between the government rhetoric of benefits as a* ‘*lifestyle choice* ’*and individual*’*s actual experiences.”*

In a recent report published by Citizen Network Research on peer support in mental health, *Growing Peer Support*, the severe impact of the DWP on mental health is obvious. In one town, Doncaster, in just one year, many people had been pushed over the edge by their experience of the benefit system (Duffy, 2021). This pattern is being repeated up and down the country, year after year. This is an ongoing and deadly assault on people’s wellbeing and human rights.

Although there seems to be some delay in publishing the latest data on suicides we know from the Office for National Statistics that the total number of suicides per year is roughly 6,000. Which mean the total number of suicides since the beginning of the welfare reform period (2008-2022) is going to be roughly around 85,000. It is very likely that the DWP has contributed to a significant number of these suicides. In addition the DWP’s inadequate and brutal benefit system has contributed to many other unnecessary deaths from illness, malnutrition, cold and social isolation.

Even if, by some amazing improbability, the data we gathered reflected all the people who have had a bad experience of the DWP then this data would still bad enough. We live in a society that has purposefully created a benefit system that causes pain, mental distress, unnecessary death and suicide.

Proper academic research (the kind the government should fund itself if it were interested in the impact of its policies) requires sophisticated systems of sampling and detailed modelling. The NHS and the public health system should also be monitoring the impact of the benefit system on our health and tracking the relationship between benefits and the mental health crises. Alternatively the DWP could simply use its own systems to keep track of outcomes and correlations. But none of this is happening; and this fact tells its own story.

Coverage

The problems described in the Channel 4 documentary are well known to a minority of people. But there is very rarely any wider coverage of these issue. Instead the mainstream media tends to promote lies and distortions about disabled people, often telling lurid stories drawn from the very low number of people who have claimed benefits falsely, completely distorting the true situation.

Given this, it was a great achievement for this documentary to be made and broadcast. As Richard Butchins, the producer and presenter said:

"*I hoped this film would garner a mainstream audience for an issue that is often ignored. It did that and we achieved a good audience in a difficult pre-Xmas slot. The reaction has been very positive."*

There was also good coverage of the film in the Scottish newspaper, *The Daily Record*:

https://www.dailyrecord.co.uk/lifestyle/money/new-disability-benefits-documentary-25723003

And also in *The i Newspaper*:

https://inews.co.uk/news/long-reads/the-truth-about-disability-benefits-people-killing-themselves-system-1353558

There is also ongoing coverage, and many additional details, in the *Disability News Service*, run by John Pring (who was also an associate producer of the television programme):

https://www.disabilitynewsservice.com/dispatches-expose-sparks-anger-and-frustration-over-cruel-and-inhuman-system/

But given the severity of this problem it may seem surprising that coverage of these shocking facts has so far been limited to only two newspapers. However this is typical of the way in which the mainstream media has behaved during the welfare reform era. Even when several different United Nations investigate committees have issued damning reports on the UK Government's failure to respect human rights, media interest has been minimal or non-existent (Benstead, 2019).

The UK has become a country that has stuck its fingers in its ears when it comes to human rights - refusing to listen to researchers or advocates and even criticising its critics for daring to speak the truth.

Background

There is a long and painful story behind these bleak statistics and the stories of bureaucratic cruelty and heartlessness. It has taken many decades of decline in moral and political standards for the UK Government to be so regularly in breach of human rights principles and so obviously cruel in its attitude towards disabled people. However the most immediate causes are reasonably clear.

Leading politicians now hold false and dangerous beliefs about disabled people and the political leadership within the DWP has created a culture which encourages a negative view of disabled people, encourages bad and dangerous policy-making and hides from any accountability for the harm it is has caused.

Many politicians (not just in the Conservative party) have found that there is an eager audience for scapegoating disabled people as somehow unworthy of support. Society holds many false beliefs about disabled people and these are amplified by most mainstream media outlets.

