

The Pretty Ugly Truth about Legal Protection for People with Facial Disfigurement in the UK

“The eyes of others our prisons; their thoughts our cages.”

— Virginia Woolf

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This dissertation is dedicated in memory of Dr. James Partridge who has given us a legacy to live up to and a dream to follow.

“Face equality, impossible? I think not. Liberating? Doable? Essential? I think so. None of us, on our own, can make this happen – but together we can.”

James Partridge, Founder of FEI

'The eyes of others our prisons; their thoughts our cages' - Virginia Woolf

Abstract

Disfigurement overlaps with concepts of appearance, making it not fit neatly into the disability legislation which currently gives it legal protection from discrimination. As it is not a functional problem like other disabilities it can be difficult for the claimant to meet the threshold of the definition and therefore come within the scope of legal protection. This dissertation critically analyses secondary resources to argue that the current requirement for a disfigurement to be 'severe' in order to come within the legal definition fails to understand the lived experience of visible difference and consequently limits access to justice. It offers discussion on whether disfigurement would be better protected as an identity rather than a disability due to the barriers being social, not functional. It is suggested that with an awareness of the prejudices, stereotypes and injustices of the past, legislation could be written, and judgements passed, that would identify and rectify the existing barriers to inclusion and could begin to influence how society sees visible differences.

Aim, Background and Context

Research has shown that 1.3million people identify as having a disfigurement in the UK and that over 40% of those asked feel discriminated against in the context of recruitment and employment.¹ While allowing for sensitivity in perception of the interviewees in this instance, this is still a high percentage that is not reflected in reported cases of facial disfigurement discrimination.² This dissertation aims to complement the growing body of research into face equality in the legal context by questioning why so few cases for disfigurement are successful, yet discrimination is highly reported. While literature specific to disfigurement and law is limited, psychology research into the impact of disfigurement points towards a more nuanced issue both in terms of external perceptions and individual adjustment. This work seeks to examine whether our current legal classification of disfigurement reflects an understanding of the lived experience of people with visible difference.³ If the experience is misunderstood, or worse undermined, then the legislation cannot address the core issues. To investigate further, this work looks at the limits of current protection within disability legislation and questions whether visible difference would be better legislated for as an identity like other protected characteristics. Moreover, it questions whether the current legal framework goes far enough to both dissuade negative attitudes as well as to promote inclusion. In doing so, it aims to show that there is an outdated understanding of visible difference and the accompanying discrimination, and this creates a barrier for both access to justice and inclusion.

Methodology

The methodology chosen for this dissertation is desk-based research which incorporates findings from secondary sources such as research reports, journal articles, legislation, and case law. This methodology has been chosen to allow an analysis of existing literature that is in-depth and includes multiple sources across several disciplines. While using desk-based

¹ Changing Faces '*Disfigurement in the UK*' (London: Changing Faces, 2017)

² A keyword search in Westlaw electronic database for "disfigurement" produced 4 cases under the heading of employment discrimination - accessed 23/09/22

³ Face Equality International was created in 2018 by Dr. James Partridge, founder of Changing Faces to further advocate for Face Equality recognition in legislation on a global basis

research is limited as it does not provide the opportunity to gain original data, there is comprehensive statistical data available from Changing Faces that far extends the scope of what could be gathered outside of the charity sector and within the time frame allocated.

Due to the case law reported being employment discrimination, the discussion will focus on that context rather than on other wider discrimination occurrences in general.

The literature is reviewed through the entirety of this dissertation, in order to review particular areas within the chapter headings. The limitations of this dissertation are that it is an emerging area of legal work and there are gaps in the research requiring more interviews to fully understand why claims are not made for discrimination.⁴

There is also a personal understanding within this dissertation as I have facial difference myself and can account for my own lived experience throughout this work to draw out some of the lesser understood implications of language, prejudice, and lack of inclusion.

Structure of Dissertation

Chapter One discusses the history of the facial disfigurement in the UK and in doing so, provides a background to why facial disfigurement leads to exclusion and is characterised as a disability. This chapter will review existing literature, theory and research to give a greater understanding of the lived experience of having a facial disfigurement in the context of a society that highly values beauty ideals and appearance. The aim is to show a link between appearance discrimination, disfigurement, and the society in which both take place. This chapter argues that without this underpinning knowledge, categorising facial disfigurement as a disability underestimates the many nuanced and specific issues the visible difference community deal with.

Chapter Two introduces the current legislation that is engaged in UK and Northern Ireland when someone with a disfigurement makes a claim of discrimination in the workplace. This chapter considers the definitions that have arisen from case law and how a discrimination claim currently comes within the scope of the legislation. It then argues that an adequate

⁴ Face Equality International formed in 2018 to look at Face Equality from a legal perspective and following the Queen Mary workshop, 'Appearance, Identity and the Law', a group of academics will further explore this topic in the coming academic year.

legislative approach towards facial disfigurement is one that fully comprehends the social disability model, and not solely the medical model which is currently at the forefront of how the legislation is applied. This chapter, therefore, introduces some of the unique characteristics of facial disfigurement, the difficulties with definition and questions whether disability is the most suitable protected characteristic to use.

Chapter three builds on chapter two looking at some of the perceptions around disability and disfigurement alongside the individual's perceptions of self to ask whether these can align or whether they are opposed to the point of impossibility. Looking at obesity as another example of an issue which spans the identity/medical divide, this chapter asks whether functionality should be the paramount consideration for allowing discrimination claims for what is otherwise appearance prejudice. It examines positive perceptions of people who are facially disfigured and how this may impact discrimination definitions and protection. This chapter argues that treatment of facial disfigurement as a disability is undermined by the wider issues of perception, including self-perception, which affect the facial difference community and go beyond physical limitations and medical issues.

Chapter Four seeks to summarise the work as well as trying to answer whether our current legal classification of disfigurement reflects an understanding of the lived experience of people with visible difference. By drawing on the previous chapters which expand on the complexities and dimensions of disfigurement, disability and appearance, this chapter proposes short term and longer-term solutions and proposes that classifying facial disfigurement as an identity is a more appropriate avenue for protection in the changing landscape of individual rights.

Terminology

The terms visible difference and facial disfigurement are used interchangeably in this dissertation because while the preferred term is visible difference, the legislation refers to facial disfigurement, and therefore at times this terminology is contextually required.

For the purpose of this dissertation both terms are used to refer to ‘a scar, mark or condition on your face or body that makes you look different.’⁵

It has been said that as Disability Studies have a key role in promoting an inclusive society, it’s a shame that published work often ‘tends to exclude rather than include non-academics.’⁶ For this reason it is intended, and indeed hoped, that this work is accessible to those it aims to represent. Therefore, it is important to note that language is used within this dissertation that may be difficult to read for some of those affected by visible difference. The purpose of including these words is to show, not endorse, the attitudes still held within society. These words should never be mistaken as representative of a person’s value, contribution, or beauty.

⁵ Changing Faces definition accessed at <https://www.changingfaces.org.uk/about-visible-difference/what-is-visible-difference> - accessed 30/08/2022

⁶ M Oliver, *‘Understanding Disability: From Theory to Practice’* (2nd ed. Basingstoke: Palgrave Macmillan, 2009) p179

Chapter 1 - A Brief History of Societal Attitudes to Appearance and Disfigurement

Outside of disability narratives, how we visually appear in society has prejudices and ideals attached that have been built over centuries of cultural norms, values and ideologies. As Hamilton describes, we are ‘always in dialogue with the powerful historical legacies of personhood.’⁷ So an additional appreciation of the social implications of living with disfigurement is gained through further exploration of the historical treatment of this group to help understand stigma and social bias. An in-depth exploration of stigma is beyond the scope of this dissertation, but we will rely on the definition of the stigma concept by Link and Phelan which defines stigma as the experience when “elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation.”⁸

Just like other minority groups, people with facial disfigurement have been overlooked by history.⁹ There are few records of lived experience but there is an understanding that can be gathered from how society viewed disfigurement legally and medically, giving a glimpse of how they reacted to, treated, and even caused, injury to the face.

1.1 Medieval Records – Something to Fear

Ideology about disfigurement is inextricable from the philosophy of beauty and the connection perceived between it and goodness, with scholars such as Thomas Aquinas contending that ‘beauty emanated from integrity’.¹⁰ Therefore a visibly flawed body, or face was often an indication of a moral shortcoming or punishment. Cnut’s law is one example where an adulterous woman, he says, shall become “a public disgrace” and lose her nose and ears.¹¹ Looking at facial disfigurement through the lens of gender provides a link between beauty and morality which is evidenced as far back as to the Old Testament where nose

⁷ Sheryl N Hamilton, *‘Impersonations: Troubling the Person in Law and Culture’* (University of Toronto Press 2009), p6

⁸ Bruce G Link and Jo C Phelan, *‘Conceptualizing Stigma’* (2001) 27 Annual Review of Sociology 363, p367

⁹ Patricia Skinner, *‘Better off Dead than Disfigured’? The Challenges of Facial Injury in the Pre-Modern Past’* (2016) 26 Transactions of the Royal Historical Society 25.

¹⁰ Thomas Aquinas, Summa, I, 39.8, quoted in Umberto Eco, *‘On Ugliness’* (Maclehose 2011), p15

¹¹ Alfred Boretius and Victor Krause, *‘Monumenta Germaniae Historica. Leges B, Capitularia Regum Francorum’* (Hanover:Hahn 1883).238–240, p240

cutting was a penalty against prostitution and since then it found its way into multiple legal codes.¹² This link is why the term “Losing Face” is short hand for honour impugned.¹³

Early medieval law codes account for this added nuance of shame by ‘fining injuries which could be perceived from a certain distance away, or those which left a permanent scar.’¹⁴

A social view of disability is apparent in early Irish law where the *Bretha Dein Checht* awards compensation for every public appearance the facially injured person had to make, thus acknowledging the social implications of looking different.¹⁵

There were no expressed positives to having facial disfigurement and even as battle scars it was read as a sign of defeat and disgrace.¹⁶ These early legal responses show that disfigurement carried with it a psychosocial consequence, that could be compensated for, but those affected were set apart. The theme of being isolated is further identified years later in literary works such as *The Hunchback of Notre Dame*¹⁷ and *The Phantom of the Opera*¹⁸, which are both fiction, but give a historical account highlighting a social understanding that those who are disfigured do not belong.

