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How to cite:

SAUNDERS, HANNAH,ELIZABETH (2020) *Does the law provide effective equality rights for people with a visible difference in the workplace?*, Durham theses, Durham University. Available at Durham E-Theses Online: http://etheses.dur.ac.uk/13707/

DOES THE LAW PROVIDE EFFECTIVE EQUALITY RIGHTS FOR PEOPLE WITH A VISIBLE DIFFERENCE IN THE WORKPLACE?

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A thesis submitted for the award of PhD in Law at
Durham University.

October 2019.

99,857 words (plus minor corrections: July 2020).

ABSTRACT

A large body of research highlights the social barriers faced by many people with a visible difference. Yet the number of reported cases under the ‘severe disfigurement’ provision in the Equality Act 2010 is low, and the topic has, to date, not been the subject of significant legal academic debate.

This work evaluates whether UK law provides effective workplace equality for people with a visible difference by reference to a framework of standards constructed from the social model of disability, principles of substantive equality and the Convention on the Rights of Persons with Disabilities. These standards, framed as eight Research Questions, assess whether the law is effective in relation to i) the scope of disadvantage of visible difference ii) intersectionality iii) reasonable adjustments iv) recognition v) access to justice vi) participation and inclusion vii) structural change and viii) remedies. A combination of doctrinal and empirical methods (qualitative interviews conducted with people with a visible difference) are employed to answer these questions. It is concluded that, overall, UK law does not provide effective workplace equality for people with a visible difference.

Options for reform are presented, ranging from discrete amendments within the existing legal structure, to a reformulation of the definition of disability, to the creation of a new protected characteristic, to changes to the individual enforcement model on which the Equality Act 2010 is based. Comparative analysis of the relevant laws in France and the USA is used to inform these proposals for change. It is concluded that an amendment to the definition of disability, combined with additional legal guidance specific to visible difference and measures to soften the individual enforcement model of equality law, offer a promising avenue for legal reform.

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DEDICATION

With thanks to my supervisors, Professors Aaron Baker and Jane MacNaughton, for their unwavering excellent support and guidance throughout, and to Professors Moreira and McGlynn for their support with the empirical aspects. My gratitude goes to the wonderful interview participants who volunteered their time and experiences as part of the research.

This thesis is for Clem.

LIST OF ABBREVIATIONS

CRPD	Convention on the Rights of Persons with Disabilities
DfD	Défenseur des Droits
DPO	Disabled People's Organisation
EAT	Employment Appeal Tribunal
ECHR	European Convention on Human Rights
EHRC	Equality and Human Rights Commission
ECtHR	European Court of Human Rights
ECJ	European Court of Justice
EEOC	Equal Employment Opportunity Commission
ET	Employment Tribunal
EU	European Union
ILO	International Labour Organisation
PSED	Public Sector Equality Duty
The Act	Equality Act 2010

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1. CONSTRUCTING AN EVALUATIVE FRAMEWORK

1.1 CHAPTER INTRODUCTION

To assess the effectiveness of UK[1] equality laws for people with a visible difference in the workplace, a framework of standards must first be defined. This framework will provide a benchmark against which to judge the 'effectiveness' of the law. This evaluative framework rests on the following three questions:

i) Should equality and non-discrimination rights apply to people who are visibly different? Why?
ii) What does 'equality' mean in legal terms?
iii) How do we measure whether the law provides equality for people who are visibly different?

This chapter will address each of these three questions in turn.

1.2 SHOULD EQUALITY RIGHTS APPLY TO PEOPLE WHO ARE VISIBLY DIFFERENT? WHY?

1.2.1 RATIONALES FOR ANTI-DISCRIMINATION LAW

Under both EU and domestic law, anti-discrimination rights have developed piecemeal over several decades. This has led many scholars to question why some grounds have been prioritised over others, what unites existing grounds and, importantly, why other characteristics remain unprotected[2]. A number of rationales have been proposed to explain the reach of anti-discrimination laws, and a brief summary of three of the main arguments – immutability, dignity and stigma – will now be presented.

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[1] The relevant parts of the Act do not apply to Northern Ireland, so this thesis focuses on visible difference equality law in the remainder of the UK.

[2] See, for example, Sharona Hoffman, 'The importance of immutability in employment discrimination law' (2011) 52 William and Mary Law Review 1483, 1529.

Immutability has played a key role in the debate over the reach of equality law. The idea that equality should extend to protect those traits which are innate within the individual and outside of her control, rather than chosen, explains why religious beliefs, for example, were not included with the early tranches of legislation[3], prior to legislators recognising that immutability should extend to fundamental beliefs which a person cannot *be expected to* change[4].

Immutability is identifiable in ECJ jurisprudence, including references to race and gender as 'inseparably linked' to an individual 'over which he has no influence'[5]. But the chosen / immutable distinction does leave grey areas. Sandra Fredman, for example, highlights pregnancy as a characteristic which can't comfortably be identified as either chosen or immutable (though undoubtedly meriting protection), and transsexualism is based on the express mutability of sex[6]. Where fundamental choices are at issue, the categories blur even further; with various ethical and political beliefs[7] having been recognised as meriting protection in UK law, the concept of immutability as an explanation for the reach of equality law feels stretched to breaking point.

Conversely, other characteristics such as height, left-handedness and eye colour[8], and even regional accents, social class[9] and genetic predispositions, would appear to be immutable yet remain out of reach of equality law. Immutability is sometimes a blunt instrument; to suggest that obese people have 'chosen' this trait ignores a

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[3] Iyiola Solanke, *Discrimination as Stigma* (1st edn, Hart Publishing 2017) 55.

[4] Douglas Laycock, 'Taking Constitutions Seriously: A theory of judicial review' (1981) 59 TEX.L.REV. 343, 383 as cited in Jessica A. Clarke, 'Against immutability (of characteristics in employment discrimination law)' (2015) 125 Yale Law Journal 2, 24.

[5] Case C-236/09 *Association Belge des Consommateurs Test-Achats ASBL and Others v Conseil Ministres* [2011] ECRI-773 opinion of Advocate General Kokott (30 September 2010) para 50. See also Solanke (n3) 55**.**

[6] Sandra Fredman, *Discrimination Law* (2nd edn, Oxford University Press 2011) 131.

[7] Humanism and pacificism are cited as qualifying beliefs in Equality and Human Rights Commission, *Religion or belief: a guide to the law* (EHRC, 2016) 5.

[8] Hoffman (n2) 1523.

[9] The TUC is campaigning for social class to become a protected characteristic in workplace equality law. See BBC News, 'TUC calls for ban on 'class discrimination' at work' (*BBC News*, 9 September 2019) <https://www.bbc.co.uk/news/business-49625848 accessed 11 September 2019.

raft of research about genetic predisposition, for example, as well as socio-economic factors which suggest a link (though not a direct correlation) between poverty and obesity[10]. In addition, excluding some chosen (mutable) traits from the reach of equality law can cause them to become legally *im*mutable. Under English law, once a mutable (or 'chosen') characteristic such as illegal drug use or alcoholism determines that someone is not entitled to equality rights on the basis of that characteristic[11], there are no second chances; a recovered user can forever be denied a job on the basis of former addiction without engaging equality rights. This sits uncomfortably with recent case law in other areas focused on the right for outdated personal data 'to be forgotten'[12].

Other attempts to identify the reach of equality have focused on dignity, which is argued to be 'inherent in the humanity of all people'[13]. Under this concept, discrimination is more than just different treatment; it is different treatment for a reason which touches on the fundamental essence of the person. This concept helps to prevent 'levelling down' to provide equality of negative treatment[14], imbuing equality with moral principles. But it, too, has its challenges. For one, Christopher McCrudden's forensic analysis of the meaning of dignity identifies a vast array of meanings across contexts, making it hard to apply with certainty[15]. Sandra Fredman argues that dignity is not robust enough to prevent a hierarchy of equality developing, where some people are regarded as "more dignified than others"[16], which undermines the very principle of equality. Furthermore, it is hard to reconcile with the current scope of domestic discrimination law; why does differential treatment on ground of age, for example, touch on human dignity while differential treatment on ground of personal appearance does not?

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[10] Alice Goisis, Amanda Sacker and Yvonne Kelly, 'Why are poorer children at higher risk of obesity and overweight? A UK cohort study' (2016) 26 The European Journal of Public Health 7, 8.

[11] Equality Act 2010 (Disability) Regulations 2010, reg 3.

[12] C-131/12 *Google Spain SL and Google Inc v Agencia Española de Protección de Datos (AEPD) and Mario Costeja González* [2014] 3 CMLR 50, para 99.

[13] Sandra Fredman, 'Substantive equality revisited' (2016) 14 International Journal Of Constitutional Law 712, 725.

[14] Ibid 724.

[15] Christopher McCrudden, 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19 European Journal of International Law 655, 655.

[16] Fredman (n13) 725.

Stigma, too, has been proposed as an underlying rationale for equality rights. Iyiola Solanke draws on Erving Goffman's[17] work in arguing that stigma is, in essence, "a mark" or the "potentially persistent social approbation which it triggers"[18]. While a complex concept which shapes itself according to context, the presence of stigma underlies discriminatory behaviour and can be keenly felt on occasion. Solanke argues that an anti-stigma principle enables the law to focus on the stigma attaching to particular traits rather than issues of group identity[19]. Her work recognises that not all stigma merits protection, however; a mechanism (which she formulates as a series of questions[20]) can be used to divide rightly stigmatised characteristics from those which merit protection. The principle of stigma has potential, as it focuses on society's reactions to a trait rather than on the trait itself (which mirrors the social model of disability discussed at 1.2.2 below); but defining stigma in legal terms, with all its changing contextual variations, is troublesome. Goffman, for example, regarded stigma as affecting most people from time to time[21], suggesting a widespread and fluid concept which is hard to isolate and pin down[22].

The above discussion of equality rationales is a deliberately simplified summary of a vast body of literature, but a more comprehensive analysis remains beyond the scope of this thesis for two reasons. First, on a practical level, all of the three rationales discussed (immutability, dignity and stigma) could be used to justify granting equality rights to people with disfigurements:

- The vast majority of disfigurements (excluding tattoos) are immutable.
- Personal appearance is a fundamental part of someone's self-image and identity, as well as having social and cultural implications within society. Discrimination based on appearance therefore touches on the fundamental dignity of the person.
- As will be shown in Chapter 3, people who are visibly different are frequently stigmatised in society.

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[17] Erving Goffman, *Notes on the management of spoiled identity* (Penguin 1990).

[18] Solanke (n3) 36.

[19] Ibid 134.

[20] Ibid 162.

[21] Goffman (n17) 152.

[22] David Wasserman, 'Stigma without impairment' in Leslie Pickering Francis and Anita Silvers (eds), *Americans with Disabilities* (Routledge 2000) 150.

Second, and perhaps more importantly, a justification for some level of disfigurement equality rights has *already* been recognised in law. Although neither disfigurement nor appearance are listed as equality grounds under EU law, the Equality Act 2010 ("the Act") specifies that someone with a severe disfigurement shall be treated as disabled[23], thereby qualifying for equality rights.

The next section considers *why* equality law links disfigurement equality rights to the protected characteristic of disability; why is looking different disabling? I will begin by analysing the meaning of the term 'disability' (through models of disability) relative to visible difference, before moving on to explore whether there is a legal obligation to provide equality rights for people with a visible difference as a result.

1.2.2 MEDICAL AND SOCIAL MODELS OF DISABILITY

Conceptions of disability have changed over time. Traditionally disability was based on an analysis of the limitations of an individual resulting from medical impairment – what the person couldn't do. This inward-focused understanding of disability is referred to as the 'medical model'. The medical model would define the disability of someone in a wheelchair as an inability to climb stairs, for example, and the disability of someone who is deaf as an inability to hear; the 'problem' of disability is located within the individual – it is what the person is unable to do. Thus, there is no room in a medical model analysis to question why aeroplanes aren't built to be wheelchair accessible, or why children don't learn sign language at school. The medical model portrays difference as deficiency, not diversity.

A major criticism of the medical model approach is that, in locating disability within the individual, it places the responsibility on that person and helps to perpetuate stereotypes of disabled people as helpless. This encourages an approach focusing on charity and welfare towards those who are disabled, rather than rights[24]. It aims, where possible, to treat disability in medical terms to achieve sameness or non-

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[23] Equality Act 2010, sch1, pt1, s3(1).

[24] Arlene S Kanter, *The Development of Disability Rights under International Law* (Routledge 2015) 46.

disabled norms[25] in society, often contributing to the removal of individual choice and control from disabled people. By locating the ‘problem’ within the individual, the medical model approach assumes that, where possible, the person’s difference should be treated to enable him to meet the non-disabled norms of society; it ignores a role for society in preventing impairment translating into disability[26].

In 1983, Mike Oliver coined the use of the phrase ‘the social model’[27] to describe a different approach emerging from the work of the Union of the Physically Impaired Against Segregation. He described this as ‘nothing more or less fundamental than a switch away from focusing on the physical or mental limitations of particular individuals to the way the physical structures, societal systems, culture and social environments impose limitations on certain groups or categories of people’[28]. Arlene Kanter explains that, whereas the medical model ‘locates the “problem of disability” in the person’, the social model ‘views disability as part of the diversity of the human experience, placing responsibility on society to remove the physical, environmental, attitudinal, and legal barriers that prevent people with disabilities from exercising their rights to inclusion and participation in society’[29].

A key aspect of this British social model concept is social oppression; disabled people are seen as a casualty of a society structured around ‘the social relations of production and reproduction in modern capitalist societies’[30]. With society focused on materialistic ideals, the perceptions of disabled people as economically hindered leads to exclusion and oppression[31]. Social model understandings therefore engender a political struggle between the (disabled) oppressed and the system which oppresses them.

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[25] Andrea Broderick, 'The Long and Winding Road to Equality and Inclusion for Persons with Disabilities' (PhD, Maastricht 2015) 22.

[26] Kanter (n24) 46.

[27] Mike Oliver, Bob Sapey and Pam Thomas, *Social Work with Disabled People* (Macmillan 2012) 15.

[28] Ibid.

[29] Kanter (n24) 46.

[30] Mark Priestley, 'We’re all Europeans now! The social model of disability and European social policy' in C Barnes and G Mercer (eds), *The Social Model of Disability: Europe and the Majority World* (The Disability Press 2005) 23.

[31] M Berghs, K Atkin and H Graham, 'Implications for public health research of models and theories of disability: a scoping study and evidence synthesis' (2016) 4(8) Public Health Res 36.

This traditional British conception of the social model of disability is noted for its rigid distinction between impairment and disability; impairment could be 'lacking all or part of a limb … or mechanism of the body'[32] whereas disability is 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities'[33]. As an interaction between an individual's personal factors and environmental factors[34], disability becomes context-dependent, so what is accepted as normal or even desirable within one culture, can create disability within another.

How do models of disability help us to understand why looking different can be a disability? Disfigurement does not fit the traditional 'medical' model mould because it often lacks the functional limits on which this concept of disability is based; the 'problem' is not usually one of effects on the individual's activities, but the perceptions and attitudes of other people. Pursuant to this analysis, a disfigurement may be an impairment, but disablement arises from the expectations and reactions of society which oppress people who are visibly different. This social model analysis explains the siting of disfigurement within disability law; the individual's participation in society can be disabled even when the functions of his body are not.

While the social model remains influential today, it is not without its critics. A common criticism is that the social model's focus on external barriers denies the reality of living with an impairment[35]. Pain, for example, can be a disabling effect of impairment which cannot be adequately explained by reference to external barriers. Similarly, just as socially constructed disability can curtail a person's activities, sometimes so can the effects of impairment itself[36]. By way of example, Shakespeare and Watson memorably argued that '[m]ost activists concede that

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[32] UPIAS and the Disability Alliance, 'Fundamental Principles of Disability' (1975) 14 as cited in Mike Oliver, *Understanding disability* (2nd edn, Palgrave Macmillan 2009) 42.

[33] Ibid.

[34] Ibid 7.

[35] See for example Dimitris Anastasiou and James M. Kauffman, 'The Social Model of Disability: Dichotomy between Impairment and Disability' (2013) 38 Journal of Medicine and Philosophy 4419.

[36] Liz Crow, 'Renewing the Social Model of Disability' (1992) <http://www.roaring-girl.com/work/renewing-the-social-model-of-disability/> accessed 25 June 2019.

behind closed doors they talk about aches and pains and urinary tract infections, even while they deny any relevance of the body while they are out campaigning'[37].

Similarly, Colin Barnes stresses the pragmatism of the 'social model impairment, disability dichotomy'[38] and highlights the danger of an academic debate which threatens to undermine the change in perception generated by the social model. For him, the social model is compatible both with the recognition of limiting effects of impairment, and the (sometimes worthwhile) role played by medical treatment to reduce or remove impairment - he argues that the social model was always capable of understanding such concerns. For Mike Oliver[39] and Colin Barnes, the social model does not need to change, but has simply been misunderstood.