A policy of privatisation and outsourcing has allowed profit-making companies to replace public servants and medical experts in the assessment and administration of benefits. There is now no guarantee that the assessors have the relevant expertise to make a correct assessment. The purpose of these organisation is to make a profit and the contractual arrangements developed by the DWP are designed to reduce benefit expenditure. In fact some private organisations have been invited into the policy-making process to help undermine the welfare state and to create profit for themselves (Stewart, 2018).

There are also many specific policies that have each introduced harmful changes to the system:

- Work Capability Assessment
- Employment & Support Allowance, replacing Incapacity Benefit
- The Work Programme and the ongoing ‘management ’of job seekers
- Personal Independence Payment, replacing the Disability Living Allowance
- Universal Credit
- Termination of the Independent Living Fund (in England)
- The increased use of sanctions
- Additional programmes of social control (e.g. Troubled Families programme)
- The Hostile Environment policy for refugees and others
- Benefit Caps
- Bedroom Tax
- Long-term devaluation of benefit levels
- Cuts to Housing Benefit

Given all these changes the experiences of Phillipa Day, Jody Whiting, Errol Graham and Roy Curtis are entirely predictable; and until there is a radical change in our approach there will be stories of unnecessary cruelty. There will also be thousands more who will experience the harm caused by the DWP, but whose stories will never be told. No connection will be made between the person’s death and the systems that caused their death.

But while understanding the immediate causes of this injustice is quite easy the deeper reasons for this long-term decline in standards of decency are more difficult to understand and any explanation is likely to be contested. However, it is my views that a number of darker forces are at work.

Economic and social change is creating increased instability and insecurity for millions. In uncertain times like these times, as thinkers like Hannah Arendt have explained, ordinary people can easily be swayed by evil rhetoric, simplistic ideology and the desire to find a scapegoat upon whom they can pin their troubles. In the UK a certain kind of meritocratic liberalism is now the dominant ideology and it has encouraged people to believe that success is measured by earnings and that those who cannot earn are worthless. We need to change our thinking and remember that every single person is valuable and that life is not about maximising our income, but living a life of meaning.

In addition, in the UK, we've discovered that our current constitution is incapable of resisting these injustices. The law, Parliament, civil society, charities and the media have largely chosen not to challenge the government, either from weakness or the desire for government patronage or personal preferment. Politically the UK is now a country where extreme right-wing policies, that would have been shunned by an earlier generation of politicians, are now normalised. Even the official opposition seems complicit, rarely challenging cuts to benefits or policies that scapegoat refugees, disabled people or people in poverty.

Alongside this we've allowed our own communities to wither. The stories of Phillipa, Jody, Errol and Roy are not just stories of bureaucratic harm; they are also stories of social isolation and loneliness. We need to look out for each other, for our neighbours and for our communities. Roy Curtis lay dead in his flat for nine months. This was not just a failure of the state, it was also a failure of the community.

There is no simple solution for these interwoven problems. It is for this reason that Citizen Network is supporting different communities, working on different fronts, to bring about the social change we need.

The UBI Lab Network works to promote radical reform of the benefits system - Universal Basic Income (UBI). Everyone should be guaranteed enough to live on, without relying on the whims of the bureaucracy. Also many disabled people need some extra income, but this can be provided without all the current complexity and fear. UBI would also help reduce the underlying anxieties which have driven the UK's drift to the extreme right.

The Neighbourhood Democracy Movement is connecting neighbourhoods who want to create thriving communities where nobody's life goes unnoticed and where nobody is left to die alone. Our Its Our Community programme is exploring how social care can be reorganised on a radically different basis - rooted in communities - and how peer support, rather than professional support, can be our starting point.

The campaign to End Westminster Rule is encouraging people to identify the radical changes we need to remake to the constitution of the UK, to protect human rights, to shift power into the hands of citizens and communities and to create a truly democratic society.

And Citizen Network Research will continue to support independent research on disability benefits, welfare reform and austerity. There are hundreds of papers, articles and reports in our library and we will continue to support further contributions.