1.2 Twentieth Century Comprehension – Something to Fix

Early twentieth century references to disfigurement were equally as negative with examples of freak shows and the well-known story of Joseph Merrick, known as ‘the elephant man’, demonstrating a society that struggled to comprehend the enormity of showing up in the world looking so obviously different from the ‘average person’.¹⁹ Joseph later lived in the London Hospital where great interest was taken in his medical condition at this time when

¹² Skinner, P, ‘*Defacing Women: The Gendering of Disfigurement in Living with Disfigurement in Early Medieval Europe. The New Middle Ages*’ (Palgrave Macmillan: New York, 2017) p147

¹³ *ibid* p4

¹⁴ *ibid* Chap. 3

¹⁵ *Bretha Dein Checht*, Cause 31, cited in Fergus Kelly, *A Guide to Early Irish Law* (Dublin Institute For Advanced Studies 1988) p132

¹⁶ Patricia Skinner, ‘*Visible prowess? Reading men’s head and face wounds in early medieval Europe to 1000CE*’ in Larissa Tracy and Kelly Robert Devries, ‘*Wounds and Wound Repair in Medieval Culture*’ (Brill, Cop 2015) p81

¹⁷ *The Hunchback of Notre Dame*, historical novel by Victor Hugo, originally published in French in 1831 as *Notre-Dame de Paris* (“Our Lady of Paris”) - Victor Hugo and Keith Wren, ‘*The Hunchback of Notre Dame : Notre-Dame de Paris*’ (Wordsworth Editions 1993)

¹⁸ *Phantom of the Opera* was written by Gaston Leroux, first published in 1910 - Diane Namm, Troy Howell and Gaston Leroux, *The Phantom of the Opera* (Sterling Pub Co 2008)

¹⁹ See - Jeanette Sitton, Mae Siu-Wai Stroshane and Joseph Carey, ‘*Measured by the Soul : The Life of Joseph Carey Merrick, Also Known as the Elephant Man*’ (Friends Of Joseph Carey Merrick 2012)

medicine was evolving.²⁰ When architect Louis Kahn, responsible for some of the most iconic buildings of the mid-twentieth century, was badly burnt on his face and hands as a child, his father expressed the sentiment that he was ‘better off dead than disfigured.’²¹ As facial injury became prevalent during the first World War attitudes were again challenged by the increased visibility of the issue of visible difference. Contemporary writings of those involved in the care of veterans talk of an uncomfortableness amongst staff and a hiding away by patients.²²

There was a “collective looking-away” which took multiple forms:

“the absence of mirrors on facial wards, the physical and psychological isolation of patients with severe facial injuries, the eventual self-censorship made possible by the development of prosthetic ‘masks’, and an unofficial censorship of facially-disfigured veterans in the British press and propaganda”.²³

As medicine grappled to treat soldiers, facial injury posed particular problems as it was difficult conceal and even harder to fix.

This, along with the weight of loss both physically and socially, was perhaps why ‘very severe facial disfigurement’ was among the injuries for which a veteran was paid the full pension.²⁴ This was in keeping with the belief that disfigurement is a loss of identity and in many ways a loss of humanity, expression and self.²⁵

Alongside emerging concepts of disability, medicine and the realities of war, appearance in the twentieth century was still a gendered concept, with women in particular being subject to societally constructed beauty ideals in order to marry.²⁶

²⁰ Vigor-Mungovin Joanne, *Joseph: The Life, Times and Places of the Elephant Man* (London: Mango Books, 2016)

²¹ Skinner (n 7)

²² Ward Muir, who worked as an orderly at the 3rd London General Hospital in Wandsworth, was surprised by his reaction to patients on the facial ward: ‘I never [before] felt any embarrassment ... confronting a patient’, he confesses, ‘however deplorable his state, however humiliating his dependence on my services, until I came in contact with certain wounds of the face’ - Ward Muir, *Observations of an Orderly: Some Glimpses of Life and Work in an English War Hospital* (Simpkin, Marshall 1917) p143

²³ S Biernoff, ‘The Rhetoric of Disfigurement in First World War Britain’ (2011) 24 *Social History of Medicine* 666

²⁴ Table of war pensions for physical injury, Ministry of Pensions Leaflet, c. 1920, reproduced in J Bourke, *Dismembering the Male: Men’s Bodies, Britain and the Great War* (London: Reaktion, 1996) p66

²⁵ Sander L Gilman, *Making the Body Beautiful : A Cultural History of Aesthetic Surgery* (Princeton University Press 2022) p162

²⁶ Annette Kellerman, *Physical Beauty: How to Keep It* (New York: George H Doran, 1918) p14 - “by no other plan [than beauty] can woman win love worth having nor keep the love she has won. On no other basis can she win or keep the admiration of the world at large”

With this mindset towards how people looked, disfigurement was something to be ashamed of, and carried the weight of humiliation and disapproval.

1.3 Society Now – Something to Filter

In her book *Perfect Me*, Heather Widdows contends that as we are living in an increasingly visual and virtual culture, the requirement to be camera ready is prevalent.²⁷ With our increasingly mobile culture, both in terms of travel and also in relation to the huge number of people we can encounter online, first impressions matter more now and it is more difficult for someone with a disfigurement to get past this stage.²⁸ Shame is still felt in relation to appearance but the narrative now imposes shame on those who “let themselves go”, or don’t invest in improving their appearance.²⁹ Positive personality traits continue to be assumed to apply to those deemed as attractive³⁰ and “the halo effect” extends into the employment market where job offers, promotion and even salaries can be higher for more physically attractive people.³¹ While our global society attaches moral value to “good looks” across the many variances that takes, no society considers disfigurement to be a value.³²

Each year there is an increase in the number of non surgical cosmetic procedures taking place, which in 2020 was 13.9% higher than previous years, with botox and facial fillers topping that list and the gendered aspect is still apparent with the majority of patients being female.³³ It is in this context Hilary Clinton said, “cosmetic surgery may be just as important for someone’s state of mind and wellbeing as any other kind of surgery.”³⁴

²⁷ Heather Widdows, *PERFECT ME : Beauty as an Ethical Ideal* (Princeton University Press 2020) p25

²⁸ *ibid* p59

²⁹ *ibid*

³⁰ Alice H Eagly and others, *What Is Beautiful Is Good, but . . . : A Meta-Analytic Review of Research on the Physical Attractiveness Stereotype.* (1991) 110 *Psychological Bulletin* 109 p121

³¹ Daniel S Hamermesh, *Beauty Pays : Why Attractive People Are More Successful* (Princeton University Press 2013) p47

³² Phyllida Swift and Kathleen Bogart, *A Hidden Community: Facial Disfigurement as a Globally Neglected Human Rights Issue* (2021) 11 *Journal of Oral Biology and Craniofacial Research* 652, p653

³³ The top five nonsurgical procedures also remained consistent: botulinum toxin (43.2% of all nonsurgical procedures), hyaluronic acid (28.1%), hair removal (12.8%), nonsurgical fat reduction (3.9%) and photo rejuvenation (3.6%). Around 85% of nonsurgical procedures were performed on women. Despite the overall reduction in surgeries, rhinoplasty and brow lift surgeries continued to increase, and nonsurgical facial rejuvenation showed a 13.9% increase compared to a decrease in both 2019 and 2018.

<https://www.isaps.org/wp-content/uploads/2021/12/2020-Press-release-final.pdf> - accessed on 3 August 2022

³⁴ Karen Lehrman, *The Lipstick Proviso : Women, Sex & Power in the Real World* (Doubleday 1997) p80 (quoting Clinton)

With the normalization of beauty practices, use of online filters and promotion of celebrity, society is 'raising the bar of normal'.³⁵

The difficulty with raising the bar of normal in terms of appearance is that the higher it goes the further people with disfigurement are from the prototypical face and aesthetic presentation that society values. As Barnes points out, the concept of being "able bodied" was a requirement for inclusion in the 19th century physically orientated workforce, however an 'able mind' may be much more important in the 20th century.³⁶ To build on that concept, and with reference to the ever increasing reliance on digital media, virtual interviews, face recognition AI and the emergence of careers such as "influencers", it could be reasoned that being 'facially typical' is equally as important in the society that is emerging in the 21st Century.

1.4 Lived Experience – Something to Hide

Awareness of the historical backdrop of shame, medicalisation and hiding away, helps illuminate some of the lived experiences people report of having a visible difference.

Those who consider themselves to have a visible difference have reported heightened concern over social participation, expecting difficult interactions and awkwardness with strangers.³⁷ In a Changing Faces survey 81% of those questioned reported having been stared at or had inappropriate comments made by strangers.³⁸ The psychosocial results of this can lead to 'low self-esteem and lack of confidence to feelings of shame and avoidance of social situations.'³⁹ Consequently some individuals may struggle with relationships in their social lives and even family lives.⁴⁰ Self-esteem and internal validation can be low also and in one

³⁵ Widdows (n 25)

³⁶ Colin Barnes and British Council Of Organizations Of Disabled People, *'Disabled People in Britain and Discrimination : A Case for Anti-Discrimination Legislation'* (London Hurst In Association With The British Council Of Organizations Of Disabled People 2000)

³⁷ Richard Lansdown, *'Visibly Different : Coping with Disfigurement'* (Butterworth-Heinemann 1997), p103

³⁸ Changing Faces (n 1)

³⁹ MP Brewin and SJ Homer, *'The Lived Experience and Quality of Life with Burn Scarring—the Results from a Large-Scale Online Survey'* (2018) 44 Burns 1801, p1802

⁴⁰ BC Brown and others, *'The Hidden Cost of Skin Scars: Quality of Life after Skin Scarring'* (2008) 61 Journal of Plastic, Reconstructive & Aesthetic Surgery 1049

study 44% of respondents had concerns and negative emotions about their appearance. They frequently described their scarring as 'ugly, unattractive or unsightly.'⁴¹

While some may suggest a level of participant sensitivity to these findings,⁴² research has also generated results from those who do not consider themselves to have a visible difference that demonstrates negative attitudes towards those with a disfigurement. Those attitudes range from negative emotions⁴³, to avoidance⁴⁴, to distrust⁴⁵ and assuming a lack of emotional strength or social ability.⁴⁶ Within the employment context people with a visible difference experience discrimination,⁴⁷ are often assumed to have other underlying illnesses⁴⁸ and are less likely to get an interview.⁴⁹ All of these reactions and outcomes lie outside of the individual and their visible difference, regardless of how it was acquired, and instead are a direct consequence of the attitudes of others.