Second, it has been argued that the social model is unable to cope with combined experiences – disabled women, for example, or black disabled people[40] – though Mike Oliver argues in response that any gap in this regard results not from the social model's inability to deal with these intersections, but from a preference of some commentators to criticise rather than contribute to research in this area[41].

A third layer of criticism perhaps stems from the distinction between law and policy; the social model has been deemed too vague to be the basis of a workable statutory definition of disability[42]. Those who have practised law in this area may have a degree of sympathy with this argument. While a medical model definition of disability can provide set criteria against which functionality can be measured, a pure social model definition would focus on measuring external barriers which are often less tangible and harder to prove. Expert evidence of medical professionals may need to cede the Tribunal stage to evidence about stereotypes, structural disadvantage and accessibility. If external barriers are judged at the individual

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[37] Tom Shakespeare and Nicholas Watson, 'The social model of disability: An outdated ideology?' in Sharon Barnartt and Barbara Altman (eds), *Exploring Theories and Expanding Methodologies: Where we are and where we need to go to*, vol 2 (Emerald Group Publishing Limited 2001) 12.

[38] Colin Barnes, 'Understanding the social model of disability: past, present and future' in Nick Watson, Alan Roulstone and Carol Thomas (eds), *Routledge Handbook of disability studies* (London; New York : Routledge 2012) 53.

[39] Oliver (n32) 48.

[40] See e.g. Susan Wendell, 'Toward a Feminist Theory of Disability' (1989) 4 Hypatia 104, 105.

[41] Oliver (n32) 49.

[42] Anna Bruce, 'Which Entitlements and for Whom? The Convention on the Rights of Persons with Disabilities and its Ideological Antecedents' (PhD thesis, Lund University 2014) 348.

level, the requirement to prove disability could ultimately be subsumed into a finding of discrimination, because 'if I have been discriminated against, I have encountered a societal barrier and am therefore disabled'; treatment and disability status become merged. On the other hand, if judged at group level by reference to statistics of barriers encountered by people who share a particular characteristic, complications arise in defining relevant groups with common experiences. This is particularly troublesome when employers are seeking to make reasonable adjustments; employers would be likely to argue that they need the clarity that comes with an occupational health report, not vague assumptions about what external barriers might be encountered. In this respect, the social model in legislative form has the potential to become a reactive concept which is hard to balance with legal duties to accommodate and be proactive.

In summary, a social model analysis provides a rationale to explain the relationship between disfigurement and disability, despite the former often producing no functional limitations. For clarity, given different academic views on the detail of the social model, references to the social model in this thesis are to be understood simply as the idea that disability arises at least partly from the interaction between impairment and external environments and attitudes.

But to what extent is UK law required to adopt a social model understanding of disability in its approach to equality? The next section seeks to answer this question by examining the concept of disability in international laws binding on Britain, and the extent to which they reflect a social model approach. The three international instruments to be considered are the CRPD, the EU Employment Equality Framework Directive (Directive 2000/78), and the European Convention on Human Rights ('ECHR'), together with relevant case law[43].

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[43] The UK has also ratified the International Labour Organisation's Discrimination (Employment and Occupational) Convention 1958 (adopted 25 June 1958) ILO C-111 which contains obligations relating to equality. However, this is less far-reaching in relevant scope than the CRPD and is therefore not discussed further in this thesis.

1.2.2.1 IS UK LAW BOUND TO ADOPT A SOCIAL MODEL APPROACH TO EQUALITY RIGHTS?

1.2.2.1.1 DISABILITY IN THE CRPD

Beginning with the CRPD, the social model is widely acknowledged to have been influential in the drafting of the convention. Article 1 offers a description (note, not a definition) of disability wide enough to encompass both disfigurement and other types 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’[44].

This description makes no mention of functional limitation (and the Committee has expressly confirmed that the definition applies to disabilities ‘that may or may not come with functional limitations’[45]). It also imposes no substantiality or severity requirement; it is the consequence, not the level, of the impairments and their interaction which matters. The drafting of Article 1 (in particular the word ‘include’ and the description in the Preamble of disability as an ‘evolving concept’[46]) is also not fixed or exhaustive, enabling it to sidestep the accusations of rigidity sometimes levelled at the social model.

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[44] The UN Convention on the Rights of Persons with Disabilities A/RES/61/106 adopted 24 January 2007, Art 1.

[45] UN Committee on the Rights of Persons with Disabilities, ‘General Comment No. 3 on Article 6’ (2016) CRPD/C/GC/3, para 5.

[46] Wiebke Ringel, 'Non-discrimination, Accommodation, and Intersectionality under the CRPD: New Trends and Challenges for the UN Human Rights System' (2017) 20 Max Planck Yearbook of United Nations Law Online 98, 106.

Much of the substance of the CRPD (which will be discussed at 1.4.1) also reflects a social model ideology, with measures targeted at changing society (such as awareness-campaigns) sitting alongside those aiming to provide rights to the individual.

Despite the strong social model roots in the CRPD, the Training Guide which accompanies the CRPD in fact expressly refers both to a social model approach and a human rights model approach[47]. It is submitted that the two social and human rights models of disability are, for the most part, broadly compatible. Theresia Degener argues that the human rights model of disability in the CRPD builds on social model principles[48] – it still sees disability as socially created rather than a problem within the individual. The distinction, perhaps, is one of focus. While the social model grew from arguments about the structural inequality of disability, the human rights model stems from moral arguments[49] about how all people should be treated. It is therefore not just about inequality, and the rights of the oppressed against society, but also dignity and universal rights which exist both with and without impairment; rights of socio-economic importance as well as non-discrimination[50]. The CRPD, for example, as an embodiment of the human rights model, encompasses 'positive' rights (such as the right to earn a living) as well as negative rights (such as being free from abuse). Liggett argues that while social oppression requires a fight against society, a rights-based approach is one in which legitimate demands for equal and specific rights can be pursued without overtly challenging the system[51]. It must be acknowledged, however, that the boundaries between the social and human rights models are vague given the many differing conceptions posed of each; one could perhaps be forgiven for conceiving a social and human rights model continuum.

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[47] United Nations, 'The Convention on the Rights of Persons with Disabilities Training Guide' (United Nations 2014) 10.

[48] Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 Laws 35, 3.

[49] Ibid 4.

[50] Ibid 5.

[51] H. Liggett, 'Stars are not born: an interactive approach to the politics of disability' (1988) cited in Priestley (n30). An interesting counterpoint is provided by Young and Quibell's work, who argue that a heavy emphasis on rights encourages an 'atomistic' society based on individual autonomy rather than mutual understanding; the potential for greater understanding of disabled people's views can get lost in a fixation on entitlements, which often fail in reality to provide sufficient flexibility to work for every individual and context. See Damon Young and Ruth Quibell, 'Why Rights are Never Enough: Rights, intellectual disability and understanding' (2000) 15 Disabiliy and Society 747.

The extension from a social model approach into a human rights model in the CRPD has some advantages. As a rights-based approach is broader than one based exclusively on disability, Degener argues that it is better placed to acknowledge intersectional identity[52] (e.g. disabled women), whereas the social model has a one-dimensional focus on disability. Similarly, the human rights approach does not ignore impairment (as the social model is often accused of doing), but acknowledges it, values it as a part of human diversity, and demands that it is taken into account[53]. The human rights model therefore affirms disabled people as rights holders irrespective of impairment and places responsibility on society to ensure these rights can be exercised in full.

Although the convention embraces this shift to a social and human rights approach to disability, enforcement of the convention is limited. Individuals in the UK can complain to the CRPD Committee over alleged breaches, but they cannot directly enforce it. In states which signed the Optional Protocol[54], people (and groups) can submit allegations of breaches of the Convention to the Committee, who may decide to launch an inquiry into the actions of the relevant state. The UK signed the Optional Protocol. However, the limitations of this as an enforcement mechanism were exemplified in 2016 when, following various complaints, the Committee opened an investigation[55] into changes to the benefits system in Britain under the Welfare Reform Act 2012. The conclusion of the Committee's inquiry was that "grave or systematic violations of the rights of persons with disabilities"[56] were taking place, and a number of recommendations for action were made. However, the UK Government's public, written response was that it "strongly disagree[d]" [57] with the findings of the inquiry. The CRPD contains no further legal enforcement mechanism after this point to hold states to account.

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[52] Degener (n48) 10.

[53] Ibid 6.

[54] Optional Protocol to the Convention on the Rights of Persons with Disabilities (United Nations 2007) A/RES/61/106.

[55] United Nations Committee on the Rights of Persons with Disabilities, 'Inquiry Concerning The United Kingdom Of Great Britain And Northern Ireland Carried Out By The Committee Under Article 6 Of The Optional Protocol To The Convention Report Of The Committee' (2016) CRPD/C/15/R.2/Rev.1.

[56] Ibid 19.

[57] 'The United Kingdom Government, 'Response To The Report By The United Nations Committee On The Rights Of Persons With Disabilities Under Article 6 Of The Optional Protocol To The Convention' (2017) 3 CRPD/C/17.R.3.

This perceived lack of legal 'teeth' became very clear during the Parliamentary Joint Committee on Human Rights' session on the Rights of Disabled People to Independent Living (a reporting session required by the CRPD), when the Minister for Disabled People referred to the CRPD on several occasions as "soft law" which "does not have legal standing", prompting a seven paragraph correction in the Session report as to its status as "legally binding […] hard law"[58].

As the UK is a dualist state, the CRPD is not incorporated into national law unless Parliament legislates to bring it into force (as, for example, it did by enacting the Human Rights Act 1998 to incorporate the European Convention on Human Rights). The Conservative government has not done so – and has also revealed plans to repeal the HRA 1998, which shares many of the same principles expounded in the CRPD. In contrast, Labour's manifesto[59] contains a pledge to enact the CRPD into UK law while, at the same time, proclaiming their commitment to a social model of disability. Pre-election promises are usually not legally binding, however[60]. So, the UK remains bound by its obligations under the CRPD, and a failure to comply with them constitutes a breach of international law, despite lacking domestic enforceability.

This looks set to remain after Brexit, too. Because the Convention is a United Nations treaty, not a piece of EU legislation, when Britain leaves the European Union, its ratification of the CRPD will be unaffected. There may be an indirect impact due to the European Union itself signing the CRPD, however. On that basis, every piece of EU legislation now produced, and every decision of the European Court of Justice, should be upholding the principles and obligations set out in the CRPD, allowing some such principles to filter through to national law. It remains to be seen how, and to what extent, existing EU law will be dealt with after Brexit but, at the very least, it is clear that CRPD-compliant aspects of new European laws

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[58] House of Lords and House of Commons Joint Committee on Human Rights, *Implementation Of The Right Of Disabled People To Independent Living* (23 of 10-12, 2012) 13.

[59] Labour Party, 'Nothing About You, Without You: A Manifesto With And For Disabled People' (2017) < https://labour.org.uk/manifesto/a-more-equal-society/#fifth> accessed 4 July 2018.

[60] *R –v- Secretary of State for Employment, ex p Begbie* [2000] ELR 1115.

which come into force after Brexit, will not be reflected in UK law unless Parliament so chooses. The UK's compliance with its obligations under the CRPD will therefore come into sharper focus.

1.2.2.1.2 DISABILITY IN THE DECISIONS OF THE ECtHR

A similar approach to defining disability in line with a social model approach is emerging in the decisions of the European Court of Human Rights ('ECtHR')[61], which domestic courts must 'take into account'[62]. Article 14 of the ECHR provides a right to non-discrimination related to other Convention rights. The ECtHR has held that this right not only encompasses disability but also 'health status', which it seems willing to apply even where there is no resulting functional limitation (i.e. the recognised barriers are social, rather than medical). In the case of *I.B. v Greece*[63], for example, an HIV positive claimant was found to fall within Article 14 despite the fact that 'the nature of the applicant's job, which did not demand excessive effort, precluded the risk of a reduction in his capacity for work since, during the many years in which a person was merely HIV-positive, his or her working capacity was not substantially reduced'[64]. In the case of *Kiyutin v Russia*[65], the court placed particular weight on the historic stigma against and exclusion of people with HIV and afforded states a narrow margin of appreciation as a result. Consistent with the social model of disability, the court recognised the disabling impact of attitudinal barriers. It is submitted that a parallel argument could be made in relation to people with disfigurements who often face stigmatisation and exclusion. Where engaged[66], the wider reach of Article 14 may prove to be a useful interpretive tool in respect of shortcomings in domestic disfigurement law.

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[61] For a more detailed discussion, see Andrea Broderick, Elise Muir and Lisa Waddington, 'A reflection on substantive equality jurisprudence' (2015) 15 International Journal of Discrimination and the Law 101, 109.

[62] Human Rights Act, s.2(1). The obligation on the British parliament to comply with the ECHR is stronger; it must 'abide' by ECtHR decisions – see Adam Wagner, 'Can Britain "ignore Europe on human rights?"', (UK human rights blog, 23 October 2011) <https://ukhumanrightsblog.com/2011/10/23/can-britain-ignore-europe-on-human-rights/>accessed 28 June 2019.

[63] App no. 552/10, (ECtHR 3 October 2013).

[64] Ibid, para 86.

[65] *Kiyutin v Russia* (2013) 53 EHRR 26, para 64.

[66] See e.g. Sandra Fredman, 'Emerging from the Shadows: Substantive Equality and Article 14 of the European Convention on Human Rights' (2016) 16 Human Rights Law Review 273, 275 for a discussion of the 'parasitic' nature of article 14.

1.2.2.1.3 DISABILITY IN EU LAW

As the EU is a party to the CRPD, the EU Employment Equality Framework Directive (Directive 2000/78) ('the Directive') 'must, as far as possible, be interpreted in a manner consistent with the Convention'[67]. Relevant domestic legislation, including the Act, in turn needs to comply with the Directive, the ECHR and the CRPD, which would seem to offer a good opportunity for a common approach. However, that opportunity has not been seized, and case law on the Directive from the Court of Justice ("ECJ") has not consistently reflected CRPD principles[68] in this respect.

In the case of *Ring*[69], the ECJ provided a definition of disability which appeared to embrace the social model. It defined disability for the purposes of the Directive as:

> 'a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers'[70].

But subsequent applications of this definition have been restrictive and have implications for disfigurement[71]. In the case of *Kaltoft*[72], the court adopted the *Ring* definition but elaborated on the need for a limitation resulting from impairment.

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[67] C-335/11 and C-337/11 *HK Danmark, acting on behalf of Ring v Dansk almennyttigt Boligselskab and HK Danmark, acting on behalf of Lone Skouboe Werge v Dansk Arbejdsgiverforening, acting on behalf of Pro Display A/S (Ring and Skouboe Werge)* [2013] 3 CMLR 21, para 32.

[68] Lisa Waddington, 'Saying All the Right Things and Still Getting it Wrong' (2015) 22 Maastricht Journal of European and Comparative Law 576, 583. See also Gauthier de Beco, 'Is obesity a disability? The definition of disability by the Court of Justice of the European Union and its consequences for the application of EU anti-discrimination law' (2016) 22 Columbia Journal of European Law 381.

[69] *Ring* (n67).

[70] Ibid para 34.

[71] Waddington (n68) 588.

[72] Case C-354/13 *FOA v Kommuneres Landsforening (Kaltoft)* [2015] 2 CMLR 19.

In *Kaltoft*, in the context of obesity, the court suggested that 'reduced mobility or the onset, in that person, of medical conditions preventing him from carrying out his work or causing discomfort when carrying out his professional activity'[73] could suffice. So, the limitation is being interpreted as something the individual is physically unable, or less able, to do in professional life as a result of the impairment. As Lisa Waddington argues, 'this seems to render it difficult to interpret the Court's definition of disability as embracing individuals who experience no physical limitation, but who are only hampered by the discriminatory attitudes of others, discriminatory rules or provisions'[74]. This interpretation is strengthened by the reference in the subsequent case of *Daouidi* to a limitation of 'capacity'[75]. It is clear that the required limitation can be a partial hindrance rather than an absolute prevention, but someone who has no physical limitation at all, and is disabled purely by external attitudinal barriers (someone with a pure disfigurement, or someone who is HIV positive[76] but asymptomatic, perhaps), may not be disabled under the Directive.

This interpretation appears to create significant distance between the Directive's concept of disability, and that espoused by Article 1 of the CRPD, despite the latter purportedly being used to interpret the former. What does this mean for someone with a visible difference? It means that a claimant who is left without a domestic remedy because of a shortcoming in the way that the Act deals with disfigurement is unlikely to be able to rely on the Directive. It also means that Parliament and the UK courts are receiving conflicting messages from the wider disability law framework about the scope of disability relating to impairments without functional limitation. This lack of functional consistency risks diluting the strong agenda for reform provided by the social model and CRPD.

Returning to the question posed at the beginning of the Chapter: should equality and non-discrimination rights apply to people who are visibly different? Why? To

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[73] Ibid para 60.

[74] Waddington (n68) 587.