Acknowledgements

I would like to end this essay with some acknowledgements.

Thanks to Richard Butchins for getting this important film made.
Thanks to John Pring for his indefatigable work in holding the DWP to account.
Thanks to Dr Anna-Carin Fagerlind Ståhl, Dr Christian Ståhl and Dr Anna Ruddock for their helpful technical assistance with the survey questionnaire and analysis of the

findings.
And thanks to the many Fellows of the Centre for Welfare Reform and other independent researchers who have shared their work with us over the past 12 years.

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Contact information for Richard Butchins and Hardcash Productions is here: https://www.hardcashproductions.com/2021/12/21/the-truth-about-disability-benefits/

If you are struggling with the benefit system a good source of advice is Benefits and Work:

https://www.benefitsandwork.co.uk

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Basic Income, disability, mental health, tax and benefits, England, Northern Ireland, Scotland, Wales, Article

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Appendix 4

Email correspondence with University of Kent in relation to their 'inclusivity' module 'Expect Respect' from 2021

To: EDI

Thank you for the "Expect respect" module. However, I am deeply disappointed and shocked to find that there is no section addressing ablism and disability in the module. This is in itself ableist and unsurprising. I would like to see the module remade or a separate compulsory module made to cover attitudes and ableism that we disabled students face on a daily basis, of which this module is a perfect example. I will refer this inappropriate learning resource to any authority that may be interested.
Kind regards
Richard Butchins

Dear Richard
Thank you for your email, I am forwarding this to Dr Margherita Laera, Deputy Director of Equality, Diversity and Inclusion for the School of Arts, for her kind attention.
Kind regards
Angela

To: Shaun May
How can the University have a module like this that does not address ableism - it is in itself ableist? Perhaps I am expecting too much to think that respect should extend to the disabled. What can be done about this? I completed the module with an increasing sense of frustration and despair at the omission. I am minded to write to the Vice Chancellor about this and to kick up a fuss. It is indicative of a particularly discriminatory attitude toward disabled students who may, of course, also be people of colour and women. Hopefully, I am not the only person that has noticed this, but the fact that the module designers and by extension the Uni administration have not addressed this
is a disgrace.

Shaun May
Thu 18/03/2021 14:39
Hi Richard,
This is a really bad oversight! I'm sorry for the anger and frustration this has caused.
I'm cc'ing in Dr. Lavinia Brydon, the EDI Director for the School of Arts. Although my understanding is that the Expect Respect module was created by someone in EDI/Student Support centrally, she may have a sense of who the best person to direct these concerns is. (I can't access the Moodle page myself but it looks like the convenor and teacher are Becky Mamyman and Auzimuth Jackson respectively, although sometimes staff are made 'teachers ' on Moodle just to give them access to the page.)

Lavinia, could we schedule a Zoom meeting with Richard? Perhaps with the aim of drawing up a list of things that we feel should be implemented in future iterations of the module, and sending them to Becky and Auzimuth? (I realise at a basic level the feedback will be "remember that disability exists", but I think something that reflects on different conditions and the notion of reasonable adjustments would be important too.)
All the best,
Shaun

18/03/2021 17:03
Good afternoon Richard,
My name is Dr. Auzimuth Jackson and I am serving as Interim Student EDI Officer while the usual Officer, Becky Lamyman, is away on leave. It is wonderful to e-meet you.
It has come to our attention that you have raised some important concerns regarding the Expect Respect module. Firstly, I want to thank you for your engagement with both the module and the university and for raising these concerns. Expect Respect was launched with the intention to directly convey the university's commitment to forging a safe and equitable campus culture. It is a module that is still undergoing shifts, and your email presents important feedback as to how we may move forward in continuing our work with Expect Respect. If you are willing and interested, I welcome the opportunity to meet and further discuss your concerns with the module. Regardless, however, please be assured that we are committed to reviewing and delivering the work that needs to be done.
I look forward to the possibility to meeting for further discussion.
Warmly,
Dr. Auzimuth Jackson (He/Him)