Social interaction can be so difficult for people with facial disfigurement that recent lockdowns and mask wearing, came as a relief for many people allowing them to escape the prying eyes, stares, comments, and harassment from strangers.⁵⁰

This daily display of difference is what sets disfigurement apart from other disabilities which result in functional issues and for which practical measures can address barriers and promote

⁴¹ Brewin and Homer (n 37)

⁴² Alan Feingold, 'Good-Looking People Are Not What We Think.' (1992) 111 *Psychological Bulletin* 304

⁴³ See: Eileen Bradbury, 'Meeting the Psychological Needs of Patients with Facial Disfigurement' (2012) 50 *British Journal of Oral and Maxillofacial Surgery* 193 and Anna Stone and Anita Potton, 'Emotional Responses to Disfigured Faces: The Influences of Perceived Anonymity, Empathy, and Disgust Sensitivity' (2014) 36 *Basic and Applied Social Psychology* 520

⁴⁴ See, for example, Nichola Rumsey, Ray Bull and Denis Gahagan, 'The Effect of Facial Disfigurement on the Proxemic Behavior of the General Public' (1982) 12 *Journal of Applied Social Psychology* 137 and John W Lawrence, Laura E Rosenberg and James A Fauerbach, 'Comparing the Body Esteem of Paediatric Survivors of Burn Injury with the Body Esteem of an Age-Matched Comparison Group without Burns.' (2007) 52 *Rehabilitation Psychology* 370.

⁴⁵ See, for example, Angela M Griffin and Judith H Langlois, 'Stereotype Directionality and Attractiveness Stereotyping: Is Beauty Good or Is Ugly Bad?' (2006) 24 *Social Cognition* 187 and Marlene Rankin and Gregory L Borah, 'Perceived Functional Impact of Abnormal Facial Appearance' (2003) 111 *Plastic and Reconstructive Surgery* 2140

⁴⁶ See Anna Stone and Toby Wright, 'Evaluations of People Depicted with Facial Disfigurement Compared to Those with Mobility Impairment' (2012) 34 *Basic and Applied Social Psychology* 212 and Bradford S Bell and Katherine J Klein, 'Effects of Disability, Gender, and Job Level on Ratings of Job Applicants.' (2001) 46 *Rehabilitation Psychology* 229

⁴⁷ Sarah V Stevenage and Yolanda McKay, 'Model Applicants: The Effect of Facial Appearance on Recruitment Decisions' (1999) 90 *British Journal of Psychology* 221

⁴⁸ Stephen Ryan and others, 'Facial Disfigurement Is Treated like an Infectious Disease' (2012) 33 *Evolution and Human Behavior* 639

⁴⁹ A. Stone and T. Wright, 'When Your Face Doesn't Fit: Employment Discrimination Against People with Facial Disfigurements' (2013) 43 *Journal of Applied Social Psychology* 515, p520

⁵⁰ Swift and Bogart (n 32) p656

inclusion. However, with visible difference the main issues are other people's reactions and the compromised perception of self, which makes the path to inclusion difficult to identify and awkward to discuss.⁵¹ For facial disfigurement, there is both something to hide and nowhere to hide and therefore every interaction carries with it the potential to be measured by your face before anyone looks at your smile.

1.5 Conclusion

Understanding the negative treatment in the past, fearful reactions and social awkwardness associated with visible difference will help inform the context in which we are making laws to protect people from discrimination. As with other characteristics, it is only by realising the historical stigmas, injustices and damage that was done, that we made moves towards equality.⁵² Jill Marshall considers that it is in our capacity to discover the historical links between our self-understanding and modes of domination that we find freedom to 'resist the ways we have already been classified by dominant discourse.'⁵³

What we have seen from this discourse is that historically disfigurement was not considered as a normal part of diversity, but as an infliction. This runs parallel with the current legislation that provides protection under disability legislation using the language of 'impairment.' But when society is constructed as a series of opposites such as, impaired and non-impaired or normal looking or disfigured, it leaves no room for gradation or overlapping.⁵⁴ Yet disfigurement and appearance are part of a spectrum, as discussed by Hannah Saunders, and this makes visible difference an awkward fit for disability legislation.⁵⁵

What is lacking from history is an identity beyond the shadows of shame where disfigurement exists. One which stands on its own, no longer a negative comparison.⁵⁶ Hamilton argues that for those seeking personification, 'law trumps even science and capital, as the best tool to

⁵¹ Guidance on possible reasonable adjustments can be found on Face Equality International - <https://faceequalityinternational.org/individual-equality-guidance/> - accessed 18/09/22

⁵² Kiyutin v Russia Application No. 2700/10, judgement 10 March 2011, para 64

⁵³ Jill Marshall, *'Human Rights Law and Personal Identity'* (Routledge 2016), p243

⁵⁴ Linda McDowell and Rosemary Pringle, *'Defining Women : Social Institutions and Gender Divisions'* (Polity Press 1992), p4

⁵⁵ Hannah Saunders, *'Difficult Distinctions in Anti-Discrimination Law: Disfigurement, Appearance and Disability'* (2020) 20 International Journal of Discrimination and the Law 21

⁵⁶ McDowell and Pringle (n53)

use, and therefore a change in legislative stance could influence how visible difference is viewed.⁵⁷

Nevertheless, legal changes at times only go part of the way to changing attitudes, for example, the removal of barriers put in place by the law was still not sufficient to 'dislodge the deeply ingrained patterns of prejudice... suffered by women.'⁵⁸ Therefore any change in legislation must be accompanied by education, application, and review.

However, a change in legislation can provide a foundation on which to build better structures, to ensure that equality is promoted and that at least inequality can be corrected. It is for this reason that law, at its core, has the ability, unlike many other tools, to 'address not only issues of discrimination but also the underlying values and inequities that form the foundation of stigma.'⁵⁹

⁵⁷ Sheryl N Hamilton, *Impersonations: 'Troubling the Person in Law and Culture'* (University of Toronto Press 2009) p20

⁵⁸ Sandra Fredman, *'Discrimination Law'* (Oxford University Press 2012) p38

⁵⁹ Michael V Stanton and Jason A Smith, *'Law, Stigma, and Meaning: Implications for Obesity and HIV Prevention'* (2017) 45 *Journal of Law, Medicine & Ethics* 492, p499

Chapter 2 – Law and Legal Interpretation of Visible Difference

Approaches to discrimination based on visible difference vary globally, with some countries such as France broadly protecting against appearance related discrimination,⁶⁰ while other countries narrow protection to terms like ‘cosmetic disfigurement.’⁶¹ In India they take a very practical approach and name acid attack injuries, alongside other conditions, within section 34 of The Rights of Persons with Disabilities Act 2016. This legislation requires government departments to reserve a percentage of jobs for those with qualifying disabilities in recognition of the difficulties they face gaining employment due to social barriers.⁶²

2.1 Legislation

In Northern Ireland the Disability Discrimination Act describes disability as a “physical or mental impairment that has a substantial, long term, adverse effect on the ability to carry out day to day activities”.⁶³

Severe disfigurement is one of the few conditions specifically named within the Disability Discrimination Act, where it is defined as:

“An impairment which consists of a severe disfigurement is to be treated as having a substantial adverse effect on the ability of the person concerned to carry out normal day-to-day activities”⁶⁴

The rest of the UK consolidated their equality legislation under the Equality Act 2010 where Sched 1, section 3 contains the same reference to severe disfigurement and Section 6 contains

⁶⁰ Code du Travail, Article 1132-1. 2

⁶¹ Americans with Disabilities Act, as amended, Title 29 CFR Part 1630.2. 4.

⁶² The Rights of Persons with Disabilities Act, 2016, section 34 Reservations

⁶³ The Disability Discrimination Act 1995 Section 1 (1)

⁶⁴ The Disability Discrimination Act 1995, Paragraph (3) of Schedule 1 to the Act “An impairment which consists of a severe disfigurement is to be treated as having a substantial adverse effect on the ability of the person concerned to carry out normal day-to-day activities.”

the twofold test for disability.⁶⁵ Due to the unique political landscape in Northern Ireland, which is beyond the scope of this dissertation, a single equality act is party policy for many representatives but has not yet come to fruition.⁶⁶

2.2 Case Law and Interpretation

Neither legislation, the Guidance to the Act, or case law provide a definition of disfigurement, however case law has established that the term is to be given “common parlance” and that the impairment relates to the cosmetic aspect of the condition.⁶⁷ The word severe has been more difficult to define with the courts applying a purposive approach⁶⁸ and considering medical evidence.⁶⁹ Tribunals have also made reference to Guidelines for the Assessment of General Damages in Personal Injury Claims, while bearing in mind that the guidelines are only of limited comparative value.⁷⁰

Bearing in mind the sensitivity of discussing a person’s appearance, it is surprising that severity is not given any definition and it is up to the tribunal to decide what to take into consideration as severe. One judgement noted the discomfort felt by the panel at their unenviable position of deciding whether someone fitted into this category.⁷¹ Terminology becomes an issue when describing what constitutes severe and this discussion can result in words like “repellent” being used in reference to appearance which goes against the ethos of the protection itself.⁷²

While government comments at the time of drafting said that it would be obvious what would fall into this category it would seem that it is anything but.⁷³

The limited case law available includes discussions around severity which have drawn on various aspects of what constitutes as severe, however what is unclear is where the severity

⁶⁵ Equality Act 2010 as amended

⁶⁶ https://www.allianceparty.org/muir_unveils_alliance_legislative_priorities - accessed on 31st July 2022

⁶⁷ *Cosgrove v Northern Ireland Ambulance Service* | [2006] NICA 44

⁶⁸ *Goodwin v The Patent Office* (1999) IRLR – “with social legislation of this kind a purposive approach to construction should be adopted.”