[75] Case C-395/15 *Daouidi v Bootes Plus SL* [2017] 2 CMLR 21, para 48. See also Case C-270/16 *Ruiz Conejero v Ferroser Servicios Auxiliares and Ministerio Fiscal*, [2018] 2 CMLR 27, para 28.

[76] See Peter McTigue, 'From Navas to Kaltoft' (2015) 15 International Journal of Discrimination and the Law 241 for a fuller discussion of ECJ case law in relation to HIV as a disability.

date, this Chapter has proven that equality rights *should* apply to people who are visibly different, because:

- As a matter of legal theory, disfigurement as a standalone concept satisfies the underlying rationale(s) for these rights (it is immutable, it is stigmatised by society, and it engages the dignity of the person affected). This is implicitly recognised by the inclusion of the 'severe disfigurement' provision in the Act; and

- The social model of disability explains how visibly different people are subject to socially created disability. The adoption of social model principles in the CRPD and some other international legal instruments places a legal obligation on the UK to provide visibly different people with equality rights as disabled people.

1.3 WHAT DOES 'EQUALITY' MEAN IN IN LEGAL TERMS?

Having established that people with disfigurements should be entitled to equality rights, the second question posed aims to understand the substance of this concept of 'equality'. This section will summarise different interpretations given to the concept and identify the meaning ascribed to it for the purpose of this thesis. It will begin by explaining the three main concepts of formal, substantive and transformative equality.

A significant body of research distinguishes between these three concepts. *Formal equality* means equality which focuses on process not effects; in other words, whether the form of a decision was equal irrespective of its outcome. This is sometimes expressed as 'things that are alike should be treated alike'[77] so that everyone is judged on merit and not according to irrelevant personal characteristics such as disability. But while this gives consistency, it does not guarantee fairness, allowing consistently bad treatment across different groups[78]. It ignores the

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[77] Ethica Nicomachea Aristotle, V.3.1131a-1131b (W. Ross trans. 1925) cited in Peter Westen, 'The empty idea of equality' (1982) 95 Harvard Law Review 537, 543.

[78] Catherine Barnard and Bob Hepple, 'Substantive Equality' (2000) 59 Cam Law J 562, 563**.**

structural causes of inequality, instead relying heavily on technical constructions of comparators[79] related to standards of sameness with the dominant group.

Substantive equality recognises that, even with like for like treatment, disadvantage often persists. Sometimes asymmetrical treatment (such as positive action) is needed to redress disadvantage and accommodate difference in order to achieve true equality[80]. The differences between people, including disability, are not irrelevant but instead should be respected, removing the detriment that attaches to difference, not the difference itself[81]. Like formal equality, substantive equality can be criticised for maintaining the status quo of the dominant group by focusing on measures to accommodate certain differences of the minority group, rather than questioning why the appropriate standard should be that of the dominant group[82].

Transformative equality builds on this, but targets the social systems which create the disadvantage, with the aim of tackling, often with positive measures, the causes of disadvantage as well as its effects, and putting the costs of such structural change onto those who can afford to pay it, rather than on the minority group. It aims to move away from the fixation on sameness and difference, instead focusing on the institutional and societal causes of disadvantage[83]. In doing so, it expands the concept of equality beyond traditionally recognised legal grounds of non-discrimination, opening up other concepts of structural inequality[84], such as poverty.

Understandings of equality have developed within a context of other social and legal changes. Theresia Degener[85] suggests that developing notions of equality

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[79] Fredman (n13) 720.
[80] Ibid 728.
[81] Ibid 729.
[82] Oddny Mjoli Arnadottir, *Equality and Non-Discrimination Under the European Convention on Human Rights*, vol 74 (International Studies in Human Rights, Martinus Nijhoff Publishers 2003) 26.
[83] Oddny Mjoll Arnadottir, 'A Future of Multidimensional Disadvantage Equality?' in Oddny Mjoll Arnadottir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities* (Martinus Nijhoff Publishers 2009) 54.
[84] Ibid 28, drawing on the work of Cliona Kimber, 'Equality or Self-determination' in Gearty, Conor and Tomkins (eds), *Understanding human rights* (London: Mansell Publishing 1996) 273. Although Arnadottir terms this concept 'structural disadvantage', comparisons with transformative equality are clear.
[85] Degener (n48) 18.

(from formal, to substantive, to transformative) coincide broadly with policy conceptions of disability; formal equality links to the medical model of disability - the individual's impairment should not influence decisions to ensure like for like treatment; substantive equality links to the social model - impairment needs to be accommodated to prevent disability from being socially constructed; and transformative equality links to a human rights model of disability - it provides an action plan to challenge socially created disability. Just as the human rights model builds on the social model, so transformative equality builds on substantive equality.

However, while there is a general consensus among most commentators that substantive equality is needed to move beyond limited principles of formal equality, the detailed parameters of this principle remain contested, and the following section briefly summarises a range of meanings which have been attributed to it to clarify further the core of substantive equality.

1.3.1 DEFINING THE CORE OF SUBSTANTIVE EQUALITY

In the move to embrace an equality approach which recognises, rather than ignores, difference and disadvantage, several alternative conceptions have been suggested.

Equality of opportunity aims to level the starting point of disadvantaged groups in order that they can compete fairly in an open market[86]. Peter Westen defines 'opportunity' as a chance for someone to achieve a goal without the hindrance of an obstacle[87]; but notes that this formula rests on the obstacles we prescribe. Hence two athletes could be said to have an equal opportunity to win if they are able to compete at the same time in the same place, but also an unequal one if one athlete has benefited from additional training. He argues that equality of opportunity is therefore an 'empty' concept dependent on the obstacles we choose to prohibit within it.

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[86] Fredman (n13) 723.

[87] Westen (n77) 849.

Sandra Fredman recognises a more substantive version of equality of opportunity[88], which goes beyond prohibiting obvious obstacles and requires positive measures to ensure that everyone can access a particular opportunity equally irrespective of existing patterns of disadvantage; to extend the sporting analogy this might require consideration of the economic accessibility of training to both athletes, or the availability of good medical care, sponsorship deals or diet. Crucially, though, equality of opportunity does not guarantee an equal outcome[89] and it can be argued that it is difficult to measure without resorting to measuring outcomes[90]; how do we know when the two athletes have equality of opportunity without seeing who won the competition?

Equality of results, on the other hand, targets outcomes, often through measures such as quotas. Although measuring outcomes sounds easy, it isn't always easy to separate discriminatory factors from other factors in explaining differential outcomes[91]. Nor is it easy to determine the desired outcome; if representation of groups proportional to the population is desired, how do intersectional groups fit within that scheme?[92] There is also surely a risk that a version of equality which focuses exclusively on required results, without tackling aspects of causative disadvantage often experienced by the relevant group, could lead to hollow results and even increase negative stereotypes. By way of example, a workplace quota on minimum numbers of disabled people may produce a section of the workforce who are unable to fulfil their potential unless accessible skills training for disabled people is provided as well.

For all of these reasons, neither equality of opportunity nor equality of results has gained a consensus of support around the full meaning of substantive equality.

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[88] Fredman (n13) 723.

[89] Catharine A. MacKinnon, 'Substantive equality revisited: A reply to Sandra Fredman' (2016) 14 International Journal Of Constitutional Law 739, 740.

[90] Mark Bell, *Racism and Equality in the European Union* (Oxford University Press 2008) 37.

[91] E Olli and B Kofod Olsen, 'Towards common measures for discrimination: exploring possibilities for combining existing data for measuring ethnic discrimination' cited in ibid 38.

[92] Fredman (n13) 721.

Sandra Fredman's proposed framework of substantive / transformative equality is based around the interaction between four 'dimensions'[93]:

1) The first dimension is 'redressing disadvantage', which Fredman coins the 'distributive dimension'. In essence, this seeks to move away from formal notions of equality which attempt to ignore a particular source of disadvantage in seeking like treatment. Instead, it means targeting the source asymmetrically, aiming to remove the disadvantage associated with the source (or characteristic) rather than ignoring the characteristic itself;

2) The second dimension is addressing stigma, stereotyping, prejudice and violence (the 'recognition dimension'). It provides a right to dignity, and to be free of a socially imposed identity. Where disability is concerned, this idea is intimately linked with the social model of disability, which sees disability as a social construct imposed by society;

3) The third dimension is enhancing voice and participation (both politically and in communities) (the 'participative dimension'). It advocates giving disadvantaged minorities a voice in policy-making processes which might historically have catered exclusively to the majority, and a right to inclusion in the community instead of being marginalised. Although Fredman's analysis is broader than this, the 'community' must be read as including a right to inclusion within the workplace and labour market; and

4) The final dimension is accommodating difference and achieving structural change (the 'transformative dimension'). This means looking to change the social structures which disadvantage people on account of a particular difference, while promoting the value of such diversity. This draws in the realm of positive action.

The nature of the disadvantage which needs to be redressed under the first dimension is predominantly socio-economic; examples given are of 'under-

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[93] Ibid 727. For another multi-dimensional framework, see Christopher McCrudden, 'The new concept of equality' (2003) 4 ERA forum scripta iuris europaei 9, 16. Given the overlap between elements of Christopher McCrudden's framework with that of Sandra Fredman, the former has not been listed here in detail.

representation in jobs, under-payment for work of equal value, or limitations on access to credit, property, or similar resources'[94]. This has the advantage of providing an objective yardstick, although one that must be used with care, as statistics as to, say, household income do not always reveal the power relations which affect who has access to that income within the family[95]. She also notes that socioeconomic factors can inhibit genuine choices, removing the ability of the individual to 'be able to be and do what she values'[96]; substantive equality requires us to see beyond 'choices' made without genuine options.

To use the dimensional model as a practical tool, it is submitted that further clarity would be beneficial on the concept of socioeconomic disadvantage. Fredman's inclusion of underpayment for work of equal value as a type of socio-economic disadvantage, for example, suggests that disadvantage can be a purely relative concept, irrespective of content; without clearer parameters, such a relative definition could lead back to principles of formal, rather than substantive, equality. In addition, proving socioeconomic disadvantage is difficult without accurate statistics, so the enforceability of this depends to some extent on the quality of available data.

Catherine MacKinnon has forcefully criticised Fredman's analysis as presenting a concept of disadvantage which 'does not come with identifying instructions'[97] and which is wide enough to subsume another of Fredman's dimensions (stereotyping, which Mackinnon views as the 'socio' part of socioeconomic disadvantage). Instead, she views the problem of social hierarchy, rather than disadvantage, as the defining core of substantive equality: "above and below, more and less, higher and lower, dominant and subordinate, superior and inferior"[98]. Fredman, in turn, concedes the importance of hierarchy but argues that, on its own, it is not sufficient to capture the complexity of power inequalities[99].

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[94] Ibid 729.
[95] Ibid.
[96] Ibid 730.
[97] MacKinnon (n89) 740.
[98] Ibid 740.
[99] Sandra Fredman, 'Substantive equality revisited: A rejoinder to Catharine MacKinnon' (2016) 14 International Journal Of Constitutional Law 747, 747.

The heated academic debate between Fredman and Mackinnon in these articles is conceptually difficult to unpick with clarity; their approaches have some aspects in common but packaged and prioritised differently. But the disagreement about how to identify disadvantage is very relevant for people with a visible difference: where should the boundaries of disadvantage meriting targeted protection be set?

By way of example, Chapter 3 will demonstrate that appearance-related disadvantage is not confined just to people with a disfigurement; there is some level of relative disadvantage attached to just looking 'plain'. (Conversely, there could sometimes be some disadvantage in being *more* beautiful than the 'norm', with stereotypes of beauty making it harder (for women in particular) to be taken seriously in a professional context[100]). As a matter of theory, should equality law aim to level this playing field for all, extending its reach to this wider level of appearance-related disadvantage, or focus on a central core of deep disadvantage outside the 'norm' experienced by many of those with a disfigurement?

This question echoes a debate which has played out in relation to other protected characteristics. Some commentators lament the law's tendency to focus on equal treatment for all at the expense of addressing the more fundamental group inequality hidden behind it[101] (demonstrated by the adoption of 'symmetrical' characteristics such as sex and race, rather than the deepest disadvantage of women and black people[102]). Others see value in the default of legal abstraction (rights that apply to everyone in the same way) rather than the creation of laws applying to specific groups of people only[103], which could be open to abuse. With regard to disability (which is not a symmetrical characteristic but grants rights to disabled people only), David Wasserman argues powerfully that:

> "many physical and mental differences not classified as impairments elicit equally contemptuous, dismissive, patronizing and over solicitous responses, that can be equally handicapping"[104]

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[100] See e.g. Nancy Etcoff, *Survival of the prettiest* (Anchor Books, 2000) 83 for a discussion of the evidence.

[101] Kate Malleson, 'Equality Law and the Protected Characteristics' (2018) 81(4) MLR 598, 599.

[102] Ibid 598.

[103] William Lucy, 'Abstraction and the Rule of Law' (2009) 29(3) OJLS 481.

[104] Wasserman (n22) 151.

suggesting that the scope of relative 'ability' disadvantage extends beyond the law's narrow definition of disability. (Interestingly, though, Wasserman does acknowledge that within this widened group some people with significant impairments would be "the most salient and aggrieved victims"[105], suggesting a nuanced, not homogenous, reality). A counterargument can be made that, the wider the distribution of equality rights, the more diluted they become[106], and less useful to those who need them most.

As a result of the academic focus on principles of substantive equality in recent years, the latter argument has gained ground. Implicit in the aim of targeting disadvantage is the recognition that, while we are almost all disadvantaged in different ways to some degree, some disadvantage is deeper and requires intervention. This focus on disadvantage 'beyond the norm' is implicit in the law's scope too and perhaps underlies the various thresholds contained within it (such as protecting only people with severe disfigurements rather than general imperfections of appearance within the normal range). While a detailed examination of the theory of disadvantage in general terms is outside the scope of this thesis, the issue is one to which I will return at various points in relation to visible difference specifically, to assess whether the law as it stands addresses the correct scope of disadvantage.

Of the various meanings of substantive equality discussed above, Sandra Fredman's model is particularly useful in my context, because it gives express focus to recognition arguments, such as stigmatisation, stereotyping, and exclusion, as well as to redistributive arguments. In addition, in the disability context, a version of Fredman's substantive equality framework has been adopted by the Committee of the Convention on the Rights of Persons with Disabilities[107] to elucidate the meaning of equality within the Convention. Together, therefore, Fredman's four-dimensional model and the principles of the CRPD form a cohesive framework of

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[105] Ibid 272.

[106] See Wasserman, ibid 153 for a discussion of these arguments.

[107] UN Committee on the Rights of Persons with Disabilities, 'General comment No. 6 on equality and non-discrimination' (United Nations, 2018) para 11.

standards to evaluate substantive equality for disabled people and will accordingly be applied in this thesis.

1.4 HOW DO WE MEASURE WHETHER THE LAW PROVIDES EQUALITY FOR PEOPLE WHO ARE VISIBLY DIFFERENT?

So far, this chapter has determined why visibly different people should benefit from principles of equality and, broadly speaking, what equality means. But, as already set out above, the dimensions of substantive equality are necessarily high-level given their required application across numerous groups; in isolation, they lack sufficient contextual detail to be applied with clarity. In the context of disability, the CRPD provides this detail. It will be argued that, together, Fredman's model of substantive equality, combined with the CRPD's guiding principles, offer a framework to assess whether the law provides substantive equality for people who are visibly different. Section 1.4.1 will provide an overview of CRPD key principles before moving on to assimilate these into a single framework of substantive equality in the visible difference context.

1.4.1 SUBSTANTIVE EQUALITY IN THE CRPD: CREATING A UNIFIED FRAMEWORK

The purpose of the CRPD (which was ratified by the UK in 2009) is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity"[108]. Although not the first Treaty to include measures to combat discrimination, many of its predecessors (including, for example, the Universal Declaration of Human Rights[109]), failed to mention disability specifically as a ground of discrimination, bundling it into a provision preventing discrimination on grounds of "other status"[110]. So, while arguably not creating many

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[108] CRPD (n44) Art 1.

[109] UNGA 'Universal Declaration of Human Rights' (10 December 1948) Res 217 A(III) Doc A/810.

[110] United Nations, (n47) 94.

new obligations, the CRPD acts as a "new tool to make the fight against discrimination on the basis of disability more informed and determined"[111] and to set out "what human rights means in the context of disability"[112]**.** The Convention's broad understanding of disability has already been outlined at 1.2.2.1.1.

The Convention applies at state level, so its obligations are for signatory states to achieve; it does not impose duties directly on private employers. The breadth of its drafting has been interpreted, both domestically[113] and by the CRPD Committee itself[114], as offering states a margin of appreciation in achieving these aims.

The CRPD sets out a number of general principles which are intended to inform its interpretation[115], among them:

> '(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
>
> (b) Non-discrimination;
>
> (c) Full and effective participation and inclusion in society;
>
> (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
>
> (e) Equality of opportunity;
>
> (f) Accessibility;
>
> (g) Equality between men and women …'[116]

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[111] Ibid 95.