Richard Butchins
Thu 18/03/2021 16:11
To:
Thank you, Shaun and hello Lavinia,
It's a fundamental protected characteristic, and as someone that has spent years making TV doc after TV doc about the problems of ableism (as well as dealing with it at a personal level) it's important to tackle the issue at an early stage - students are crucial to shifting societies, at present, unpleasant and patronising attitude to disability. Ableist privilege really exists - as this module so succinctly demonstrates.
Happy to discuss as and when
Best
Richard

Hello Richard,
I have sent over a schedule meeting request via Teams for us to connect on Monday, March 22, 2021 to discuss Expect Respect. I look forward to the meeting. Please let me know if there are any accommodations that you need for attending via Teams.
Unfortunately, as the module currently discusses Sexual Violence & Racial Antagonism/Harassment, it would be inappropriate to "remove" it at this time. Abruptly removing it may further obscure conveying support intended for assisting university members

in times of crisis. However, I can assure you that I will promptly take measures to communicate to the campus community that Expect Respect is still undergoing revision.

Again, we remain committed to ensuring that we uphold our commitment to creating an equitable university culture and community, where discrimination and violence is intolerable in any form.

Warm regards,
Dr. Auzimuth Jackson (He/Him)

Well, you clearly are not - "committed to ensuring that we uphold our commitment to creating an equitable university culture and community, where discrimination and violence is intolerable in any form" Try and imagine this: There is a module "Expect Respect" oh...but it forgot to mention racism......never mind we'll put it in the next one....The fact that you are so dismissive of disability is a considerable worry.

Dear Lavina

I think it would be very helpful if you could join the conversation. I can't say I'm much impressed
with the "thanks for the feedback, we can't take the module down, but it's undergoing revisions" attitude that I'm currently receiving. The fact is that disability was either, a) deliberately not included, or b) forgotten about. Both are disturbing. I don't know which is worse really, especially from a University which was home to Mike Oliver and the Social Model of Disability.

I'm eager to hear what the designers of this module have to say about this and how the situation can be rectified? Imagine if the module had gone out and forgotten to address racism....I don't know whether to laugh, bellow in rage, or just silently sob in despair.

best wishes
Richard

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Appendix 5

List of interviewees from PhD (untitled) film

Tom Shakespeare: Professor of Disability Research at the London School of Hygiene and Tropical Medicine.

Marie Kilby (Sophia Disgrace): Former performance artist, poet, and musician

Alan Gardener: Garden designer and public speaker; former television presenter

Lee Ridley: Non-verbal comedian (not a mime artist) and winner of Britain's got Talent

Appendix 6

Hansard on Debate in HOC Tuesday 18 April 2023

https://hansard.parliament.uk/Commons/2023-04-18/debates/ABBFCE73-540A-4C49-8953-6DD6AF4E8E31/details

Breightmet Centre for Autism ordered to close

https://www.theboltonnews.co.uk/news/23589859.bolton-breightmet-centre-autism-ordered-close/

Littlebrook hospital inspection as a result of Documentary

https://www.disabilitynewsservice.com/?s=littlebrook+hospital+

Appendix 7

Films submitted for this PaR:

'*The Disordered Eye*':
https://vimeo.com/397139863?share=copy
PW: @disseye

'*Targeted: The Truth About Disability Hate Crime*':
https://vimeo.com/500523223?share=copy
PW: @dhcoffline

'*The Truth About Disability Benefits*':
https://www.channel4.com/programmes/truth-about-disability-benefits-dispatches

'*Locked Away: Our Autism Scandal*':
https://www.channel4.com/programmes/locked-away-our-autism-scandal-dispatches

'*Untitled*':
https://vimeo.com/856240688?share=copy
PW: @Finalcut

Films from chapter 4:

'*The Last American Freak Show*':
https://vimeo.com/326887900?share=copy
PW: lafs123

'*Sayonara CP*':
https://vimeo.com/24199126
(no password)

'*Crip Camp*' is on Netflix