⁶⁹ *Hutchinson 3G UK LTD v Mr C Edwards* UKEAT/0467/13/DM, para 57

⁷⁰ *Hand v. The Police Authority for Northern Ireland* [2002] NIIT 1691_01

⁷¹ *Hutchinson* (n 68), para 56

⁷² *Johansson v. Fountain Street Community Development Association* [2005] NIIT 311_03

⁷³ House of Commons Standing Committee E Debate, 7 February 1995, per Mr Gerrard

must lie, is it in a medical context, does it extend to the social or personal context, and which carries more weight.

2.3 Medical Context

A starting point is to apply a medical definition of disability considering the “degree of the disfigurement”⁷⁴ and to rely on medical reports, which in the case of *Hutchinson* was the only evidence of the disfigurement because the claimant chose to conceal his condition at tribunal, as he did daily.⁷⁵

Another indicator of severity can be the position of the disfigurement which was noted in *Hand* as an important factor considering her scar was clearly seen and in the middle of her face.⁷⁶ However, in the case of *Johansson*, it was observed that while, “scarring was visible at conversational distances, there was no distortion of her facial features, and her facial expressions are normal and appropriate” therefore the position was less important than the extent of ‘distortion’.⁷⁷ Similarly, in *Hutchinson* the claimant’s disfigurement was his chest formation, which was possible to partially conceal, yet due to the extent of the condition was considered substantial enough to be “severe” for the purposes of the tribunal.⁷⁸ Consequently while visibility is at times considered, it would seem that the scale of the diagnosis is predominant in deciding severity. This is a very medicalised approach to definition that lacks any context which, when dealing with disfigurement, is of paramount consideration. It is the context, comparative and cultural, that determines which faces fit and which don’t.⁷⁹

The medical model approach also views the individual with pity, as defective, or as having an impairment that must be eliminated, treated, or cured.⁸⁰ Face Equality International remark that disfigurement in this context is a defect to be fixed through medical and surgical

⁷⁴ Hand (n 69)

⁷⁵ Hutchinson (n 68)

⁷⁶ Hand (n 69)

⁷⁷ Johansson (n 71)

⁷⁸ Hutchinson (n 68)

⁷⁹ Social Constructivist theory argues that it is the discourse around the subject rather than the condition itself that is the disabling factor depending on what is viewed as “normal”. See - Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (Routledge 1990) and Sally French, Mairian Corker and Open University Press, *Disability Discourse* (Open University Press 1999)

⁸⁰ D Goodley, *Dis/ability Studies: Theorising Disablism and Ableism* (London: Routledge, 2014)

interventions.⁸¹ This upholds existing biases by not acknowledging a range of human differences and creates stereotypes which then become cemented in the public's mind.⁸²

Additionally, it presents an ableist view because the starting point is that there is a 'normal' person, that person is 'able', or in terms of appearance 'prototypical', and impairments exist for those who fall outside of that definition.⁸³ As such, the concept of disability is socially constructed, and based upon a dominant able-bodied hegemonic model. The result is that limits are placed on those with visible differences simply because of other people's inability to imagine living life looking how they do. The projected weakness of the 'normal' gets mistaken for the inherent weakness of the different.

The pity that accompanies this perhaps goes some way to explaining why law protects some and not others. Those who are seen as being part of the typical variances of life compared to those who have been 'impaired' in a way unimaginable within normalcy. However, far from providing adequate protection against discrimination, this further validates stereotypes and is itself a form of perception-based discrimination.⁸⁴

2.4 Problems with the Medical Approach – No Diagnosis

In some cases, the medical model, functional restriction, and thus the definition of disability, will be satisfied. However, unlike other disabilities, with visual difference there may be no functional limitations at all. Consequently, disfigurement doesn't fit neatly into the definition or concepts of disability as it can occur with no diagnosable physical, psychological or mental conditions.⁸⁵

One such case is that of *Campbell*, a case concerning baldness, with extensive details of impact which included teasing, name calling and humiliation.⁸⁶ The claimant was arguing that he had

⁸¹ Swift and Bogart (n 30) p654

⁸² Deborah Marks, 'Models of Disability' (1997) 19 Disability and Rehabilitation 85, p87

⁸³ F. Kumari Campbell, 'Contours of Ableism: The Production of Disability and Abledness' (Palgrave MacMillan, 2009)

⁸⁴ Lillie Louise Teden, "Does the Protected Characteristics Framework Properly Accommodate Perception-Based Discrimination against Minority Groups?" (2021) 4 Edinburgh Student L Rev 95

⁸⁵ Swift and Bogart (n 30)

⁸⁶ *Campbell v. Falkirk Council* [2008] S/136261/07

a disability, not disfigurement, nevertheless it was in relation to his appearance, not function, and therefore it informs our understanding of how appearance is considered.

He did not meet the threshold of disability as it was not caused by a medical condition, it was a 'normal' aged related male condition.

The difficulty with this outcome is that baldness can be caused by conditions such as alopecia⁸⁷, trichotillomania⁸⁸ or burns. In that situation the condition, alongside the impact of baldness, could then mean that it is classed as a severe disfigurement. While it is clear that disability legislation does not intend to protect differences of appearance without impairment, the focus on the cause of the visible difference, results in a lack of clarity in where the line is drawn on discrimination towards a feature of appearance such as baldness. Protecting a diagnosis rather than the feature does not portray which behaviour is prohibited, conversely it makes the behaviour at best unpunishable, and at worst acceptable, in certain circumstances.

What's left is a situation where two bald people can be discriminated against in exactly the same way and one is protected and one not because of the "othering" created by disability narratives.⁸⁹ Hannah Saunders concludes that 'clarity on ascertaining impairments of appearance, rather than of function is therefore essential to expand the protection for visible difference.'⁹⁰ This would also incorporate cases where a medical diagnosis is present but is considered mild, such as a non-extensive skin condition or small scar, which currently would not come within the scope of the legislation.⁹¹

Furthermore, visible difference, because of its extended reach across the medical social divide, could be more effectively legislated for if treated like other protected characteristics such as race, gender or sexuality, that are equally immutable, but do not have to be considered as impairments before gaining protected status.⁹²

⁸⁷Alopecia areata is a chronic, inflammatory condition affecting the hair follicles which leads to sudden onset of non-scarring alopecia, Alopecia areata is a relatively common condition and is estimated to affect 15 in 10,000 people in the UK - see <https://cks.nice.org.uk/topics/alopecia-areata/>

⁸⁸ Trichotillomania (hair-pulling disorder) is a body-focused repetitive behaviour disorder characterized by recurrent hair-pulling which results in noticeable hair loss and significant distress or impairment in functioning – see Rohit Ghate and others, 'Characterizing the Content, Messaging, and Tone of Trichotillomania on YouTube: A Content Analysis' (2022) 151 *Journal of Psychiatric Research* 150

⁸⁹ Marks (n 81) p87

⁹⁰ Saunders (n 55) p28

⁹¹ Whyte v. First Capital East Limited [2005] UKEAT/0686/04/DM and Johansson (n 71)

⁹² Colin Barnes, 'A Working Social Model? Disability, Work and Disability Politics in the 21st Century' (2000) 20 *Critical Social Policy* 441, p444

2.5 Social Context

As position, 'distortion' and visibility all factor in assessing severity of disfigurement for the purposes of meeting the legal criteria, then it is partially recognised that the issue is how other people see the difference and judge the appearance of the claimant.

This acknowledges the social model of disability which identifies that barriers for disabled people exist outside of themselves and operate in a society that does not accommodate a full spectrum of ability.⁹³ As Hannah Saunders notes, 'the social model explains the overlapping conceptual relationship between disability and disfigurement: attitudes facing someone who looks different can be disabling.'⁹⁴

These attitudes can be identified when considering the impact on the claimant as part of a discrimination claim. While severe disfigurement does not need to satisfy the "substantial adverse effect" component of the disability test, because it will automatically apply where severe disfigurement exists, impact is highly significant when assessing whether the 'severe' threshold has been met.

In the case of *Hutchinson*, impact was deemed as "potentially the best way to ascertain severity," which then leaves a claimant back at the regular 'disability' starting point of having to prove impact or adverse effect.⁹⁵ Where this is the case it renders the severe disfigurement provision in the Act of little added value.

It is not suggested here that the test for severe disfigurement should be entirely subjective, this may lead to claims that would dilute the reality of living with disfigurement, which could further isolate people whose appearance is met with significant barriers.⁹⁶

⁹³ Union of Physically Impaired Against Segregation (UPIAS) 1976 stated that exclusion was due to the way employment was organised. See UPIAS (1976) *Fundamental Principles of Disability*. (London: Union of the Physically Impaired Against Segregation)

⁹⁴ Saunders (n 54) p26

⁹⁵ Hutchinson (n 68) p59

⁹⁶ Ibid p60

Yet, the obvious problem arising from measuring impact on the individual, is the risk that it becomes medicalised where a diagnosis of depression or anxiety may be required to prove difficulty with socialising.⁹⁷ Yet research has shown there are many psychological reasons why those with disfigurement struggle and that some, such as burn survivors, are on a continuum between acceptance and resentment regarding injury.⁹⁸ It is also rarely a linear experience, as pointed out by Thompson and Kent, because ‘negative and intrusive reactions towards those who are visibly disfigured lead to fluctuations in mood and behaviour.’⁹⁹ Therefore, for visible difference to be understood and fully protected it is essential it is recognised that it involves psychological, life altering difficulties in, and of, itself without a further diagnosis.¹⁰⁰

2.6 Problems with Social Context – Appearing to Fit In

This raises the question of how do we measure impact if people appear to cope socially? This was noted in the case of *Johansson* where it was stated that the claimant had successfully managed to work for twenty years, thus diluting her contention that her scarring was affecting her employment now.¹⁰¹ While there were other factors in that case which ultimately led to her losing her claim, the point was an interesting one. If the ability to hold down a job can be taken as evidence that the impact of visible difference is less, it moves towards a system that fails to recognise how difficult holding down a job may be for people with a visible difference. Particularly as studies have indicated that especially for women with disfigurement, they are taking their changed appearance into consideration and actively incorporating this into their decision making on a daily basis.¹⁰² Therefore, one person’s resilience in the face of obstacles should never be taken as evidence that those obstacles do not exist.