[112] Equality and Human Rights Commission, 'UN Convention on the Rights of Persons with Disabilities' (2018) <https://www.equalityhumanrights.com/en/our-human-rights-work/monitoring-and-promoting-un-treaties/un-convention-rights-persons-disabilities> accessed 25 June 2019.

[113] House of Lords Select Committee, *The Equality Act 2010: the impact on disabled people*, (HL Paper 117, 2016) para 75-79.

[114] See e.g. CRPD Committee 02.10.2014, Communication No. 5/2011, *Marie-Louise Jungelin v Sweden*, CRPD/C/12/D/5/2011 para 10.5: a margin of appreciation to decide "the reasonableness and proportionality of accommodation measures".

[115] Lawson A, The United Nations convention on the rights of persons with disabilities: new era or false dawn? (2007) 34 Syracuse Journal of International Law and Commerce 563, 591.

[116] CRPD (n44) art 3.

There are accompanying general obligations[117] on state parties (including an obligation to take measures to eliminate discrimination[118]), and a series of specific obligations, the most relevant for present purposes being Equality and Non-Discrimination[119], Awareness-Raising[120], Access to Justice[121], and Work and Employment[122]. While the civil and political rights under the CRPD (such as Awareness-raising under Article 8) are subject to immediate realization, the economic, social and cultural rights (including the right to employment under Article 27) are generally subject to progressive realization[123]. (An exception to this is the duty of reasonable accommodation in the employment context, which has been held to apply immediately[124].) Progressive realization recognises that change may take time and be influenced by available resources, hence it is linked with the state's economic situation and periods of austerity may delay implementation[125]; as such, judging compliance at a given point in time must be contextual.

The concepts of equality and non-discrimination, together with principles of human rights, are central to the CRPD. While principles of both formal equality (in the concept of direct discrimination, for example) and substantive equality (see references to 'equality of opportunity[126]', for instance) were inherent within the CRPD at the point of signature, the Committee has also demonstrated its desire to keep the Convention's notion of equality up to date. In April 2018, the Committee published its General Comment No. 6[127] which announced:

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[117] Ibid art 4.
[118] Ibid art 4(e).
[119] Ibid art 5.
[120] Ibid art 8.
[121] Ibid art 13.
[122] Ibid art 27.
[123] Andrew Byrnes and others, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities* (UN-DESA, OHCHR and IPU, 2007) 19.
[124] Marco Fasciglione, 'Article 27 of the CRPD and the Right of Inclusive Employment of People with Autism' in V Della Fina and R Cera (eds), *Protecting the Rights of People with Autism in the Fields of Education and Employment* (Springer 2015) 167.
[125] Ibid.
[126] CRPD (n44) art 3(e).
[127] UN Committee on the Rights of Persons with Disabilities, (n107) para 11.

> "… a new model of equality developed throughout the Convention. It embraces a substantive model of equality and extends and elaborates on the content of equality in: (a) a fair redistributive dimension to address socioeconomic disadvantages; (b) a recognition dimension to combat stigma, stereotyping, prejudice and violence and to recognize the dignity of human beings and their intersectionality; (c) a participative dimension to reaffirm the social nature of people as members of social groups and the full recognition of humanity through inclusion in society; and (d) an accommodating dimension to make space for difference as a matter of human dignity. The Convention is based on inclusive equality."[128]

As mentioned earlier, despite the change of name from 'substantive' to 'inclusive', and some slight re-wording of the transformative dimension to an 'accommodating' dimension, the parallels here with Sandra Fredman's model of substantive equality are clear. Unless differences between the two become apparent in the Committee's judgments, it seems safe to assume that the minor differences in wording between the two concepts do not reveal any significant intended material difference of meaning, and the term 'substantive equality' in this thesis will be used as referring equally to this notion of inclusive equality.

How can these four dimensions be discerned in the text of the Convention? Given that the focus of this thesis is specific to visible difference in the workplace, the starting point for this analysis of substantive equality in the CRPD will be Article 27 ('Work and employment'), but several of the employment-specific provisions link to general themes detailed elsewhere in the Convention. The table at Figure A below sets out how these four dimensions of substantive equality (listed in column 1) manifest themselves in the CRPD in the workplace context (column 2). It should be stressed that there is some overlap across dimensions but, for simplicity, where such overlaps occur the content is not repeated. In order to ensure that these dimensions of substantive equality, as detailed in the CRPD, can form a useful a

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[128] Ibid.

lens through which to answer the thesis title, column 3 turns these dimensions and principles into a series of research questions which will be used in the following chapters as a basis for this evaluation.

Figure A

Substantive equality dimension	**CRPD principles relevant to the employment context**	**Research questions identified**
Redistributive dimension (redressing disadvantage)	The CRPD targets the disadvantage of disability (which is identified explicitly in the preamble (particularly paras (e), (k), (p) and (t)) in both who it applies to and the understanding of equality that it applies: In terms of who it applies to, the Convention (although lacking an express definition) describes disability by reference to disadvantage itself. Art 1 links the description of disability to those whose impairments 'in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others', thus describing disability as potential societal disadvantage rather than an additional medical criterion. This helps to ensure that those who benefit are those who are disadvantaged, reducing the risk of certain pockets of disadvantage falling outside of the scope of the concept. In terms of equality aims, the Convention includes a capacious definition of non-discrimination, and goes beyond formal equality (found for example in the concept of	Q1 (a): Are visibly different people a disadvantaged group? And Q1(b): Does UK equality law identify and target this disadvantage? (together 'Research Question 1: targeting disadvantage')

	direct discrimination and equality ‘before and under the law’[129] which suggests equal treatment) towards substantive equality (found in the concept of ‘equal opportunities [130] ’ and indirect discrimination among others). This targets disadvantage because it focuses not on equal treatment but on levelling up the opportunities for disabled people to account for structural and past disadvantage. Examples include programmes of assistance, work experience and training for disabled people to help with finding, retaining and progressing in work (Art 27 (1) (d), (e), (j) and (k)).	
	The CRPD identifies disabled women and children as likely to be particularly disadvantaged (Preamble paras (p) and (q), Art 3(g) and (h)) and in need of support measures. General Comment No. 6 on equality and non-discrimination requires intersectionality with other characteristics, including age and race, to be assessed too[131].	Q2(a): Does visible difference intersect with the characteristics of gender, race or age to produce crossovers of additional disadvantage? Q2(b): If so, does equality law redress this increased disadvantage?

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[129] Bruce (n42) 227.
[130] CRPD (n44) art 3(e).
[131] UN Committee on the Rights of Persons with Disabilities, (n107) para 21.

		(together 'Research Question 2: intersectionality'). (The intersections between disfigurement and gender, race and age have been selected for consideration in this thesis due to practical constraints, but it is recognised that the CRPD's intersectionality obligation could extend more widely than this. This thesis will also not address the issue of children with disabilities given its workplace focus).
	The CRPD duty to make reasonable accommodation for disabled people aims to redress disadvantage by accommodating impairment effects.	Q3(a) Does the duty to make reasonable adjustments under UK equality law effectively accommodate difference?

		Q3(b): To what extent is this duty applied to people with a visible difference, both in theory and practice? (together 'Research Question 3: Reasonable adjustments')

Recognition dimension (addressing stigma, stereotyping, prejudice and violence)	The CRPD concept of disability is based on the social / human rights model of disability. This recognises that disability is a social construct arising from the experience of barriers existing within society which prevent disabled people from being recognised on an equal basis with others, free from stereotypes and stigma. To address this, it provides that measures shall be taken to raise awareness and foster respect for the rights and dignity of disabled people (Art 8 (1)(a)), to combat stereotypes, prejudices and harmful practices (Article 8 (1)(b)), and to promote awareness of the capabilities and contributions of disabled people (Art 8(1)(c)). So, too, there is a wider obligation on states to encourage the media to portray disabled people in a manner consistent with the Convention[132], with the aim of reducing such barriers. (There is link here with the transformative dimension as structural change may be required to remove these attitudinal barriers).	Q4: Does the law foster awareness and respect for people with a visible difference, and their rights, dignity, capabilities and contributions and combat stereotypes and prejudice relating to visible difference? ('Research Question 4: recognition')

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[132] CRPD (n44) art 8(2)(c).

	The CRPD calls for just and favourable forms and conditions of work for disabled people, which includes 'the redress of grievances' (Art 27 (1)(b)). This links to Article 5 (Equality and Non-discrimination), which demands 'equal and effective legal protection against discrimination' (Art 5 (2)) and Article 13 (Access to Justice) which requires 'effective access to justice' including procedural accommodations where needed (Art 13 (1)).	Q5) Do visibly different people have effective access to justice in challenging discrimination? If not, why? ('Research Question 5: access to justice')
Participative dimension	The CRPD includes 'full and effective participation and inclusion in society' as one of its General Principles (Art 3 (c)). In the work context, this is found, for example, in the following ways:	Q6: Does UK equality law promote and ensure the participation and inclusion of people who are visibly different

	• enabling access to vocational training and placement services (Art 27(1)(d) to assist inclusion in the labour market; • the right to 'gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible' (Art 27(1)). Work 'freely chosen' includes preventing visibly different people being restricted in their opportunities within the labour market (e.g. to low grade or back office roles). Professional inclusion continues once employed, with the promotion of 'career advancement' opportunities (Art 27(1) (e)) and the importance of social inclusion within the work community is also recognised.	in the workplace and labour market? ('Research Question 6: participation and inclusion').
Transformative dimension (accommodating difference and achieving structural change)	The CRPD provides a general cross-cutting principle of accessibility, which applies to technology and services as well as buildings and environments. This is transformative because universally accessible design means creating an environment which works for everyone, thus eliminating physical and technological barriers which disable people with impairments.	Given that many people with a visible difference have no functional limitation, accessibility will not be addressed further in this thesis.
	The CRPD provides that 'specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination' (Art 5(4)) and this theme continues specifically in the work context, with State parties required to 'safeguard and promote the realization of the right to work' by measures including:	Q7: To what extent does domestic equality law pursue structural change which accommodates people who are

	- employing disabled people in the public sector - promoting the employment of disabled people in the private sector through 'appropriate policies and measures, which may include affirmative action programmes, incentives and other measures' (Art 27(1)(h)). - providing training to employers on reasonable accommodation and related issues[133]. This is an example of the transformative dimension because it focuses on changing the societal structures which create disability.	visibly different? ('Research Question 7: structural change'). (Measures referred to in the CRPD can also include non-legal measures - such as the Disability Confident scheme, designed to encourage employers to adopt positive action, or the specialist disability advice available through Job Centre Plus - but, given the legal focus of the research question, these will not be discussed in detail in this thesis.)
	The CRPD committee has clarified that 'forward-looking, non-pecuniary remedies[134]' should be provided for discrimination by private parties, given that the 'mere granting	Q8: Do the available remedies for discrimination under UK

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[133] UN Committee on the Rights of Persons with Disabilities, (n107) para 67 (h).
[134] Ibid para 22.

	of compensation to an individual may not have any real effect in terms of changing the approach'[135]. This is a transformative approach aimed at bringing about structural change in the future.	equality law include effective 'forward-looking, non-pecuniary remedies'? (Research Question 8: remedies').

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[135] Ibid.

1.5 CHAPTER 1 SUMMARY

This chapter has set out the rationale for my thesis and the legal framework for my examination of disfigurement as a disadvantaged characteristic within the workplace. Using the structure of substantive equality as applied within the CRPD, I have outlined eight Research Questions which I intend to address in this thesis.

Chapter 2 will now summarise the methodology adopted to answer these questions and chapter 3 will consider existing literature and the extent to which it enables these Research Questions to be addressed. Chapters 4, 5 and 6 outline my original contribution to answering them.

2. METHODOLOGY

2.1 CHAPTER INTRODUCTION

Answering the Research Questions requires a combination of methods. Several of the questions require an examination of the law itself. Others require an understanding of the subjective reality of having a visible difference in the workplace. Some require a combination of both.

Two different methodologies have therefore been used. Doctrinal analysis is employed to evaluate the law itself. And empirical research is employed to develop an understanding of the perspective of those with a visible difference, and how this relates to equality rights.

An outline of each methodology will now be set out.

2.2 DOCTRINAL RESEARCH

I must be honest that, probably in common with many academics and practitioners, my doctrinal research did not start with a theoretically influenced doctrinal process in mind beyond searching for everything which appeared relevant! As a former solicitor, I am well accustomed to researching particular aspects of law, and had partly researched this topic before starting my PhD.

But there is an important distinction, however, between the research that I used to undertake in practice, and that required by my PhD; whereas practitioner research focuses on describing and applying the law to a given set of facts, my academic research needed to go beyond this in order to critique the law. So, rather than taking the law at face value, my PhD research aims to evaluate it by reference to the framework of standards set out in Chapter 1. This requires a focus not just on what the law says, but why, and a consideration of other ways that it could better achieve its underlying aims. I therefore needed to adapt my doctrinal approach as my research progressed to develop this critical stance. Although this process occurred organically of necessity during my PhD, with hindsight this is similar to the process described by Australian academic, Terry Hutchison, who argues that:

> “Pure doctrinal research identifies and analyses the current law. Reform-oriented research recommends change. Most ‘good’ quality doctrinal research goes well beyond description, analysis, and critique, and invariably suggests ways the law could be amended or the philosophy, processes or administration of the law could be improved.”[136]

My research process was often non-linear, enabling me to explore tangents from time to time – such as the considerable scholarship linked to obesity rather than disfigurement. I used a number of mainstream legal databases including Westlaw, PLC, Bailii and others, but had to adopt other methods from time to time – such as visiting the archiving office of the Employment Tribunals[137] to try to obtain copies of unpublished case documents. My research began with primary sources – particularly the Equality Act 2010 and case law under it – but quickly progressed to secondary sources including statutory guidance and existing scholarship.

A dearth of relevant legal academic scholarship relating to disfigurement rights under UK law quickly became apparent. This difficulty was compounded by the Employment Tribunals’ policy of destroying judgments more than 6 years old. On occasions, my analysis therefore had to rely on law reports rather than primary judgments, but this required caution as I was unable to verify the details and had to tailor my analysis to take account of this uncertainty in places.

Two specific challenges in my doctrinal research are worthy of individual comment – the methodology underlying the literature review presented in Chapter 3, and that underlying the comparative legal analysis in Chapter 6.

2.2.1 LITERATURE REVIEW METHODOLOGY

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[136] Terry Hutchinson, 'The Doctrinal Method: Incorporating Interdisciplinary Methods in Reforming the Law' (2015) 3 Erasmus Law Review 130, 132.

[137] Bury St Edmunds Employment Tribunal holds the archives of the Employment Tribunal service.

Although there was very little existing legal scholarship on disfigurement equality, there was a considerable amount relating to the social and psychological effects. However, scoping my literature review was difficult because this body of scholarship lacked a clear, consistent definition of the concept of ‘disfigurement’. So, having begun my literature search looking for the keywords ‘disfigurement’ and ‘visible difference’, I progressed to look for literature relating to conditions which might commonly linked with disfigurement, such as birth marks, psoriasis and burns injuries. To prevent my search from becoming too tangential, I focused on legal, social and psychological literature rather than medical literature (which tended instead to focus on treatment options). Completing a very brief online training session provided by the Centre for Appearance Research at UWE[138] provided a useful cross-check for my literature review by confirming the themes and key literature that I had identified from my search.

I completed my literature review prior to undertaking the remaining doctrinal and empirical work. This enabled me to establish the extent to which the Research Questions could already be answered by existing research, and therefore where to focus my work to ensure originality and usefulness.

2.2.1.1 REFLECTION ON VISIBLE DIFFERENCE RESEARCH METHODOLOGIES IN EXISTING LITERATURE

Although my literature review revealed large numbers of studies with relevance to visible difference, drawing reliable conclusions from them to inform legal analysis is complex in several respects. Many of the studies referenced in Chapter 3 are specific to particular conditions, such as psoriasis or cleft lip. It is difficult to draw generalisations as a result, because the different conditions often have different symptoms, as well as different ages of presentation or acquisition, different causes, and different severities. Where the condition under examination can have both functional and disfiguring consequences, such as psoriasis, studies tend not to differentiate between the two, making it hard to determine the relevance for other disfiguring conditions.

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[138] See <https://www1.uwe.ac.uk/hls/research/appearanceresearch.aspx> accessed 30 June 2020.

The people within the studies represent a further level of diversity, spanning an array of personal characteristics. And the studies themselves often use small, self-selecting sample sizes[139] which tend to focus on people connected with either support organisations or medical facilities, meaning that those who do not seek help are underrepresented[140].

In addition, almost all studies in this area are cross-sectional rather than longitudinal[141], meaning that patterns of adjustment and variations throughout life are poorly understood, and some studies tend to focus on a time of particular sensitivity, such as the period following an injury, or when returning to work.