Using employment status as an indicator of adjustment to one’s appearance also overlooks how difficult it may have been to get a job or to be included within the workplace. When

⁹⁷ Campbell (n 85)

⁹⁸ Julien Christian Mirivel and Avinash Thombre, ‘*Surviving Online: An Analysis of How Burn Survivors Recover from Life Crises*’ (2010) 75 *Southern Communication Journal* 232

⁹⁹ Andrew R Thompson, Gerry Kent and Jonathan A Smith, ‘*Living with Vitiligo: Dealing with Difference*’ (2002) 7 *British Journal of Health Psychology* 213

¹⁰⁰ Problems such as anxiety, depression, a sense of helplessness, anger, guilt, low self-esteem and self-confidence that may lead to withdrawal and social isolation – see Dalia Gilboa, ‘*Long-Term Psychosocial Adjustment after Burn Injury*’ (2001) 27 *Burns* 335

¹⁰¹ *Johansson* (n 71)

¹⁰² Tevya A Hunter and others, ‘*“Put on Your Face to Face the World”: Women’s Narratives of Burn Injury*’ (2013) 39 *Burns* 1588

considering inclusion at work, it involves not just employing a diverse range of people but also actively ‘incorporating them in key work-related processes’ such as decision making, access to information and resources and pathways to success.¹⁰³ Unequal treatment in this circumstance is not just denying access to employment but lack of access within employment. Referencing the claimant’s employment history focuses on the fact she was there rather than on what it was like when there. It also ignores the point that one workplace may have been supportive, yet another one may not be or may cease to be and the existence of one does not eliminate the other.

Within the research around disfigurement, it has been recognised that there is a need to establish a clearer definition of the concept of adjustment beyond just low levels of anxiety or depression.¹⁰⁴ To fully reflect lived experience it must also include ‘behavioural (e.g., full engagement in social activities) and cognitive (e.g., the absence of worry and negative thoughts) dimensions as well.’¹⁰⁵ An individual might be able to cope with high levels of social anxiety through such coping strategies as avoidance, concealment and camouflage.¹⁰⁶ But such strategies meet a short term aim and ‘they can also serve to maintain distress and, indeed, may exacerbate the problem by resulting in disability.’¹⁰⁷

Even where social impact is accepted, as in the case of *Hand*, definition of severity is still focuses on the condition and associated medical identifiers.¹⁰⁸ This is problematic for disfigurement cases because research has shown that as negativity towards those with facial disfigurement is subject to the perceptions, preconditioning and prejudices of the onlooker, the reaction is not always relative to the severity, or cause, of the disfigurement.¹⁰⁹ Therefore

¹⁰³ Michàlle E Mor Barak, Gil Luria and Kim C Brimhall, ‘*What Leaders Say versus What They Do: Inclusive Leadership, Policy-Practice Decoupling, and the Anomaly of Climate for Inclusion*’ (2021) 47 (4) *Group & Organization Management* 840, p842

¹⁰⁴ Andrew Thompson and Gerry Kent, ‘*Adjusting to Disfigurement: Processes Involved in Dealing with Being Visibly Different*’ (2001) 21 *Clinical Psychology Review* 663, p666

¹⁰⁵ *ibid*

¹⁰⁶ *Ibid* p676 and for further discussion see: G Kent, ‘*Understanding the Experiences of People with Disfigurements: An Integration of Four Models of Social and Psychological Functioning*’ (2000) 5 *Psychology, Health & Medicine* 117 and Mark R Leary and others, ‘*Interpersonal Concerns and Psychological Difficulties of Psoriasis Patients: Effects of Disease Severity and Fear of Negative Evaluation.*’ (1998) 17 *Health Psychology* 530

¹⁰⁷ Thompson and Kent (n 103) p677

¹⁰⁸ *Hand* (n 73)

¹⁰⁹ Timothy P Moss, ‘*The Relationships between Objective and Subjective Ratings of Disfigurement Severity, and Psychological Adjustment*’ (2005) 2 *Body Image* 151

the reaction, and consequently the social impact, could be significant even if the scar, mark or condition is not.

In addition, research also highlights that clinical severity is not aligned with levels of psychological distress.¹¹⁰ With some clinical studies pointing towards medically less severe blemishes being harder to overcome for some than more significant injuries.¹¹¹

The provision within legislation that severe disfigurement is to be treated as having a substantial adverse effect on the ability of the person concerned to carry out daily activities, may have aimed to address psychosocial impact and acknowledges that daily challenges exist. However, where it falls short is that it attaches them only to “severe” disfigurement without defining it or truly understanding the link between the physical and psychological impact.

2.10 Individual Impact

When the tribunal assesses impact, they may take some account of the claimant’s own description of day-to-day life, noting for example social anxiety or a preference to cover up a particular mark or scar.¹¹² However impact is challenged where no ‘impairment’ exists or where the claimant’s appearance, while notable, is deemed prevalent in society.

The earlier mentioned case of *Campbell* is one where prevalence, and lack of diagnosis, bore more weight than the claimant’s description of the impact his appearance was having in his workplace.¹¹³ It did so with reference to the gender norms associated with hair loss, pointing out that for men this is commonplace.¹¹⁴ Conversely the case of *Hussain* concerning a man who was 4ft8 ignored the gender norms, and biological characteristics, for male stature and compared him to women, and even children, to conclude that his height was prevalent in society.¹¹⁵ While it is not argued here that height is a disfigurement, it is on the spectrum of appearance and the experience he documented of trying to fit into society is relative to the

¹¹⁰ R Lansdown and others, *Visibly Different. Coping with Disfigurement* (Oxford: Butterworth Heinmann 1997) p102

¹¹¹ Frances Cooke Macgregor, ‘Facial Disfigurement: Problems and Management of Social Interaction and Implications for Mental Health’ (1990) 14 *Aesthetic Plastic Surgery* 249

¹¹² Hutchinson (n 68) p3 and Hand (73), p2

¹¹³ Campbell (n 85)

¹¹⁴ Another case considering male hair norms decided that a man was not discriminated against on the grounds of sex because his employer required him to cut long hair which was not the same requirement for women - see *Smith v Safeway plc* [1996] IRLR 456, CA

¹¹⁵ *Hussain v Sky in Home Services Ltd* ET/2300908/16

experiences of those who do have a visible difference. Even though he did encounter functional barriers, he also describes how people related to him such as making assumptions, asking uncomfortable questions, and offering unsolicited help.¹¹⁶

2.11 Problems with Individual Impact – It’s Individual

Both cases fail to give credence to the fact that each particular feature of appearance under discussion was undesirable for the claimant and, that despite an expected acceptance, was instead resulting in unwanted public reaction and internalised distress.¹¹⁷

When understanding disfigurement, how someone adjusts to their appearance is part of the condition itself. Research has shown that the impact of a disfigurement on the individual is related to its ‘perceived visibility, the level of preoccupation and worry about negative evaluation from others and the number and variety of positive coping strategies that are used.’¹¹⁸

Consequently, whether someone considers themselves to be disfigured is more integral than is accounted for because ‘the concept of disfigurement is jointly defined by both the individual and the society in which he or she lives.’¹¹⁹ In some studies it is even indicated that self-perceived appearance is only modestly related to the social reality of appearance.¹²⁰ The impact on the individual was held as the best indicator of severity for some cases in *Hutchinson*, and the rationale in that case could be applied as a standard rather than an ‘aesthetic’ measure the disfigurement itself.¹²¹

¹¹⁶ See: Brewin and Homer (n 37) - In one study people with burns reported receiving unwanted attention via frequent questioning about their scarring, as well as problems with people ‘looking’ and ‘staring’ along with a fear of being judged or misunderstood

¹¹⁷ Statistics show that each year the number of men who seek restorative surgery, or other interventions, in order to regain hair increases, more than 2.2 million hair restoration patients were treated in 2021 – see <https://ishrs.org/2022-practice-census> - accessed on 12th August 2022

¹¹⁸ D Harcourt and N Rumsey, ‘*Psychological Difficulties Associated with Visible Difference : The Psychology of Appearance, Health Psychology Series*’ (London: Open University Press 2004)

¹¹⁹ Thompson and Kent (n 103)

¹²⁰ See David Ben-Tovim and M Kay Walker, ‘*Body Image, Disfigurement and Disability*’ (1995) 39 *Journal of Psychosomatic Research* 283 and Jonathan W Butters and Thomas F Cash, ‘Cognitive-Behavioral Treatment of Women’s Body-Image Dissatisfaction.’ (1987) 55 *Journal of Consulting and Clinical Psychology* 889

¹²¹ *Hutchinson* (n 68), para 57

2.9 Conclusion

In conclusion what current case law and the application of legislation fails to reference is the context of the individuals themselves or the multiple dominant attitudes in the society they live in. As Bunbury suggests, in some cases the law inadvertently perpetrates the attitudes that reinforce, rather than combat, discrimination by failing to use the social model and continuing to operate within the ambit of a medicalised approach.¹²² While models of disability are debated and some argue that conceptualising disability doesn't articulate the actual experience of disability, they can provide a useful way of understanding legal application.¹²³ However, this is less so when it comes to visible difference because it is poorly understood when viewed through the existing disability models and 'justice based discourse is reliant upon an accurate modelling of the experiences of those it seeks to promote justice for.'¹²⁴ As a definition of disfigurement is drawn from across physical, social and individual contexts, the legislation requirement of 'severity' tries to add too simplistic a measure to a multi-faceted issue.

As a result, the impairment indicator is not directed towards the two most relevant factors when discussing visible difference, the individual and the social context. Which both reference not only what is seen as culturally 'able' as with disability discourse, but what is considered culturally 'beautiful'.

¹²² Stephen Bunbury, *"Unconscious Bias and the Medical Model: How the Social Model May Hold the Key to Transformative Thinking about Disability Discrimination"* (2019) 19(1) *International Journal of Discrimination and the Law* 26, p28

¹²³ Christopher A Riddle, *'Why We Do Not Need a "Stronger" Social Model of Disability'* (2020) 35 *Disability & Society* 1, 1509, p 1513

¹²⁴ *Ibid* p 1512

Chapter 3 – Perception

As part of the difficulty surrounding disfigurement is perception and inclusion, then it is useful to look further at how the courts deal with perception of visible differences in other claims of discrimination, and in personal injury cases. This chapter will also consider whether there are positive or gendered perceptions of disfigurement, as well as discussing how people with visible differences could address the perception of others particularly in the employment context.

3.1 How Disfigurement is Perceived in Other Court Cases

A recognition of the impact of visible difference for women is also noted within the handling of disfigurement cases which come before the courts outside of discrimination matters such as personal injury claims and at times within the context of a criminal trial.

One such criminal case is that of Roxanne Williams who inflicted a facial injury on Cheryl Stewart leaving her with permanent visible scarring. The judge commented that she “will see the results of this attack on her every day when she makes up her face and does her hair and will realise that she has been disfigured for life.”¹²⁵ It was the permanence and inescapability from the injury that resulted in a review and increase of the initial sentence handed down to the perpetrator.

Personal injury cases, such as one where a facelift was negligently performed resulting in facial nerve damage, are acutely cognisant of the psychological consequences and undermined confidence that occur as a consequence of such an injury.¹²⁶

This demonstrates an awareness at least of some of the wider realities of disfigurement, that at times can be acknowledged without an over reliance on a medical model.

Yet in discrimination cases the understanding that it could be hoped would be underlying, as in personal injury cases, gives way to an “impairment” approach because of the need to satisfy a definition of disability. A definition that was not designed to encompass the issues disfigurement creates in the realities of those it affects.

¹²⁵ Attorney General's Reference (No.67 of 1999), 2000 WL 824077 (2000)

¹²⁶ Johnson v Fourie, 2011 WL 1151872 (2011), p70

3.2 Obesity – Another form of Appearance Discrimination

In the case of *Walker*, the court discussed obesity in the framework of disability and impairment.¹²⁷ Like facial differences, obesity is subject to stigma and perception that results in discrimination regardless of the physical implications the condition may have.¹²⁸ In the case of *Walker*, the claimant had multiple physical “impairments” that resulted from being obese and while the obesity in itself was not a disability, the outcome of it, did result in physical difficulties which brought him within the definition of disabled.¹²⁹

However, if the case had been that he had been discriminated against because of prejudices related to obesity and he had no physical limitations, as in the ECJ case of *Kaltoft*, it is unlikely he would have been defined as disabled, thus rendering him outside of discrimination legislation.¹³⁰ In *Kaltoft*, the ECJ expressly stated that EU law was not laying down a general principle of non-discrimination on grounds of obesity which left it clear that this was not a protected characteristic in itself.¹³¹ This has implications for how facial disfigurement is interpreted because it still shows a substantial reliance on a physical outworking of a condition, and subsequent label of disabled, even when a known stigma exists.

3.3 Identifying as Disabled – Personal Perception

On one hand using a definition of disability and attaching the label of “disease” can offer a stigmatized group a manner to verbalize the very real challenges they face and removes ‘blame’.¹³² When looked at from a practical point of view, the term disability offers a degree of freedom, choice, justice and ‘appears to operate quite successfully in terms of developing

¹²⁷ *Walker v Sita Information Networking Computing Ltd* [2013] UKEAT 0097_12_0802

¹²⁸ In the context of obesity, an individual’s excess weight might be viewed as either the consequence of poor eating and exercising behaviours or the consequence of a disease see - Rebecca Puhl and Young Suh, ‘*Health Consequences of Weight Stigma: Implications for Obesity Prevention and Treatment*’ (2015) 4 *Current Obesity Reports* 182

¹²⁹ *Walker* (n 123)

¹³⁰ Case C-354/13 *FOA v Kommuneres Landsforening (Kaltoft)* (Court of Justice) p40

¹³¹ *ibid*

¹³² Samantha L Thomas and others, ‘*Being “Fat” in Today’s World: A Qualitative Study of the Lived Experiences of People with Obesity in Australia*’ (2008) 11 *Health Expectations* 321

policies and promoting equality for those who fall within the criteria that we decide defines the category.’¹³³

But not all will choose to use the term disabled to describe themselves because it also has stigmas and negative assumptions attached.¹³⁴ Rather than being a neutral difference between able and disabled, it is based on the principal of impairment in comparison to ‘normal’ which creates ‘otherness’.¹³⁵ Wendy Hollway discusses the outworking of ‘othering’ in reference to feminism when she says that “in many ways to be equal to men she had to not be like women... I did not include myself in the group I was talking about”.¹³⁶ Research has shown that individuals with visible differences try to blend in by using coping techniques such as camouflage, avoidance, and concealment.¹³⁷ Perhaps most obviously because ‘the antithesis of difference in most usages is sameness or identity.’¹³⁸ So from a coping perspective, there is a tendency to try to fit in, or at least not stand out. Consequently, needing to identify as disabled could present a classification hurdle that will exclude some experiences of discrimination faced by those with visible difference from the scope of protection available.¹³⁹

3.4 Positive Perception of Disability and Disfigurement in the Media

Perceptions of disability change from impairment to ability when there are stories of triumph over adversity, including examples such as sporting success, career achievement or starting a charity. “Supercrip” is one term that encompasses this and traditionally represents inspirational, disabled people.¹⁴⁰ In the past, the supercrip narrative was criticised for making obvious the low expectations from society for people with disabilities.¹⁴¹ It also supports the

¹³³ John Swinton, ‘*From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness*’ (2012) 16 *Journal of Religion, Disability & Health* 172, 15 p17

¹³⁴ Swift and Bogart (n 30)

¹³⁵ Simone De Beauvoir, *The Second Sex* (London: Penguin Books, 1972)

¹³⁶ See Wendy Hollway, ‘*Gender Difference and the Production of Subjectivity*’ in Helen Crawley and Susan Himmelweit, ‘*Knowing Women*’ (Cambridge: The Open University, 1992), p 241

¹³⁷ Thompson and Kent (n 103)

¹³⁸ McDowell and Pringle (n 53) p261

¹³⁹ Stanton and Smith (n 58) p497

¹⁴⁰ Chia Wei Fahn, ‘*Marketing the Prosthesis: Supercrip and Superhuman Narratives in Contemporary Cultural Representations*’ (2020) 5 *Philosophies* 11

¹⁴¹ CF Silva and PD Howe, ‘“*The (In)Validity of Supercrip Representation of Paralympian Athletes*”’ (2012) 36 *J. Sport Soc. Issues* 174

notion that someone who ‘deviates from the norm needs to find some way to compensate.’¹⁴² However some disabled people do find value in this representation and validation that their ‘actions are purposeful, their words meaningful and they do inspire’.¹⁴³

When it comes to disfigurement the same ‘supercrip’ type ideologies exist, alongside counter narratives, despite not being referenced specifically within wider disability rights discourse.¹⁴⁴

An example is Katie Piper, a woman from England who was injured in an acid attack, and is now a TV presenter, author and charity founder. However, even though she is widely known and inspirational to many, does her integration into the public sphere change how others are perceived when there is still a high incidence of discrimination felt by many.¹⁴⁵ Does this focus on extreme success amongst disabled people further concepts of the “self-made man” and “blaming-the-victim” that work against implementation of the social model?¹⁴⁶ Or does this challenge the prototypical face begin a slow, but important, societal shift towards seeing appearance as a less binary concept?¹⁴⁷

It is difficult to measure the impact of challenging public perception in this way, but there are, unexpectedly, many positives because of a life with visible difference and not just despite it.¹⁴⁸ To present it as only negative would be accepting the stereotype that we are trying to move away from, that life isn’t worth living if disfigured.¹⁴⁹

¹⁴² McDowell and Pringle (n 53) pg 61

¹⁴³ Simi Linton, *My Body Politic: A Memoir*. (Michigan: Univ Of Michigan Press 2007)

¹⁴⁴ While the media can make changes, a minority of positive representations alone will not undo the many years of negative portrayals across the television and film industry that link facial difference with “evil” and cast the villain in movies as someone who has scarring or other disfigurements.

<https://www.changingfaces.org.uk/get-involved/campaign-with-us/i-am-not-your-villain/> - accessed on 12/08/22

¹⁴⁵ Skinner (n 7)

¹⁴⁶ Ronald J Berger, ‘*Disability and the Dedicated Wheelchair Athlete*’ (2008) 37 *Journal of Contemporary Ethnography* 647, p648

¹⁴⁷ “Revolutionary change is not the sprint of a specific campaign, but a marathon of life work” - William P Quigley, ‘*Revolutionary Lawyering: Addressing the Root Causes of Poverty and Wealth*’ (2006) 20 *SSRN Electronic Journal* 101

¹⁴⁸ This is my experience after 30 years.