Variability in methods and findings represents, perhaps, one of the biggest challenges facing the law – creating a system which is specific enough to enable clarity of application, but wide enough to work for a disparate group. While it is impractical to analyse the needs of people with each condition separately, meaning that a high degree of generalisation is inevitable, this thesis will seek to recognise such distinctions where they impact on the required legal approach.

2.2.2 COMPARATIVE LAW METHODOLOGY

Another doctrinal challenge came when researching laws in the US and France (see Chapter 6).

France and the USA were chosen for specific reasons:

1. France's labour code[142] provides the right not to be discriminated against on the basis of appearance generally, as well as separate protected characteristics of disability and health conditions;

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[139] Emma Robinson, 'Psychological research on visible differences in adults' in Richard Lansdown and others (eds), *Visibly Different* (Butterworth-Heinemann 1997) 104.
[140] Nichola Rumsey and Diana Harcourt, 'Body image and disfigurement: issues and interventions' (2004) 1 Body Image 83, 94.
[141] Ibid.
[142] Code du Travail, art 1132-1.

2. the USA has both federal and local laws which provide an interesting contrast to each other. (Federal laws apply to the whole of the US, but some states enact their own equality laws as well, and indeed some cities within particular states go further with their own local laws. Each layer of law must be at least as protective as the layer of law above it). US law has also developed quickly; until the early 1970s, 'ugly laws'[143] existed in some US cities which made it unlawful to show a disfigurement in public. For example, an early Chicago ugly law provided "any person, who is diseased, maimed, mutilated or in any way deformed, so as to be an unsightly or disgusting object, or an improper person to be allowed on the streets, highways, thoroughfares, or public places in this city, shall not therein or thereon expose himself to public view …"[144]. Susan Schweik cites the last arrest under an ugly law in the US as having taken place in 1974[145]. The USA therefore provides a good example of radical ideological transformation in this area.

I chose not to summarise or compare the legal equality systems in these jurisdictions as a whole, because overly simplified comparisons risk presenting a distorted picture of complex social, legal, and cultural contexts. For example, any conclusion that a particular French legal equality provision was 'more effective' than its UK equivalent would ignore a myriad of other differences, including cultural distinctions, differences in social security procedures, alternative legal enforcement mechanisms, the existence of a disabled worker quota system in France, differing roles of trade unions and state bodies, a greater role for works doctors in France, the potential impact of criminal liability for discrimination in France, etc – all of which may play a part in this effectiveness[146]. Instead, my comparative approach was functional, in line with that proposed by Zweigert and

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[143] Susan M Schweik, *The Ugly Laws: Disability in Public* (New York University Press 2009) 3. The US was not the only country to have versions of an 'ugly law' – see ibid, 4 – but the introduction of ugly laws in the US was closely related with attempts to prevent street begging: see ibid 41.

[144] Chicago Municipal Code 1881 cited in ibid 2. Schweik notes, however, some variety in the detail of these laws and the exact scope of their prohibitions: ibid, 9.

[145] Schweik (n143) 6.

[146] See, for example, Susan Corby, Laura William and Sarah Richard, 'Combatting disability discrimination: A comparison of France and Great Britain' (2019) 25 European Journal of Industrial Relations 41, 44.

Kotz[147], aiming to 'look at the way practical problems of solving conflicts of interest are dealt with in different societies according to different legal systems'.[148] The starting point for my comparative legal research was therefore to focus on the specific problems identified in UK law, using international comparisons to explore alternative approaches on these points.

I began by researching some French legal vocabulary, and used the hardcopy comparative law resources at Cambridge University Library to supplement Durham's resources. Finding recent case law in both countries was a challenge. In relation to both France and the US, I found previous scholarship on related issues (particularly general appearance discrimination) but my own searches did yield some new results not mentioned by other academics (for example, see 6.3.1).

The US presented particular problems in searching for decisions, because most federal law complaints are channelled through the Equal Employment Opportunity Commission ('EEOC'), and these decisions are confidential[149]. Some local state laws in the US have confidentiality restrictions on judgments too, but in some cases I was able to supplement my own case research with direct email exchanges with relevant authorities in the US. This was a useful way of accessing additional information or, in one case, confirming that the reason I had found no case law was because none had ever been filed[150].

While my French and US case research was not able to be quite as comprehensive as my research in Britain (both due to limited available international resources and the sheer volume of different laws applicable in different states of the US), I was able to use it in two ways. First, it enabled me to analyse the alternative approaches adopted in legislation in these jurisdictions, looking for different angles in the areas where I believed the Act fell short. Second, international case research enabled me to understand general levels of enforcement of these international provisions and

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[147] Konrad Zweigert and Hein Kotz, *Introduction to comparative law* (3rd rev. ed. edn, Oxford : Clarendon Press 1998).

[148] Mark Van Hoecke, 'Methodology of Comparative Legal Research' (2015) *Law and Method* 1, 9.

[149] US Equal Employment Opportunity Commission, 'Confidentiality' (*EEOC,* undated) <https://www.eeoc.gov//employees/confidentiality.cfm> accessed 8 July 2019.

[150] City of Santa Cruz Human Resources Department to Hannah Saunders, 'Email: physical characteristics discrimination ' (13 June 2019)

compare this with the level of case law under the Act. Given the context of my research, I feel that this level of comparative information was sufficient; creating a comprehensive database of every appearance-related claim ever filed in every jurisdiction would not have enabled me to answer my thesis question better, and may have distracted from the broader comparisons of approach between jurisdictions.

2.3 EMPIRICAL RESEARCH

When I began my PhD, my research proposal referred to the use of an online survey to seek the views of people with a visible difference about specific issues. My assumption (at that stage not having explored the theoretical aspects of methodology) was that, by obtaining a broad response to an online survey, answers to these questions would emerge and I would be able to create objective generalisations such as '60% of visibly different people are reluctant to enforce their rights because of the personal stress involved'.

This initial assumption speaks to my personal view of reality at that stage (my ontology), probably informed by my background in legal practice. Although I didn't realise it, my initial assumption that a large-scale survey would yield the most reliable data had positivistic underpinnings – in other words, a belief that reality was out there, able to be captured by asking the right questions of a sufficient number of people.

As my research progressed, however, I began to question whether an online survey would bring me the answers I sought. There were some methodological difficulties:

- Without a sampling frame[151] available in my context, online surveys bring difficulties verifying the people who complete them, which affects the reliability of the results.

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[151] A sampling frame is all possible participants or data which falls within the parameters of the study. The sampling frame here would have consisted of a list of adults with a visible difference with experience of working or seeking work in the UK.

- They are a rather blunt instrument in terms of the data they collect – they provide no context to answers given, and no opportunity to clarify particular points, running the risk of losing the real meaning behind the responses.

- Ready answers with tick boxes make them easy and quick to complete (thus encouraging responses) but rely on me having a sufficient understanding to predetermine the right tick boxes, which affords me the potential to (unintentionally) influence the research from the beginning.

- There are also practical constraints getting enough responses for the data to be representative of the relevant group.

Perhaps more fundamentally, the early stages of my research introduced me to the complexity of researching this area, where perceived experiences can vary from one person to the next according to a wide variety of factors, both personal and contextual, suggesting a more complex interplay than a survey could reveal.

This thought process led me to question not only the methods I had planned, but also my research paradigm. In common with many researchers, particularly those inexperienced in qualitative interviewing, this process was revisited on several occasions as the research progressed, as new insights during the data collection and analysis process caused me to reconsider my research paradigm, exploring theoretical perspectives such as social constructivism, critical realism and interpretivism in this process of alignment.

The following section sets out the research paradigm which this process ultimately led me to, and which has been adopted in the empirical work set out in this Chapter. In this chapter I will first describe the theory of each component of the paradigm – beginning with ontology and epistemology – explaining what each means and how the position taken could impact on a piece of research. I will then set out the position that *this* research takes within each component, and why I believe this is appropriate for this project.

My analysis will then describe and defend the method choices made in this project, for both data collection and data analysis, and explain how key criteria such as ethics and data security were met. Finally, the chapter will conclude with my reflections on the data gathering and analysis process adopted. The findings of my empirical research are contained in Chapter 5.

2.3.1 RESEARCH PARADIGM

2.3.1.1 ONTOLOGY, EPISTEMOLOGY AND THEORETICAL PERSPECTIVE

A research paradigm creates a theoretical framework which affects how research works, and the claims it can ultimately make. Good research should demonstrate a logical connection between all aspects of its paradigm[152].

A useful starting point is to consider the opposing approaches of positivism and interpretivism. A positivist approach suggests that the social world can be studied scientifically; that social research can reveal durable, objective truths about a particular topic, and that researchers and their methods need to strive for impartiality, generalisability, replicability and objectivity. Interpretivism, on the other hand, highlights the fluid, multi-faceted nature of society and social interaction and argues that there is no one 'truth' to be discovered, but that each person has a different subjective reality. Interpretivist research can't therefore seek to reveal a single truth but to understand and describe these multiple social realities. The interpretivist researcher is part of the social world and therefore brings preconceptions and values to it which unavoidably influence the research. Suggestions of research objectivity are therefore impossible; the researcher's job is to interpret not to prove.

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[152] Michael Crotty, *The Foundations of Social research* (Sage Publications Ltd 1998) 10.

The contrast of positivism and interpretivism neatly demonstrates how the theoretical approach should have a big impact on the research, in terms of methods chosen, claims made, and the internal process of the researcher. Positivist research, for example, has historically tended to be associated with quantitative methods (which focus on generalisability and finding scientific explanations) and interpretivist research has focused on qualitative methods (which focus on understanding detailed accounts in their own right).

A number of paradigmatic aspects - such as ontology and epistemology - make up each theoretical approach. Ontology is the 'study of being or reality[153]'. Simply put, ontology describes what (in the social world, at least) exists. An ontological claim could be realist – where external reality exists independent of any human meanings attributed to it, as in positivism – or relativist – where multiple realities exist because all reality is subjective being in the minds of human beings, as in interpretivism. If my ontology were to research bias against visible difference from an objective stance, the phenomenon would be explored as a durable social reality which exists independently of the people involved with it (much like, say, material phenomena in the natural world) which cannot be altered by the actions of individuals. Researching the same topic from a relativist ontological standpoint would assume that the phenomenon only exists within the interactive experiences of individual people and the meaning-making processes which they engage in, hence social realities are usually multiple and sometimes conflict because the account of this reality may differ between people and over time. Because there is no objective, durable, external 'truth' against which to judge it, each version of reality presented is equally valid. Although a detailed explanation is beyond the scope of this thesis, it is worth noting that ontological perspectives do not always follow this simple, diametric pattern; Berger and Luckman, for example, saw the social world as created by individual interaction thus subjectively real, but argued that some subjective, institutional realities become so engrained and habitual that they can be seen as objective social realities[154].

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[153] Kevin O'Gorman and Robert MacIntosh, 'Mapping Research Methods' in Kevin O'Gorman and Robert Macintosh (eds), *Research Methods for Business and Management* (Goodfellow Publishers Ltd 2015) 55.

[154] Peter L. Berger, *The social construction of reality : a treatise in the sociology of knowledge* (Harmondsworth : Penguin 1967) 78.

Ontology is closely related to epistemology (indeed some theorists see the connection as so close that they are merged[155]). A realist ontology usually suggests an objective epistemology resulting from a positivist perspective[156]; "the social world can be studied in the same way as the natural world, that there is a method for studying the social world that is value-free, and that explanations of a causal nature can be provided"[157]. In other words, because there is an objective, durable truth to social reality, it is verifiable by hypothesizing, testing and observing it to discover its essence.

Relativist ontology, on the other hand, is often linked with a constructivist epistemology[158]. Constructivism is a form of interpretivism which suggests that people construct knowledge from their own experiences and interactions with others. The method of finding out about social reality must therefore focus on the accounts of it as explained by participants. The researcher and participant engage in a meaning-making process where knowledge about the phenomenon being studied is not independently discovered but generated, made sense of, and interpreted. This knowledge, once constructed, can provide a detailed understanding of the subject's personal reality, but is not a basis for generalising more broadly.

Braun and Clarke's 'window' analogy provides a useful summary of the difference in theoretical positions[159]. An objective, realist position treats research as the windows all around one's home; one can look through them confident in knowing that what is outside the window will mirror exactly what one sees as one looks

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[155] Crotty (n152) 17.

[156] Exceptions to this include theoretical perspectives like critical realism, which argues for an objective ontology and a subjective epistemology.

[157] Donna M. Mertens, *Research and evaluation in education and psychology : integrating diversity with quantitative, qualitative, and mixed methods* (Fourth edition. edn, Thousand Oaks, CA : SAGE Publications, Inc. 2015) 10.

[158] It is worth noting, however, that some constructionists adopt an ontologically ambivalent stance, arguing that constructionism focuses just on the process of knowing rather than whether an external reality exists. See, for example, Tom Andrews, 'What is Social Constructionism?' (2012) Grounded Theory Review <http://groundedtheoryreview.com/2012/06/01/what-is-social-constructionism/> accessed 11 October 2018.

[159] Virginia Braun and Victoria Clarke, *Successful qualitative research : a practical guide for beginners* (London : SAGE 2013) 48.

through the glass. A relativist position, such as interpretivism, on the other hand, is like looking through a small prison cell window; one gains only a partial view which one cannot test to check whether it is 'real' or not or to verify what is beyond our view.

2.3.1.2 DEFINING THE PARADIGM OF THIS RESEARCH

Understanding where my research sat on this theoretical spectrum began with a detailed consideration of my Research Questions. As set out earlier, the eight Research Questions covered a wide area, but the empirical aspect was most relevant to Question 2 (Intersectionality), Question 3(b) (Reasonable Adjustments), Question 4 (Recognition), Q5 (Access to Justice) and Q6 (Participation and Inclusion).

To answer these questions, my data needs to focus mainly on *understanding* rather than explaining, although there are aspects of both. Taking Research Question 3(b) as an example, my research seeks to understand whether, and how, participants subjectively experience reasonable adjustments in the workplace – which means seeking to understand not just *what* their recounted experiences are (have they had, or requested, adjustments?) but *how* the meanings of concepts like 'reasonable adjustment', 'disability' and 'disfigurement' in the minds of the participants have informed their approach to the workplace and their legal rights within it. While a straightforward recollection of experience and opinion could, on its own, lend itself to a positivist approach which attempts to report *what* participants think objectively, the need to understand *how* the participants make sense of their experiences requires the more nuanced approach of interpretivism, which aims rather to understand the subjective realities of individuals.

Acknowledging that my research questions required mixed types of data (both experiential 'whats' and sense-making 'hows') did complicate the choice of paradigm somewhat, but this was a feature of the fact that the empirical research formed one part of a larger legal project which had helped to determine its scope. Interpretivism offered the most research freedom to assess these mixed questions.

The second point to note about these Research Questions is that there was little existing research on most of the areas touched on, so an exploratory approach would be appropriate. Interpretivism is useful where, as here, there is little existing research on a topic[160] because, by encouraging rich data, it places fewer restrictions on the participants' accounts, meaning that unexpected data may lead to new insights. Qualitative research often tends to be categorised as inductive (data-driven) rather than deductive (theory or research question-driven), though examples of both approaches exist[161]. I felt that an inductive approach would fit well within the exploratory, interpretive framework.

Third, an interpretive paradigm offers a greater opportunity for the nuances and detail of participant accounts to be heard, which gives a useful counterbalance to the present near invisibility of people with a visible difference in discrimination case law.

In the light of these observations, an interpretivist theoretical approach was chosen, with a constructivist epistemology.

2.3.1.3 CONSTRUCTIONISM AND CONSTRUCTIVISM: DEFINING THE STANDPOINT OF THE RESEARCH

Having chosen a constructivist epistemology as a constituent part of my interpretivist framework, a crucial distinction in wider literature between social construct*ion*ism and social construc*tiv*ism must be addressed. The two have some aspects in common - in particular a belief that meanings are broadly socially constructed. Kenneth Gergen[162] gives the example of a bottle of water which, he argues, is a socially constructed concept based on our shared understandings of it; without these shared understandings, what we know as a bottle of water could

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[160] Anol Bhattacherjee, *Social Science Research: Principles, Methods and Practices* (Scholar Commons 2012) 105.

[161] For an example of an implicitly deductive (and explicitly theory-driven) approach in qualitative research, see Victoria Clarke and Megan Smith, '"Not Hiding, Not Shouting, Just Me": Gay Men Negotiate Their Visual Identities' (2014) 62 Journal of Homosexuality 1.

[162] Kenneth Gergen, 'Social Construction' (2010) <www.youtube.com/watch?v=-AsKFFX9Ib0accessed> accessed 23 April 2019.

equally be described by another name, or by nonsense syllables. I think this logic would make sense within both constructivism and constructionism, but the distinction between the two concerns the primary influence on these constructions.

The distinction is perhaps best thought of as the difference between the 'macro' and the 'micro'[163]. Constructionism focuses broadly on the idea that knowledge is socially constructed on a 'macro' level. Social constructionist research therefore often focuses on the ways that certain things are portrayed in the media and other institutions[164] or wider social discourse. This research stems from the work of Foucault and is often critically oriented and theory-driven, aimed at identifying, unmasking and exposing the oppressive nature of certain social concepts which persist largely unquestioned in wider societal structures. Burr argues that 'the concept of power is therefore at the heart of this form of social constructionism'.