Research has shown that post traumatic growth can occur following visible difference injuries with ‘four identified dimensions of PTG emerging: personal strength, a new life philosophy, sharing self with significant others and altruism born of suffering. - J. Zhai, X. Liu, J. Wu, H. Jiang, ‘*What does posttraumatic growth mean to Chinese burn patients: a phenomenological study*’ (2010) *J Burn Care Res*, 31 (3)p. 433- see also Sarah E Baillie, William Sellwood and Julie A Wisely, ‘*Post-Traumatic Growth in Adults Following a Burn*’ (2014) 40 *Burns* 1089

¹⁴⁹ Skinner (n 7)

3.5 Gendered Perceptions of Disfigurement

When we compare Katie's story to that of Simon Weston the war Veteran, we also see other narratives emerge such as 'survivorship' as well as a gendered approach. As people know their stories, ideas about who they are form in their minds based on stereotypes of war heroes with battle scars or injured women who are "still beautiful", seeing them as victims or survivors depending on their perspective. Whether it is pity or awe, or the questions people ask in order to decide which of those to view someone through, they carry stigmas, judgements and can hinder inclusion. To return to the earlier point, it is as if society is finding other labels to compensate for the deviation from the 'norm.'¹⁵⁰

But despite the potential to foster respect and validation, Beauregard and Fletcher point out that these positive stereotypes serve to 'illustrate the power of the dominant in-group to define the bounds within which the minority group are valued and can be successful.'¹⁵¹

There are differences in how men and women view their own injuries too. While not indicative of all men, one study did show 'evidence of some bravado among young men in the sample, some of whom saw injuries as a badge of honour.'¹⁵² This approach is not apparent in the interviews with women and is equally not how we hear their stories told particularly in the two examples above. Some research indicates that the impact of disfigurement is more significant for women than men due to cultural values and female roles.¹⁵³

One study of female burn survivors highlighted how women are particularly socialised to 'self-silencing'¹⁵⁴ and 'survivorship', whereby they downplay their injuries and distress in order to maintain relationships and continue in their caring roles.¹⁵⁵ Another study with female cancer survivors identified a "tyranny of cheerfulness" whereby women are encouraged to see their condition as 'a lucky gift, leaving no accommodation for psychological distress, grief or

¹⁵⁰ McDowell and Pringle (n 53)

¹⁵¹ Luke Fletcher and T Alexandra Beauregard, 'The Psychology of Diversity and Its Implications for Workplace (In)Equality: Looking Back at the Last Decade and Forward to the Next' (2022) 95 Journal of Occupational and Organizational Psychology 577, p583

¹⁵² Emmylou Rahtz and others, 'Are Facial Injuries Really Different? An Observational Cohort Study Comparing Appearance Concern and Psychological Distress in Facial Trauma and Non-Facial Trauma Patients' (2018) 71 Journal of Plastic, Reconstructive & Aesthetic Surgery 62

¹⁵³ See Matthew D Gardiner and others, 'Differential Judgements about Disfigurement: The Role of Location, Age and Gender in Decisions Made by Observers' (2010) 63 Journal of Plastic, Reconstructive & Aesthetic Surgery 73

¹⁵⁴ D.C. Jack, 'Silencing the Self: Women and Depression' (Cambridge: Harvard University Press, 1991)

¹⁵⁵ Hunter (n 102)

dissatisfaction.¹⁵⁶ This draws attention to the fact that the ‘empowered patient’ and the survivor culture may not always be the experience of patients but rather an institutionalized stance of health care providers.¹⁵⁷

Far from being helpful, these beliefs and labels that people need to live up to, or are assumed to embody, create difficulties and counter narratives.¹⁵⁸ Going back to the earlier question of how to measure the social impact of disfigurement we can see the burdens created not only by the reality of the condition but by the perceptions and gendered expectations that follow.

3.6 How Should People with Disfigurement Manage Perceptions

With negative stereotypes in mind and to account for potential discrimination, individuals with visible differences are faced with decisions about how to manage first meetings in a way that communicates their variations on their own terms.¹⁵⁹ This is particularly relevant in employment, where employees have reported more positive evaluations about working with individuals who acknowledge, versus do not acknowledge, their disabilities.¹⁶⁰ This may be because it creates a direct challenge to ideas that the individual is ‘fragile, inefficacious, or pitiful’¹⁶¹ and helps to shape others’ perceptions, avoiding discrimination, and gaining acceptance.¹⁶²

Identity management strategies can empower people to increase opportunities within employment contexts rather than being passive objects of other people’s perceptions.¹⁶³

¹⁵⁶ S. King *Pink Ribbons, Inc.: breast cancer and the politics of philanthropy* University of Minnesota Press, Minneapolis (2006) p101

¹⁵⁷ AW Frank, ‘*Tricksters and Truth Tellers: Narrating Illness in an Age of Authenticity and Appropriation*’ (2009) 28 *Literature and Medicine* 185

¹⁵⁸ Hunter (n 102)

¹⁵⁹ Judith A Clair, Joy E Beatty and Tammy L Maclean, ‘*Out of Sight but Not out of Mind: Managing Invisible Social Identities in the Workplace*’ (2005) 30 *Academy of Management Review* 78

¹⁶⁰ Michelle R Hebl and Robert E Kleck, ‘*Acknowledging One’s Stigma in the Interview Setting: Effective Strategy or Liability?*’ (2002) 32 *Journal of Applied Social Psychology* 223

¹⁶¹ Fred Davis, ‘*Deviance Disavowal: The Management of Strained Interaction by the Visibly Handicapped*’ (1961) 9 *Social Problems* 120 and B Weiner, ‘*Judgements of Responsibility: A Foundation for a Theory of Social Conduct*’ (New York: Guilford Press 1995)

¹⁶² Kristen P Jones and Eden B King, ‘*Managing Concealable Stigmas at Work*’ (2013) 40 *Journal of Management* 1466

¹⁶³ Brent Lyons et al, ‘*To Say or Not to Say: Different Strategies of Acknowledging a Visible Disability*’ (2018) Vol. 44 No. 5, 1980–2007, p1981

However, many people feel they need to overcompensate for their perceived inadequacies and that “part of being disabled is ... you have to do extra work. You have to be assertive without being aggressive. ... You have to act like you don’t have a disability”.¹⁶⁴

In a disfigurement context, at a job interview, this would mean being confident, friendly, making eye contact, all in a bid to correct the potential impression of low self-esteem stemming from appearance.

Another approach is to acknowledge the disfigurement early in the employment process and highlight one’s ability to perform the job, this is known as ‘claiming’, while others recommend minimizing the impact of the disfigurement, known as ‘downplaying’.¹⁶⁵

Research examining both approaches indicated that openly ‘claiming the disability by framing it in a positive light is a particularly successful strategy for individuals with visible disabilities in influencing others’ evaluations.’¹⁶⁶

However, the case law surrounding other employment disputes, such as *Hutchinson*, where the claimant was already an employee and was forthcoming about his condition, does not support a finding that being up front when employed reduces difficulties.¹⁶⁷ This may be due to the previously mentioned gap in understanding of lived experience of disfigurement. In addition, while this may work in some interview situations, it places a burden on the individual to explain when it is legally up to the employer not to discriminate. It also creates a drawback in that the individual needs to talk about sensitive, potentially traumatising, details within an interview that other candidates do not have to prepare for, thus putting them at a disadvantage.

3.7 Conclusion

In conclusion, perception creates variable paradigms for the individual to navigate and as with disability there are negative preconceptions, with few positives providing a counterbalance that is sustainable for most people.

¹⁶⁴ L H Jans, S H Kaye, & Jones, E. C. Jones ‘Getting hired: Successfully employed people with disabilities offer advice on disclosure, interviewing, and job search’ (2012) *Journal of Occupational Rehabilitation*, 22: 155-165, p161

¹⁶⁵ *ibid*

¹⁶⁶ Lyons (n 160) p2004

¹⁶⁷ *Hutchinson* (n 68)

People with disfigurement need to be confident enough to own their differences¹⁶⁸ and pretty enough to keep pace with the rising bar of acceptable appearance.¹⁶⁹ They need to exude enough confidence to undo society's ingrained ideology that pretty only falls within a certain range.¹⁷⁰ Then if they need to go to an employment tribunal because prejudice still existed, they need to be ugly.¹⁷¹ Ugly enough to be 'severe', different enough to be disabled, and 'repellent' enough to deserve protection.¹⁷²

For many people proving they are severely disfigured is a painful, undignified and intrusive process that doesn't line up with how they need to approach their appearance in any other context.¹⁷³

This juxtaposition of pretty and ugly, being pretty in interview, coping in work, ugly in tribunal, is what makes access to justice out of reach because the individual's perception of self may not match, or be malleable to, what is required to fit in with the perception of others or indeed the tribunal.

¹⁶⁸ Lyons (n 160) p2004

¹⁶⁹ Widdows(n 25)

¹⁷⁰ Eco (n 8)

¹⁷¹ The Disability Discrimination Act 1995

¹⁷² Johansson (n 71)

¹⁷³ This is an example of cognitive dissonance where inconsistency in belief or behaviour causes psychological tension and threatens an individual's sense of self – see L Festinger, *A Theory of Cognitive Dissonance*. (Row, Peterson 1957) and See Fletcher (n 150)

Chapter 4 – Seeing things Differently

This dissertation sought to highlight some of the perceptions and issues around the subject of disfigurement and to ask whether the current legislative framework operates in a way that positively impacts the lived experience of those with visible difference.

The constraint created by the word severe, difficulty with disfigurement fitting into disability narratives and the overall societal context of appearance, including the lack of understanding around living with a visible difference, all point towards some suggestions for change.

As with other stigmatised groups the way forward balances several seemingly conflicting goals.¹⁷⁴ One goal is to advocate strongly that visible differences are not a disability and the other is to defend visibly different people as a group within disability legislation. The two must coexist because until we have a ‘true revolution of values’ visibly different people need to try to fit into the legal framework that exists.¹⁷⁵

4.1 Short to Mid Term Changes

One short term solution would be to remove the word severe from the wording of the Disability Discrimination Act for Northern Ireland and Equality Act in UK.

Removing the term severe would bring the wording in line with research that indicates severity is not necessarily a precursor to discrimination.¹⁷⁶ This would enable impact to be accounted for without needing to satisfy the high standard implied by severity, a word usually reserved only for the worst of scenarios. While some may suggest this may dilute the seriousness of claims or open the floodgates for claims without merit there is little to indicate from other jurisdictions that this would be the case.¹⁷⁷ The current low number of cases would imply that the balance is tipped in the other direction, with over restriction leaving

¹⁷⁴ Holloway (n 132)

¹⁷⁵ Martin Luther King, James Melvin Washington and Harpercollins Publishers, *‘A Testament of Hope : The Essential Writings and Speeches of Martin Luther King, Jr.’* (Harperone, An Imprint Of Harpercollins Publishers, 2006)

¹⁷⁶ Judith H Langlois and others, *‘Maxims or Myths of Beauty? A Meta-Analytic and Theoretical Review.’* (2000) 126 Psychological Bulletin 390, p403

¹⁷⁷ Lord Mackay of Ardbrecknish discussed not drawing the definition of disability too wide for the 1995 Disability Discrimination Act - *‘The issue falls into some form of disrespect; or ... the provisions cannot be operated and the very people whom we wish to help are not helped’* - HL Deb, 1995 v564, c1650

people without remedy and lacking a supportive value base from the law to positively influence societal perception.

In addition, the disfigurement inclusion within existing disability legislation could be reworded in a way that reflects the UNCRPD description of disability.¹⁷⁸

Article 1 of CRPD provides a description of disability:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”¹⁷⁹

Using this a template an alternative legal description of disfigurement could be:

Persons with disfigurements include those who have long-term impairments of appearance, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others

Without the word severe, ‘impairments of appearance’ could be interpreted with reference to the individual, wider context and in line with the definition of impairment in *Rugamer v Sony* of ‘some damage, defect, disorder or disease.’¹⁸⁰ This moves beyond the field of diagnosis and recognises social barriers, yet still qualifies the term to avoid an open appearance discrimination claim.

It could also extend to whether or not there was a perception that the individual’s appearance was impaired, or subject to imperfection, that then led to treatment satisfying the existing definition in equality legislation of what constitutes discrimination.¹⁸¹

¹⁷⁸ UN Convention on the Rights of Persons with Disabilities A/RES/61/106 - The UK ratified the CRPD and its Optional Protocol in 2009 and while not directly enforceable, it does provide a framework for disability legislation.

¹⁷⁹ *ibid*

¹⁸⁰ *Rugamer v Sony Music Entertainment UK Ltd.* [2001] IRLR 644 p34

¹⁸¹ For a definition of perceptive discrimination see - *The Chief Constable of Norfolk v Coffey* UKEAT/0260/16/BA, para 51

A greater focus on perception and behaviour of discrimination could also begin to highlight the unacceptable conduct.¹⁸² Since negative reaction to how someone looks is based on the cognition, comprehension and conditioning, of the onlooker¹⁸³ it is appropriate to draw attention to their behaviour, and perception, as much as to the features of the person they have prejudices against. The question of perception was debated in the House of Lords when the Disability Discrimination Act was originally being discussed and while some said you cannot legislate for perception, others said that dealing with perceptions in disability discrimination legislation was no different to what was already in place for discrimination on the basis of gender or race.¹⁸⁴

Removing “severe” and widening the definition to include perception, would ensure, as described in *Hutchinson*, that the ‘statute is not defeated by an over-emphasis about the specificity of the label to be attached to a particular situation.’¹⁸⁵

The drawback of this approach is that it still requires those with visible differences to identify as disabled, which they are reluctant to do given that this is another stigmatized label and they already feel ostracised and isolated.¹⁸⁶ But as it would not require a significant shift in current legal construct it may offer a mid-term, politically viable solution to some of the identified issues.

4.2 Longer Term Aims

When considering the use of law proactively for change, rather than reactively for protection, a discussion emerges around how disability and normalcy are currently defined.¹⁸⁷

While exploring completely removing disability as a societal construct is beyond the scope of this discussion, the discourse around what we endorse as normal, impaired or disabled impacts where we situate disfigurement within equality legislation.

¹⁸² D. Rhodes, *The Beauty Bias* (New York: Oxford University Press, 2010), 127

¹⁸³ For a summary of research showing that facial symmetry is linked to a perception of attractiveness and health see: Domagoj Švegar, ‘What Does Facial Symmetry Reveal about Health and Personality?’ (2016) 47 *Polish Psychological Bulletin* 356, p357

¹⁸⁴ Baroness Farrington of Ribbleton, HL Deb, 1995 v564, c1652

¹⁸⁵ *Hutchinson* (n 68) para 49

¹⁸⁶ *Swift and Bogart* (n 32) p656

¹⁸⁷ See Mark Cammack et al, “Legislating Social Change in an Islamic Society— Indonesia's Marriage Law” (1996) *The American Journal of Comparative Law* Volume: 44 Issue 1, p46

The term disability overall does seem to operate quite successfully in terms of ‘developing policies that offer a degree of freedom, choice, justice, and equality for those who fall within the criteria that we decide defines the category.’¹⁸⁸ If we remove all definition of disability then this would leave no parameters within to define discrimination, and therefore no means of extending protection. Terzi concludes that were this to happen, ‘the social model would be brought to its knees.’¹⁸⁹ It may also, as Nancy Mairs explained, ‘degenerate the language to the extent that it denies that there is any loss or suffering beyond the everyday differences that distinguish people from each other.’¹⁹⁰

However, despite this, others have suggested that the ideas of ‘disability’ and ‘impairment’ are what drive discrimination by endorsing the idea of ‘normal’.¹⁹¹ Blair argues that disability as impairment within individuals is ‘theoretically untenable’ because all humans are subject to some limitations and thus by definition everyone is to some extent disabled, the only question that remains is where the line is drawn.¹⁹² The same applies to concepts of disfigurement when viewed as part of a spectrum of appearance. Other commentators point out that ‘the truth is the only real norm for human beings, even at a genetic level, is difference’.¹⁹³

What is imperative point when using the word ‘difference’ when discussing disfigurement is that we use it to encompass diversity, and not from a negative comparison with non - disfigured people. Moving from a negative comparison allows it to become, as Irigaray describes, ‘an autonomous self-defined identity.’¹⁹⁴

Disfigurement could become a protected characteristic and an identity by adjusting the current legal understanding of what it is to be disfigured, allowing people to identify as such without reference to disability or impairment. This would move towards equality legislation that upholds appearance as an inherent part of who someone is, thus beginning to create a rights based model. The wording, as with other protected characteristics would consist of a

¹⁸⁸ Swinton (n 129) p175

¹⁸⁹ Lorella Terzi, ‘The Social Model of Disability: A Philosophical Critique’ (2004) 21 *Journal of Applied Philosophy* 141

¹⁹⁰ Nancy Mairs in MacDowell and Pringle (n 53), p57

¹⁹¹ G Payne (ed) ‘*Social Divisions*’ (London: Palgrave Macmillan, 2006) p253

¹⁹² W Daniel Blair, ‘Christian Theology and Human Disability’ (2003) 7 *Journal of Religion, Disability & Health* 69

¹⁹³ See Swinton n 129 and for further research see: T Shakespeare & N Watson, ‘*The social model of disability: An outdated ideology?*’ in Barbara Mandell Altman and Sharon N Barnartt, ‘*Exploring Theories and Expanding Methodologies ; Where We Are and Where We Need to Go*’ (Emerald Group Publishing Limited 2009)

¹⁹⁴ Luce Irigaray, *This Sex Which Is Not One* (Cornell University Press 1985)

definition such as the one constructed by Changing Faces, along with further examples and exclusions.¹⁹⁵ One drawback is that losing disability status would remove the positive duty on employers to make reasonable adjustment but in the context of disfigurement they are difficult to identify, rely on meeting the disability definition and there is an awkwardness on approaching the conversation for both employer and employee.¹⁹⁶ A protected characteristic would be within the remit of anti-discrimination policies in workplaces, as well as legislation, and this in itself could be enough to ensure proactive measures are taken.

Critics may argue that this would lead to frivolous claims but as with the Americans with Disabilities Act, a list of exclusions of 'normal range' characteristics could apply to exclude things such as eye colour, hair colour and other features outside of the intention of the legislation.¹⁹⁷ As with all legislation it would be open to judicial interpretation and a purposive approach, as is currently taken with equality legislation, along with a more research informed understanding of the lived experience of visible differences would help prevent misuse of the provisions.¹⁹⁸

In the same way as being homosexual can be protected without being considered an "impairment of sexuality", so too could facial disfigurement exist as characteristic that warrants protection, but that is celebrated as part of the diversity of humanity.

Allowing for a spectrum of appearance and acknowledging that the human form has many variances would begin to deconstruct current concepts of "normal appearance", which would benefit all of society and provide a much safer environment for people to fully embody who they are. This approach would involve a change in current thinking because it would require, as Herring describes it, 'society accepting difference and recognizing that individuals have vulnerabilities.'¹⁹⁹ When we think back to the earlier chapter discussing the historical attitudes towards disfigurement, it would be a colossal change of perspective, but we must

¹⁹⁵ Changing Faces (n 3)

¹⁹⁶ For further discussion on adjustments for visible difference in the workplace see Hannah Saunders, 'The Invisible Law of Visible Difference' (2019) 48 *Industrial Law Journal* 4, 497, 507

¹⁹⁷ The Interpretive Guidance to ADA, refers to "an impairment of cosmetic disfigurement as excluding "physical characteristics such as eye colour, hair colour, left-handedness, or height, weight or muscle tone that are within 'normal' range." - . Title 29 CFR Appendix to Part 1630, Interpretive Guidance of Title 1 of the Americans with Disabilities Act 1630.2(h)

¹⁹⁸ Goodwin (n 67)

¹⁹⁹ Herring J 'Caring and the Law' (Oxford: Hart Publishing 2013)

continue to believe there are choices other than ‘merely accepting the situation, or making superficial reforms.’²⁰⁰

Admittedly this does feel like an aspirational goal, but the language we use going forward can begin to correct some of the negative connotations created around disability, identity and appearance.

4.3 Conclusion

Widening the concept of disfigurement by removing ‘severe’, including reference to social barriers, allowing for perception and focusing on the behaviour of the respondent rather than just the features of the claimant may all go some way towards balancing the provisions in the current equality legislation. Thus, realigning them with the overall aim of providing protection against appearance-based discrimination.

Moving beyond how things currently stand, another suggestion would be repositioning disfigurement out of the disability category altogether and making it a protected identity like sexuality or gender. With an awareness of the prejudices, stereotypes and injustices of the past, legislation could be written, and judgements passed, that would identify and rectify the existing barriers to inclusion and could begin to influence how society sees visible differences. A change in perspective would allow the individual to see themselves differently too, free from the prison of societal gaze, finally seeing through their own eyes, with the freedom to define what that means.

²⁰⁰ Quigley (n 142) p 161

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