Micro approaches (more accurately termed constructivism but there is some overlap in usage of the terms) focus more on 'micro structures of language use in interaction'[165]. The focus in micro constructionism is the individual learning and meaning-creation processes – what meanings things hold for people resulting from interactions, and how these influence their actions. Charmaz's approach is a good example of this constructivist approach; she argues that research sharing her approach "stress[es] social contexts, interaction, sharing viewpoints, and interpretive understandings"[166].

This micro definition is the approach adopted in this research because it fits with my aim of understanding how, and why, individuals position themselves in relation to their legal rights, and is aligned accordingly with an inductive (rather than theory-driven) approach.

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[163] Vivien Burr, *Social constructionism* (Third edition. edn, London; New York:Routledge 2015) 24.

[164] For an example of this approach, see Kirsty Budds, Abigail Locke and Vivien Burr, '"Risky Business": Constructing the "choice" to "delay" motherhood in the British press' (2013) 13 Feminist Media Studies 132.

[165] Burr (n163) 24.

[166] Kathy Charmaz, *Constructing Grounded Theory* (SAGE Publications Ltd 2014) 14.

2.3.1.4 RESEARCHER SUBJECTIVITY: ACKNOWLEDGING MY INFLUENCE

The impact of my own lens and context, as researcher, must be recognised within this interpretivist framework[167]. As a researcher who has been employed for a considerable number of years, I felt that it was unavoidable that I came to the research with preconceptions about how the world of work operates, as well as assumptions connected with my personal social context in 2019. All researchers inevitably bring particular biases with them resulting not just from their personal context but also more widely from the fact that we are all part of the society which is engaged in this process of knowledge construction.

What the interpretivist researcher can do to remove her socio-historic context is debated; Thomas Schwandt, for example argues that most interpretivists claim to adopt some kind of method to 'step outside their historical frames of reference'[168] and thus achieve an objective interpretation of the participant's subjective reality. Others (particularly, as here, in the realm of constructivism) suggest that researcher objectivity is impossible, 'like trying to step outside of our own skins'[169] and subjectivity should therefore be openly acknowledged and treated as a "resource (rather than a problem to be managed"[170]) . Lincoln and Guba use the term 'mutual shaping' to describe the impact of both the researcher's and the participant's value system[171].

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[167] Bhattacherjee (n160) 106; ibid 241.

[168] Thomas Schwandt, 'Three Epistemological Stances for Qualitative Inquiry' in Yvonna S. Lincoln and Norman K. Denzin (eds), *The Landscape of Qualitative Research* (3rd edn, SAGE 2008) 298.

[169] S Gallagher, 'Hermeneutics and education' in Norman K. Denzin and Yvonna S. Lincoln (eds), *The landscape of qualitative research* (3rd ed. edn, SAGE 2008), 301.

[170] Victoria Clarke and Virginia Braun, 'Using thematic analysis in counselling and psychotherapy research: A critical reflection' (2018) 18 Counselling and Psychotherapy Research 107, 107.

[171] Yvonna S. Lincoln, *Naturalistic inquiry* (Newbury Park : Sage 1985) 39.

I took a middle ground between these two positions; I engaged in reflection to identify the impact of my own subjective perspective, while at the same time recognising the naivety of claiming that objectivity and externality is possible.

As a researcher without a visible difference, my own positionality could have influenced the research. Equally, the potential impact of my gender, age, race, social class and other personal characteristics cannot be discounted. This potential impact could take a number of forms. First, factors such as the drafting of my participant advert, the photo accompanying my university profile webpage, or the sound of my voice during initial discussions prior to interview could have made some people more or less willing to participate. Second, the way that participants presented their accounts could have been influenced by their perceptions of me. By way of example, one participant, having recounted an experience of harassment, recalled using violence to end the situation, but then clarified that 'I don't go around walloping people anymore, by the way', which suggested a concern about being judged about the experiences recounted. Third, as a researcher working within an interpretive paradigm, my interpretations cannot be separate from my personal context, and what seemed more relevant to me in the data. See 2.3.1.5 below for a discussion of the methodological safeguards adopted in this regard.

2.3.1.5 INTERPRETIVISM AND LAW: NEVER THE TWAIN?

Some may see interpretivism as an unlikely choice for a legal project, because we are used to thinking of law as an objective, independent set of rules (though social constructionism would strongly dispute this!). An argument might typically follow that law cannot be criticised and evaluated according to the varied experiences of a small group of individuals, and should instead operate using objective, generalisable statistics to reflect the 'truth' of the majority of people within the group to which the law applies. I would counter this argument in a number of respects, however:

- First, generalisable statistics tend to lose the depth available through an interpretivist approach. A statistic that 'X% of visibly different people wanted reasonable adjustments' doesn't tell us what adjustments they wanted, why, how they related themselves to the concept of reasonable adjustment, whether the adjustments related to visible difference or other symptoms too, whether the adjustment needs changed over time, etc.

- Second, the legal provision on severe disfigurement does not allow a wholly objective approach; assessing severe disfigurement requires an implicitly normative assessment which is culturally specific (hence what is classed as severe disfigurement in one country or point in history may be different in others). In other words, legal concepts of disfigurement cannot be disassociated from their societal context, which the more sensitive touch of interpretivism is better placed to explore and understand.

- Although small qualitative samples make no claim to representativeness or objective 'accuracy', a well-designed research process builds in ways to minimise the risk of data being skewed by mistaken perceptions of particular events in individual accounts (such as a job applicant who perceives that she was refused an interview because of visible difference when, in fact, the interviewer had been unaware of her appearance). In this study the following measures were taken to this end:

    - the interpretivist approach adopted is comparative, meaning that data is viewed across participants and the researcher seeks to reconcile different accounts and synthesize themes. Charmaz argues that this comparative process 'offsets the negative effects of several misleading accounts and thus reduces the likelihood of the researcher making misleading claims'[172].

    - A well-prepared interviewer can, gently and respectfully, probe the participant's perception to encourage him / her to make sense of it, enabling the researcher to gain a greater understanding of the context and perhaps eliciting clarification from the participant[173]. The researcher's role is not to 'judge' as an arbiter of accuracy but to encourage the participant to clarify and reflect on their own reported perceptions.

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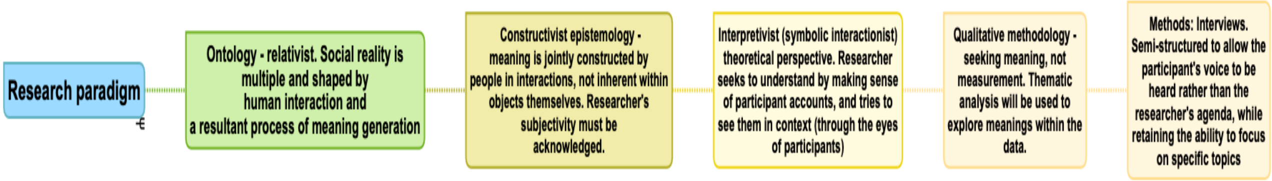
[172] Charmaz (n166) 89.

[173] Ibid 69.

- The researcher, in presenting research findings, needs to be clear about her epistemological stance[174], with statements such as ‘most of the participants had been refused an interview because of visible difference’ giving way to clearer statements such as ‘most of the participants perceived that they had been refused an interview because of their appearance’, and a greater interpretive focus on the interplay between perceptions of events, meanings, and future actions.

The paradigm adopted in this research is summarised below[175]



2.3.2 EMPIRICAL DATA COLLECTION METHODS

As outlined above, the research process in this study is qualitative – to encourage rich, detailed data. The research is not replicable in the sense that, if the interviews were conducted again, the same findings would not necessarily occur, because there may be differences occurring in the participants’ experiences over time, or between different groups of participants. Nor is it a satisfactory basis for generalisations, as the sample size is too small to be representative.

But qualitative research still needs rigor. *Lincoln and Guba*, for example, argue that interpretive research must meet four standards to prove its worth[176]:

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[174] Virginia Braun and Victoria Clarke, 'Using thematic analysis in psychology' (2006) 3 Qualitative Research in Psychology 77, 78.
[175] The breakdown in fig 1 is adapted from Michael Crotty’s book, with the exception of ontology, which Crotty sees as indistinguishable from epistemology. See Crotty (n152) 17.
[176] Lincoln (n171) 301.

- First, a degree of *dependability* should be possible in the analysis of the research; that is, that the research should provide sufficient details of the data set and interpretation process that another researcher would reach similar conclusions[177]. The analysis later in this chapter achieves this with a detailed description of both the process and interview data, which goes to the quality of the research overall.

- The interpretations reached should be *credible*[178] based on the data gathered and the methods used. While some of Lincoln's measures of credibility are more relevant for ethnographic observational research, others proved useful here. In particular, Lincoln encourages triangulation of results using different sources, which I fulfilled by combining a number of empirical interviews with a review of existing literature and an additional doctrinal analysis. This triangulation enables different perspectives to be compared and synthesized. I had originally hoped to add an extra point of triangulation by interviewing employers who had taken part in the Changing Faces Face Equality scheme about their experiences, as it was assumed that they would be likely to have engaged with relevant issues to some degree. Unfortunately, this proved not to be possible; the scheme has recently been discontinued by Changing Faces and none of the former business members that I contacted responded to requests for an interview. Other attempts to find employers who had engaged with issues relating to visible difference equality produced no viable options. I contacted both the EHRC and the Business Disability Forum but neither knew of any employers who had engaged with, or given significant consideration to, visible difference equality.

  It is sometimes appropriate to check the post-analysis credibility of research findings with participants too, but this was impractical here. This was partly for ethical reasons (to prevent participants being burdened in terms of time or being reminded of potentially distressing events for a second time), but also for practical reasons – as the analysis took place after data collection by a single researcher, there would be a considerable time gap of

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[177] Ibid 316.
[178] Ibid 301.

up to a year between the first interviews and the findings being ready, so it may not have been possible to reach participants again, or their views may have changed in the interim. Instead, during the interviews, I was careful to clarify ambiguous meanings by repeating back the point to the participant in other words and asking them to confirm whether I had understood correctly.

- The interpretations should be *confirmable*[179] (which ensures that the researcher has not placed inaccurate interpretations on top of the data, distorting the intended meaning; the researcher can prove her results). Confirmation suggests keeping records of the research process, including the raw data and the analysis[180], which I complied with in this study. In addition, the interpretive codes were kept fairly close to the original data, which helps to ensure that there is a confirmable connection between the data and the research findings; this is discussed further at 2.3.6.2. Several layers of checks between the raw data, its codes and resultant themes also helped meet this criterion – these are discussed at 2.3.6.2 below. A high number of quotations have been provided to evidence this credibility between data and analysis.

- Finally, the research must give sufficient detail for an assessment to be made of its *transferability*[181]. In other words, any contextual factors limiting the transferability of the data should be recognised. Important details which could affect this transferability in the present research include:

    - Geographical constraints – all participants were discussing their experience of working in the UK. As different legal systems have different provisions, this is an important contextual factor.

    - All participants had worked in the UK. Some participants had experiences reflecting a combination of employment, self-employment, voluntary roles and education, and my plan to unpick

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[179] Ibid 318.
[180] Ibid.
[181] Ibid 316.

these aspects in their accounts felt, in practice, both difficult and artificial. So, the data reflects predominantly experiences of employment, but with some periods of self-employment, education and voluntary work included for some participants.

- The nature and severity of the visible difference. Participants were asked to describe and self-rate their visible difference but no attempt was made at objective verification, so it is impossible to be sure whether the participants would have qualified as a disabled person under the Act at any time (see 2.3.3 below).

- Time periods – participants were asked about their experiences over their lifetimes. As some participants were now in their 50s, 60s and 70s, this meant that some recollections related to periods prior to the coming into force of the Equality Act (and even the DDA 1995).

Interviews were selected as the data collection method, because they allow a detailed shared understanding to be constructed and clarified. Interpretivism focuses on the use of language as a medium through which to understand participants' realities[182], so recorded interviews offer the chance to explore this in detail. Consideration was also given to other methods e.g. participant observation, which offers a stronger link with the participant's own context, but it was concluded that, in addition to ethical difficulties with this, it would be impractical gaining access to work environments, and many people would be unwilling to agree to this, making it harder to find participants.

Consistent with the inductive approach, a semi-structured interview format was chosen. Given the sensitivity of the topic, this also allowed me, as researcher, more flexibility to change the rhythm of the interview if the participant became upset, and the freedom to follow up interesting ideas as they arose in the discussion.

My question template was very much a guideline for my use, rather than a verbatim interview script. I was influenced in this by Charmaz, who argues that

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[182] Bhattacherjee (n160) 106.

inexperienced researchers should prepare a full interview guide to avoid 'using awkward, poorly timed, intrusive questions that you may fill with unexamined preconceptions'[183]. Consistent with an inductive approach, the questions are designed to direct the participants to a particular area, without leading them on what they feel is relevant to that area. However, more direct questions were included from time to time, as required, to probe a particular area or refocus discussion. This was felt to be appropriate provided that the more direct approach was, as it is here, recognised in research findings.

Constructivist interviewing is noted for being a consciously active process of meaning generation. Accordingly, the interviewing approach planned was one of "talking back"[184]which sought to encourage some degree of "two-way dialogue"[185] and a "more egalitarian exchange"[186] than often portrayed in interview settings within an objective framework. Holstein and Gubrium, for example, refer to the 'constitutive activeness of the interview process', as interviewer and interviewee interact and collaborate in meaning construction. The interviewer therefore has a role not just in recording the interviewee's thoughts but in 'activating, stimulating and cultivating' the interviewee's interpretations; she 'intentionally provokes responses by indicating – even suggesting – narrative positions, resources, orientations and precedents'… in order to 'activate the respondent's stock of knowledge'. Constructivist interviewing is therefore a far cry from blankly reading a set of predetermined questions off a sheet; it is a two-way engagement between interviewer and interviewee. There were moments during the interviews when I sensed this reflective, constitutive process in action. The following extract from Participant N's interview, for example, shows her re-evaluating her initial interpretations of experiences during the interview:

> PARTICIPANT N: "So, whether that was visible difference or whether that was because I was [public service employer], I couldn't pinpoint it down".

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[183] Charmaz (n166) 63.
[184] Gary W. Taylor and Jane M. Ussher, 'Making Sense of S& M: A Discourse Analytic Account' (2001) 4 Sexualities 293, 296.
[185] Ibid.
[186] Charmaz (n166) 86, in relation to intensive interviewing in a constructivist grounded theory framework.

> INTERVIEWER: “Yeah”
>
> PARTICIPANT N: “It’s only now that you’ve actually made me think about it…”
>
> INTERVIEWER: “Yeah”
>
> PARTICIPANT N: “… and I was never conscious of that being a problem”.
>
> INTERVIEWER: “No”
>
> PARTICIPANT N: “but that doesn’t mean to say it wasn’t a problem”.

And the following extract demonstrates Participant Q making sense of the concept of disability as it relates to her experiences, resulting in a slight shift in perspective during the interview:

> PARTICIPANT Q: “So I feel like I'm not bad enough to think of myself as disabled any more, really. Yes, it doesn't quite feel like the right category for me”.
>
> INTERVIEWER: “No? Okay. What about the wording of 'severe disfigurement'? Is that clear to you? Would you hear that and think either, ‘Yes, I am covered,’ or, ‘No, I know I'm not covered?’ Are there any observations about the wording of 'severe disfigurement' that's in the Act?”
>
> PARTICIPANT Q: “Yes, well, that's a tricky one, isn't it, because, immediately, when you say that, somebody like Katie Piper springs to mind, where you think that she, clearly, has got something that everybody would recognise as a disfigurement. I think, probably, the way I looked in the first half of last year, I would have felt like I looked as bad as that in a way; that it would have been obvious that there was something wrong. But I think when you get to the point I am now, where I don't feel quite right but nobody else would recognise it, I fall between the gaps somehow”.

> INTERVIEWER: “Yeah”
>
> PARTICIPANT Q: “It's like a bit of a grey area, because it's not just the fact that you're severely disfigured, but the problem somehow is (.) the way you feel about yourself has changed and that, actually, there are still some issues, sort of, physically. It's not just about looks with the facial palsy; it does affect things like eating and drinking, going out for meals and all those kinds of things that you didn't used to think about that actually become an issue for you. I guess if something is affecting you that much, it almost is a bit of a disability”.

This two-way interviewing process was factored into the design stage of the interviews, as advocated by McLachlin and Garcia[187]. Although it was relevant to my research to ask some more factual questions (such as ‘what happened…’ and ‘were you offered any adjustments at work?’), it was also important to move beyond factual description to access the meanings attributed to interactions. Epistemologically, this sense-making process was facilitated in planning questions which sought reflections, personal opinions, and reasons for particular decisions. This is demonstrated by the following question from the template:

> ‘Are you aware that someone with a severe disfigurement is classed as a disabled person for the purpose of non-discrimination law? [If you had known this, would this have changed the way you would have dealt with any work situations?]’

The first part of the question is designed to check awareness, and the second is designed to encourage reflection and meanings linked to experiences and motivations. The semi-structured interview format also enabled opportunities for underlying meanings to be seized as and when they arose, as demonstrated in action by the following transcript extract, in which the questions are aimed at understanding how the participant makes sense of the concept of disability and relates this to herself:

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[187] CJ McLachlan and RJ Garcia, 'Philosophy in practice? Doctoral struggles with ontology and subjectivity in qualitative interviewing' (2015) 195, 196.

> INTERVIEWER: “You said earlier, you said that, ‘I don’t know whether I fulfil the criteria of disability.’ Do you see yourself as disabled?”
>
> PARTICIPANT H: “ (.) I see myself as different. I feel myself as less- well, not a normal person because of it and therefore less worthy. Do I see myself as disabled? No, I see myself as disfigured. How you make sense of that, I don’t know [laughs]”
>
> INTERVIEWER: “Yes. What is it that disability means to you that means that you don’t see yourself as disabled?”
>
> PARTICIPANT H: “I guess a physical impairment more so, so issues with walking, sight, mobility issues. I can still function normally other than my face”.

2.3.3 FINDING PARTICIPANTS AND SAMPLING

No sampling frame of names was available to me of adults living in Britain with a visible difference. I was therefore not able (or ethically willing) to approach possible participants directly. Accordingly, a self-selecting sample was used by placing advertisements on message boards for people with a visible difference (or with specific medical conditions likely to produce visible difference). In addition, various charities were approached and asked to advertise the search for participants to their members. The advertisement used is shown in Appendix 1, although some of the charities chose to present the information in their own format. The table below shows the location of the advertisements and the responses generated.

Advert location	**Medium**	**Initial responses from potential participants**	**Consent forms returned**	**Participant interviews conducted**

Birthmark Support Group UK	Social Media	0	0	0
Changing Faces	Social Media	2	1	1
Cleft Lip and Palate Association	Website and social media and newsletter	5	4	4
Facial Palsy UK	Website and social media	11	7[188]	7
Headlines Craniofacial support group	Website and social media	0	0	0
Nerve Tumours UK	Website and social media	8	4	4
Poppy Factory	Noticeboard	0	0	0
Psoriasis and Psoriatic Arthritis Alliance	Website and emailed to willing participants list	1	1	1
Psoriasis Association	Website and social media	1	1	1
Saving Faces	Website	0	0	0

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[188] One interview was excluded from the final data set due to a misunderstanding during the interview which only became apparent on reading the transcript. I had misinterpreted the interviewee's rating of her severity and felt concerned that this may have impacted on the interaction of the rest of the interview.

Talkhealth forums on: general health / acne / scars and wounds / psoriasis / rosacea / eczema / British Skin Foundation (permission obtained from moderator)	Online message board	0	0	0
Vitiligo Society UK	Social media and newsletter	0	0	0
Unclear where seen		2	0	0

A further five charities were contacted but either did not respond or did not advertise. An anonymous breakdown of the participants is provided at Appendix 3.

One potential limitation of this methodology is that the people in contact with these charities or message boards are perhaps likely to be either people who are active in disability rights campaigning, which may affect their perceptions, or those who feel in need of support. However, while recognising this risk, the data gathered was quite mixed, with a number of participants reporting very positive work experiences, despite being in contact with support organisations. A snowball methodology was considered to try to widen the sample – however in the context of visible difference this was felt to be ethically untenable, as it could create awkwardness or upset for anyone approached as a result. For the same reason, offers made by participants to ask friends to join the research too were not accepted.

The target group of participants was adults living in the UK with a visible difference who had experience of the workplace or the job market. One challenge was how to ensure that those who responded to the advert fell within the target group. The advertisement included a definition of visible difference as 'any condition or injury which alters appearance' to try to reduce misunderstandings, as the term visible difference could perhaps be construed more widely to include racial and religious differences of appearance. But this does not completely remove the risk that participants may (deliberately or mistakenly) respond without falling within the target sample group. I felt that it would be inappropriate to ask people at the recruitment stage for details of their visible difference – especially prior to the consent process having been completed. So, the research design meant waiting until interview to clarify the existence of a visible difference by asking the participants this (though some had volunteered this information in their initial emails). Although during some face to face interviews the difference could be observed by the researcher, to ensure both consistency and respect in all cases, the description was provided by the participant.

A further difficulty arose with whether, and how, to categorise a difference either in terms of severity, visibility, or type. The law imposes a threshold of severe disfigurement – but it was not clear whether any of the participants being interviewed would be likely to meet this threshold despite all of them reporting a visible difference of some kind. It would be both unethical and impractical[189] to try to 'verify' or judge the disfigurement in any way, whether through medical evidence or observation. Participants were therefore asked to self-rate their disfigurement in terms of its visibility and severity. This was the right choice as it enabled the researcher to take a non-judgmental standpoint which could otherwise have damaged the rapport of the interview and been distressing for the participants. (One participant, for example, expressed worry before the interview that she would be asked to provide a photograph if it was conducted by telephone). One limitation of asking participants to self-rate their severity, however, is that there is no way of

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[189] In their study, Rumsey et al only managed to obtain independent severity ratings from medical sources for 42% of participants. See Nichola Rumsey and others, 'Altered body image: appearance-related concerns of people with visible disfigurement' (2004) 48 Journal of Advanced Nursing 443, 445.

telling whether the participants would have fallen under the ‘severe disfigurement’ provision in the Equality Act 2010, which imposes a primarily objective, not subjective, test of severity.

2.3.3.1 ETHICS, INFORMATION AND CONSENT

Prior to placing the advertisement, the empirical research design was put before the University’s Ethics Committee. The topic of the research was sensitive, meaning that considerable care was needed to ensure that the research design minimised any possible upset or harm to the participants. The Ethics application listed a number of steps taken to do so, including:

- Ensuring an informed consent process with participants given plenty of time to ask questions and make up their mind before signing up.

- A relaxed, informal, friendly approach to interviews, with participants being informed that they can withdraw or refuse to answer particular questions without consequence, and the option to have a friend present throughout.

- A flexible approach to semi-structured interviewing, enabling the researcher to adjust topics of discussion to prioritise the welfare of the participant if needed.

- Participants were offered the opportunity to be kept informed of findings, to understand the purpose and result of their involvement.

- Participants were offered an information sheet containing contact details of support organisations and resources for free legal advice on related topics.

- A follow-up interview was offered in case participants wanted to clarify any points after the event. One participant took advantage of this offer and one other emailed additional thoughts to me after the interview.

- Subject to geography, participants were offered a choice of either telephone or face to face interviews in their home[190]. I chose to offer a home interview where geographically practicable so that participants could choose an interview venue and medium where they felt most comfortable. In three cases, a separate external meeting room was arranged to allow a face to face private meeting in a quiet public venue. This helped reassure any participants who preferred a face-to-face interview but who may have been nervous allowing a researcher into their home.

Once a response to an advertisement was received, the potential participant was provided with a copy of the participant information sheet by post or email (or both, depending on their preference). In most cases, it was also possible to make telephone contact with the potential participant to answer any questions about the research before the consent form was signed and returned. If telephone contact was not made, or the participant chose to return the consent form before telephone contact was made, the participant was given a further opportunity to ask questions in the pre-interview discussion. 18 out of 30 initial responses returned the signed consent forms. A PO Box was set up for this purpose, to ensure that my private address was not used and there was no risk of consent forms being opened by others in the University's post system. The key information (including the ability to stop the interview at any time or refuse to answer specific questions) was also reiterated verbally at the beginning of the interview.

5 face to face interviews were conducted and 13 telephone interviews. The interviews were recorded (with the participants' explicit consent, both written and verbal) and transcribed – some by me and some by a remote transcription service (all were checked by me).

2.3.4 DATA SECURITY DURING THE RESEARCH PROCESS

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[190] A risk assessment was conducted which included safeguards for home visits, given the need to protect my safety as well as that of the participants.

Given that the interviews contained sensitive personal data relating to health especially, considerable planning went into ensuring data security in the research. Measures included:

- Use of participant codes rather than names
- Ensuring that the transcription agency had signed the appropriate data sharing agreement and the University's confidentiality terms (this was done in conjunction with the University's legal service and Information Governance teams)
- Relevant documents were password protected, with encryption and anti-virus measures put in place.
- Regular back-ups of information onto an external hard-drive
- Names and addresses of participants were stored in hard copy in a locked safe separately from data gathered.
- Once received, transcripts were anonymised (both for names, exact ages, and identifiable job information).

2.3.5 REFLECTIONS ON THE DATA GATHERING PROCESS

As a first-time qualitative researcher, the research process yielded significant learning points to me. First, the wording of the research advertisement is crucial to the hunt for participants. My initial advertisement wording was brief and relatively formal, and produced few volunteers. After a number of months, one charity requested a less formal 'blog' to accompany it. This was an opportunity to explain more about the research process and aims. Providing this level of detail had a much higher success rate in terms of enquiries. I therefore supplied a similar blog to a few other charities and this helped in recruiting participants (see Appendix 1).

The wording of the advert is also important to help participants understand the scope of the study. One early volunteer declined to participate, indicating that she didn't think her contribution would be valuable as she hadn't experienced any problems at work – her assumption from a 'neutral' advertisement was that I was only looking for people who had had problems at work. Thus in the 'blog' wording I was clear to point out that *all* experiences are useful, not just negative ones. Again, this seemed to reassure people that all contributions would be welcomed, and helped to make the research more balanced.

Second, I became aware that the anticipated interviews were, for some participants, a source of anxiety. I therefore began trying to reassure participants in advance that the process was informal and that they could control which questions they answered, to help alleviate any anxiety before the interview. This is one reason why I believe that initial contact by telephone was an important aspect of the research design, despite on occasions being logistically difficult to achieve. Many seemed to relax once they had spoken to me and I had explained the process informally.

Third, I became aware, after the first interviews, that my determination not to upset anyone was at risk of skewing (or eliminating) one aspect of useful data. In assessing whether they were aware that someone with a severe disfigurement could be classed as disabled under the Equality Act 2010, I would often preface saying the words 'severe disfigurement' with a phrase such as 'and I don't like this wording but it's what the Act says' in an attempt to prevent upset or damage to my rapport with the participant. However, this meant that I was unable to gather any unbiased data about what the participants themselves felt about the wording, which would have proved useful. In later interviews, I therefore toned down my approach – referring simply to 'the Act's wording' without expressing personal views of it.

Fourth, there is a delicate balance, in qualitative interviewing, between gaining useful data, prioritising the welfare of participants, and avoiding leading the interviewee's responses. I found this more challenging than I had anticipated in a number of respects:

- The subject matter was extremely sensitive and I was very conscious of the priority not to upset participants or make them feel awkward. Keeping a dialogue going, with plenty of 'Mmms' and 'yeahs' felt like a natural way to approach this. While I don't believe that my supportive interjections influenced the content of what the participants said (and indeed some researchers actively encourage such verbal engagement[191]), I would, on my next project, try to limit this, both to avoid giving the appearance of confirming a particular perception, and to avoid interrupting the flow of participant dialogue.

- My desire to be supportive was on occasions more express too – when people were recounting emotionally difficult experiences, I felt compelled to acknowledge and express understanding of their emotion, as demonstrated by the following extract:

> PARTICIPANT J: "…they were definitely mocking me, yes".
> INTERVIEWER: "…your palsy? Gosh, that sounds a horrible environment to work in".
> PARTICIPANT J: "Oh, it was awful".

This was perhaps particularly acute during telephone interviews, when the lack of visible body language made verbal support feel more vital. Reflecting on this, I feel that, while the need to support participants was critical, I could have done this differently on occasion. With this in mind, in future research, I will be mindful of thinking of phrases which are supportive but still neutral.

- I was very conscious of the words that I used during the participant recruitment and interview process too – referring, for example, to visible difference rather than disfigurement. While on balance I feel this was the right decision, I did notice a definite disadvantage of this. 'Visible difference' is a term used widely by relevant charities but is perhaps rather ambiguous; while I was using it as a more sensitive way of describing the concept of disfigurement which appears in the law, some participants seemed to define it differently, using it to distinguish simply between conditions which can be

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[191] Charmaz (n166) 91.

seen (such as mobility impairments which cause limping) and conditions which are invisible. This reflection is relevant in terms of any reframing of the law, where clarity is vital.

- I became conscious during some interviews that some of my questions were assuming an unrealistic level of familiarity with concepts and terminology. By way of example, one of my planned questions was “Have you adopted any techniques / strategies to deal with visible difference at work? Have they been effective?” It soon became clear to me that, while ‘coping strategies’ are a recognised concept in existing research, some participants might not understand what this question meant. Next time, I would bear this in mind the need to avoid specific terminology when drafting the question template.

- As the interview process progressed, it was interesting to hear some common themes mentioned by participants cropping up repeatedly. But, as noted by other researchers, it is then difficult not to allow discussion in later interviews to be unintentionally informed by this knowledge, especially given the emphasis in constructive interviewing on fully exploring emergent themes from earlier interviews. It is surprisingly difficult to explore a theme without giving any clues about what the theme is! But a related strength that I believe I demonstrated during this process was the ability to focus intensively on what the participants were saying, able to follow up new points or areas of discussion which lacked clarity as they arose, rather than sticking rigidly to a pre-determined list of questions. While sometimes I recognise that I could have phrased a question better, this has to be balanced against the added clarity that came from probing unexpected comments when they occurred, which often led to a deeper and clearer understanding. I do feel that my abilities as a qualitative researcher developed during this period partly thanks to the self-reflection encouraged by the interpretive paradigm adopted.

2.3.6 DATA ANALYSIS METHODOLOGY

A number of possible data analysis strategies were considered, including various forms of text analysis (such as Content Analysis, Discourse Analysis or Conversation Analysis) and two were identified as meriting deeper investigation. The first was constructivist grounded theory (as proposed by Charmaz) and the second was the version of thematic analysis proposed by Braun and Clarke[192], described as "a method for systematically identifying, organizing, and offering insight into patterns of meaning (themes) across a data set"[193].

These two approaches have much in common. They can both be used inductively[194], allowing the data to speak rather than imposing existing ideas or theories onto it. Both rely on multi-stage coding analysis which involves breaking down the text into fragments, categorising them, and interpreting them to identify meanings. Both recognise the subjectivity of the researcher's presence in the interview and both describe an iterative, rather than linear, process, so that the researcher moves from data to analysis and back again as required.

But there are also differences. Grounded Theory, even the more 'modern' version proposed by Charmaz, has more 'rules' than Braun and Clarke's model, such as encouraging the researcher to adopt theoretical sampling and sensitizing concepts. Given the practical and ethical constraints in my context, this made grounded theory feel like a 'riskier' choice. For example, I didn't know at the beginning of the project what theories I might interpret in the data and what theoretical sampling this would then require – which raised ethical and practical uncertainties of seeking further targeted data given that University Ethics approval needed to be granted based on a specific research design. In addition, while grounded theory seeks to develop theory, thematic analysis aims to develop themes. Given that my interviews needed to touch on three specific areas – experiences of the workplace / job market, reasonable adjustments and access to justice – I felt that the challenge

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[192] Braun and Clarke (n174). Braun and Clarke argue that thematic analysis should be seen as a method rather than a methodology because it can be used within multiple frameworks – see ibid 108.

[193] Virginia Braun and Victoria Clarke, 'Thematic Analysis' in H Cooper (ed), *APA Handbook of Research Methods in Psychology* (The American Psychological Association 2012) 57.

[194] Braun and Clarke's approach to thematic analysis can be used either inductively or deductively, as it is a method which comes without a bounded theoretical perspective, enabling the researcher to determine her own accompanying paradigm.

of identifying overarching 'theory' might risk pushing my data into generalisations which could not be justified, whereas themes allowed greater potential to deal with multiple topics. Grounded Theory's argument that the literature review should be postponed until after data collection was also impractical in my context, as I had done significant reading before commencing my PhD.

Of even greater practical relevance was grounded theory's engagement with theoretical sampling (a requirement that the researcher should be able to return to the interview arena on multiple occasions to investigate emerging themes, until no new themes emerge). While I would have valued being able to do this, it became clear early in the participant recruitment process that theoretical sampling assumed a ready supply of willing participants which could be accessed at different points over the course of the research. Despite the research being widely advertised as set out above, finding potential participant volunteers was extremely hard, and it became obvious that I couldn't rely on being able to return to the field at my convenience as the research progressed.

I was concerned, in selecting a data analysis method, to ensure that my method of analysis would enable my research to be credible. Braun and Clarke initially acknowledged (in 2006, when their first paper on this topic was written) that thematic analysis did not have the recognisable prestige of grounded theory, as it was rarely specifically acknowledged as a method in its own right. However, that position has changed, with their version of thematic analysis achieving increasing 'brand recognition'[195] over the last few years. Of particular relevance, I had already noted several papers since 2006 which specifically adopted this method in the area of appearance research, suggesting that it had since gained momentum within the field of my research. I also noted that, although grounded theory was a well-respected approach, Charmaz's constructivist version had proved contentious with some in the academic community, who disputed its logic for departing from the tenets of classic grounded theory. Thematic analysis was therefore selected as the appropriate tool for analysis.

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[195] Virginia Braun and Victoria Clarke, 'Teaching thematic analysis' (2013) 26 The Psychologist 120, 120.

Whereas Grounded Theory is a methodology which comes complete with its own theoretical underpinnings, thematic analysis is best described as a method. This makes it very flexible, able to be used in a variety of contexts. It also forces the researcher to engage actively in the theoretical assumptions underpinning her research, ensuring that all aspects, from the research questions, to the ontological and epistemological position, to the methods and process of analysis, are sufficiently aligned (as set out above). As a researcher new to these methods, this process was certainly difficult but ultimately useful.

The model of thematic analysis proposed by Braun and Clarke offers a six-stage approach to evaluating the data. In brief, these six stages guide the researcher through the process of line by line analysis of the data, creating 'codes' to explain what is important about fragments of data. These codes are then reworked, refined, and grouped to develop structured themes. The themes, and their relationship to each other, form the backbone of the written analysis created from the data. Each stage of the process, and how it applied to this research, is set out below.

2.3.6.1 STAGE 1: FAMILIARISATION WITH THE DATA

I felt at an advantage in this respect, having conducted all the interviews myself. I also transcribed many of them myself, which boosted my familiarity with the data even further. For those interviews which were transcribed by a third party, I read through each transcript, often several times, while listening to the audio, both to check its accuracy and to listen to subtle intonations which would not be picked up by the written transcript. While third party transcription was good, it often left out some conversational interjections such as 'erm' and 'yeah' which I felt it helpful to include and which were therefore added back in at this stage. Research stresses that the transcription process is itself interpretive, so ensuring that all the transcripts were clear and followed the same transcription code was important. The main codes used in transcription, mostly borrowed from Braun and Clarke[196], were:

(.)	small pause

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[196] Braun and Clarke (n159) 224.

(pause)	long pause
…	continued sentence

2.3.6.2 STAGE 2: GENERATING INITIAL CODES

I used Nvivo software to help with analysing the interview transcripts. Prior reading had given me some ideas of how to approach this, but the process also evolved over time. My coding approach took place in three stages:

a) Creating a 'case' for each participant. This involves recording key data (such as age, type of visible difference etc) against criteria created by me. This is useful because it means that, when analysing the data, it can be searched according to a particular criterion – e.g. what were the experiences on recruitment of those participants aged over 50?

b) Collating 'bucket' themes (domain-summaries). As set out above, despite using an inductive process overall, the legal framework of my research had already produced a number of topics which I was keen to explore, such as reasonable adjustments, access to justice, discrimination experiences etc. The second step of working on a particular transcript was therefore to categorise fragments of text to the relevant domain-summaries. This was not 'coding' but a deductive process of collating information relevant to the topics identified in chapters 1 – 3. There was no interpretation involved here but, once complete, it acted as a useful 'check' against my coded data to ensure that I had considered all data extracts and ideas relevant to a particular topic.

c) Inductive coding. This involved working through each data item and applying open codes to summarise what is interesting about particular fragments of text. Codes are "the building blocks for themes, (larger) patterns of meaning, underpinned by a central organizing concept – a shared core idea"[197]. Braun and Clarke identify two types of coding: semantic and

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[197] Victoria Clarke and Virginia Braun, 'Thematic analysis' (2017) 12 The Journal of Positive Psychology 297, 297.

latent[198]. The decision on whether to apply primarily semantic, or latent, codes should be determined by the nature of the research aims. Hence it needs to be considered as part of the overall research paradigm. Semantic codes involve summarising and interpreting the fragments of text to understand what the participant explicitly chose to say. Latent coding involves looking beyond the explicit coding for evidence of underlying deeper themes. Semantic coding is appropriate where the aim of the research questions is to understand experiences, views and choices. It will often be appropriate where the overall approach is inductive because "the codes and themes derive from the content of the data themselves – so that what is mapped by the researcher during analysis closely matches the content of the data"[199]. Latent coding, on the other hand, is a better choice for getting at underlying patterns (such as, for example, the social forces which determine particular meanings). Latent coding is often performed deductively where the researcher is interested in a particular theory which she is looking to develop, prove or disprove, so "what is mapped by the researcher during analysis does not necessarily closely link to the semantic content of the data"[200].

By way of example, assume a fictional interview transcript in a study about healthy eating and obesity. The participant comments that 'Except at Easter, I try only to eat one Crème Egg per day because, obviously, we all have to watch our cholesterol and things'. If the study aims to understand the experiences and views of participants on this topic, semantic coding would aim to summarise and interpret this fragment of text. The coding might therefore be something like 'limiting unhealthy food choices because of health' or 'health concerns constraining food choices except at times of celebration'. If, on the other hand, the aim of the research were to understand how social constructs of obesity and healthy food are generated, a latent code might focus on what *makes* the participant say this. Latent coding might therefore focus more on the sense of embarrassment or guilt which seems to be implicit in the participant's justification in that sentence,

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[198] Braun and Clarke (n174) 84.
[199] Braun and Clarke (n193) 58.
[200] Ibid.

or on the perception that times of celebration can be used to justify departure from socially acceptable food norms.

Given that many of my research questions focus on the experiences and views of participants, the content of their accounts was relevant and therefore semantic coding was the appropriate choice. That said, Braun and Clarke acknowledge that some degree of flexibility may sometimes be required and accordingly I kept an active eye on the data and on a few occasions felt justified adopting a slightly more in-depth, rather than semantic, code. This can be seen particularly in relation to the coding relating to self-identity and its relationship with disability.

Once all data had been coded, I spent some time reviewing the codes and merging some which had, in essence, been duplicated. At this stage I had approximately 550 codes across 17 interview transcripts.

The process of coding was necessarily reflexive; focusing on what was important in a particular extract of data involved my assumptions, perhaps informed by pre-reading of earlier research, suppositions about what I might find, and as the process went on, expectations resulting from earlier interviews. In reflecting, I sought to acknowledge my role in the creation of the meanings, but also to minimise the risk of being pushed too far away from the data. I found it helpful often to code in gerunds, as advocated by numerous researchers[201], to keep the focus on what is happening in a particular piece of text rather than producing a descriptive category of it.

2.3.6.3 THEME DEVELOPMENT AND THEME REVISION (STAGES 3 AND 4 RESPECTIVELY)

The third and fourth stages proposed by Braun and Clarke are theme development and, latterly, theme revision. This involves re-organising codes and seeking to identify key themes from the codes. This was time-consuming

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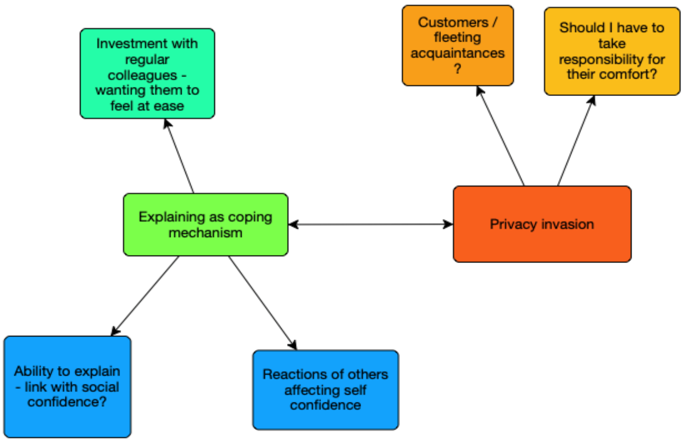
[201] See, for example, Charmaz (n166) 120.

because it was helpful to return to the original coded data extracts rather than simply relying on my codes, hence the process involved some backwards steps at times.

Braun and Clarke's guidance on theme development involves much more than simply grouping codes; themes have to be clear, identifiable, and avoid overlap. Braun and Clarke advocate for the identification of a central organising concept as a way of achieving clarity on the essence of a proposed theme. I found this a helpful, if time-consuming, way of creating and revising my themes. My themes were reorganised numerous times until I felt that they captured what was important in the data and worked together to create a picture of the relevant data. The second theme of *Coping, explaining and privacy*, for example, originally formed part of Theme 1, but during the revision process I separated it out to recognise the importance of this process in its own right.

I used memo-writing as a way of identifying potential themes too, which I found to be a helpful way to keep track of ideas and possible links. I wrote a memo relating to each interview transcript. Having created my themes, I returned to these memos as a way of double checking that my themes represented what had stood out from each interview when I had conducted it. This led me to make a few tweaks to bring out certain aspects of my themes, though reassuringly, it also reaffirmed the essence of the themes. I also occasionally used diagrams as a way of mapping the themes emerging from my research process. By way of example, the short diagram below helped to clarify for me the relationship between the common theme of explaining one's difference to manage the reactions of others, and feeling that one's privacy has been invaded by having to explain. The 'bubbles' around the outside highlight some of the factors which influenced these themes (e.g. seeing explaining to colleagues as an 'investment' as opposed to fleeting contact with customers). There was such variety in the data gathered that these diagrams are not attempting to reflect all of the relevant information, but simply to conceptualise the relationship between some major themes and sub-themes



2.3.6.4 DEFINING AND NAMING THEMES (PHASE 5)

The fifth stage is to define and refine the identified themes, working out what their essence is, and finding a "concise punchy" name for them[202]. This involves going back to the data extracts within each theme and ensuring consistency and alignment. At this stage, as advocated by Braun and Clarke, I wrote a detailed memo describing the meaning of each theme and how it related to wider patterns in the data. As my data set was relatively large and detailed, I found this quite difficult, because I simply couldn't include every idea raised in my theme descriptions – I had to select those which I felt were stronger or which provided a better insight into my topic. This process of picking and choosing felt a little unnatural but was essential to prevent the themes from becoming simply glorified lists of everything that had been said, which would have lacked meaningful coherence. Choosing what to leave to one side was therefore often harder than choosing what to focus on.

2.3.6.5 PRODUCING THE REPORT (PHASE 6)

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[202] Braun and Clarke (n174) 92.

This stage involves telling "the complicated story of your data in a way which convinces the reader of the merit and validity of your analysis"[203]. Extracts, where used, must accompany, not replace, the analytic story and interpretation of the data.

I felt slightly conflicted in writing up; on the one hand, quoting some of the more sensitive, personal moments of the interviews would help to make the research report stand out and show how much it means to some of those involved. On the other hand, I felt that some of these extracts were too personal to quote, particularly without the context which surrounded them. I resolved this conflict by forcing myself to consider what was relevant about a particular piece of data. If other data extracts illustrated the point equally, there was no justification for 'sensationalising' the point by using the more emotional quotations.

I chose to refer to the participants in my report using letters (e.g. Participant A) rather than pseudonyms to maintain gender anonymity where possible, given that only two of the participants were male.

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[203] Ibid 93.

2.4 CHAPTER 2 SUMMARY

This Chapter has explained why the Research Questions require a combination of methodological approaches, and has explained those approaches in both theoretical and practical terms. My literature review is contained in Chapter 3, and the findings of my doctrinal and empirical research are set out in Chapters 4 and 5 respectively.

3. LITERATURE REVIEW

3.1 CHAPTER INTRODUCTION

The literature summary is divided into three areas of focus:

i. An evaluation of the psychological impact, or 'the view from the inside'[204];
ii. An analysis of the social consequences; the 'view from the outside…how appearance influences social perceptions and interactions'[205]; and
iii. An analysis of equality law relating to visible difference at work.

The remaining chapters of the thesis focus on iii above, but i and ii provide important background of the lived experience, to enable evaluation of the extent to which law connects with reality.

It should be noted that there is considerable overlap between i and ii above due to interaction between the experiences of an individual within society, and her psychological state. Grey areas frequently appear with concepts like 'social anxiety', 'felt stigma' and 'fear of negative evaluation by others' which suggest a deep interaction between the two dimensions'[206]. While attempting to deal with both the psychological and social dimensions of disfigurement, this thesis recognises a degree of fluidity between the two.

3.2 LITERATURE REVIEW: PSYCHOLOGICAL IMPACT

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[204] Andrew Thompson and Gerry Kent, 'Adjusting to disfigurement: processes involved in dealing with being visibly different' (2001) 21 Clinical Psychology Review 663, 664.

[205] Ibid.

[206] Gerry Kent and Steve Keohane, 'Social anxiety and disfigurement: The moderating effects of fear of negative evaluation and past experience' (2001) 40 British Journal of Clinical Psychology 23, 24.

3.2.1 COMMON PSYCHOLOGICAL CONSEQUENCES OF DISFIGUREMENT

Numerous studies have attempted to measure the psychological impact of disfigurement. Emma Robinson notes “a host of psychological problems, including social anxiety, lowered self-confidence, negative self-image, depression and lowered self-esteem all of which can have a cumulative effect on future interactions”[207]. For example, Jowett and Ryan found that 61% of hospital outpatients with longstanding skin disorders experience anxiety, and 29% also suffered from depression[208]. (Methodological considerations suggest that this data needs further probing, though: first, the findings were based on the participants’ expressions of emotional impact rather than clinical criteria, and second, the findings were not moderated by reference to a control group to compare self-reported levels in the general population, which may have helped to contextualise the data.)

Newell and Marks[209] found that people with facial disfigurements displayed fear questionnaire scores equivalent to people with social phobia (though the authors admit that the validity of this finding would have benefited from triangulation through other methods, as questionnaires alone do not provide a complete picture).

Research also demonstrates how *expectations* of a negative response from others (from participants who wrongly believed themselves to be wearing a simulated disfigurement in a social situation) can alter the individual’s perception of events[210], reinforcing the subjectivity of methodologies based exclusively on participants’ reported experiences.

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[207] Ibid 103.

[208] Sandra Jowett and Terence Ryan, 'Skin disease and handicap: An analysis of the impact of skin conditions' (1985) 20 Social Science & Medicine 425, 427.

[209] R. Newell and I. Marks, 'Phobic nature of social difficulty in facially disfigured people' (2000) 176 The British journal of psychiatry : the journal of mental science 177, 177.

[210] Robert E. Kleck and Angelo Strenta, 'Perceptions of the impact of negatively valued physical characteristics on social interaction' (1980) 39 Journal of Personality and Social Psychology 861, 871.

Despite strong evidence of psychological distress in some studies, other research has found little psychological impact from visible difference and many people coping well[211].

3.2.2 EXPLAINING VARIANCE IN PSYCHOLOGICAL OUTCOME

Research has questioned why some people ‘cope’ with disfigurement better than others. Some explanations focus on the individual, such as:

- the use of **coping strategies** to combat stigma (e.g. avoidance, hiding the disability or downplaying it[212]);

- **resilience**, or positive factors which ‘appear to buffer a person against the stresses and strains of living with a visible difference’[213], such as family support, faith, humour, sense of self, social skills, determination and networking[214]. (Research also demonstrates, however, that even those who have such resilience can falter at times, either with sporadic bad days or more sustained periods of poor coping[215]. The law needs to be flexible enough to deal with fluctuations in the emotional impact of disfigurement);

- the role of the **self-schema** (the way an individual conceives appearance, which can ‘guide the processing of self-related information contained in an individual’s social experience’[216]); and

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[211] Katie Egan, Diana Harcourt and Nichola Rumsey, 'A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference' (2011) 16 Journal of health psychology 739, 740; I.K. Carlsson, L.B.Dahlin, and H.E.Rosberg, ‘Congenital thumb abnormalities and the consequences for daily life patients’ long-term experience after corrective surgery: A qualitative study’ (2018) 40(1) Disability and Rehabilitation 69, 81. See also William Eiserman, 'Unique Outcomes and Positive Contributions Associated with Facial Difference: Expanding Research and Practice' (2001) 38 The Cleft Palate-Craniofacial Journal 236, 237.

[212] Goffman (n17) 125.

[213] Rumsey and Harcourt (n140) 86.

[214] Marion D. Meyerson, 'Resiliency and Success in Adults with Moebius Syndrome' (2001) 38 The Cleft Palate-Craniofacial Journal 231, 233.

[215] Egan, Harcourt and Rumsey (n211) 745.

[216] Hazel Markus, 'Self- schemata and processing information about the self' (1977) 35 Journal of Personality and Social Psychology 63, 64.

- differing levels of **adjustment** relating to the age of acquisition of a disfigurement. People who develop their self-image before an acquired injury, have sometimes been found to experience higher levels of distress[217] than those who are born with it from a young age. However, variation exists here too[218], with different methodologies and different disfiguring conditions making it hard to pinpoint why. Blanket distinctions between congenital and acquired conditions are also complicated by the progressive or fluctuating nature of some conditions (such as NF1 and psoriasis respectively).

Other studies have sought to explain variable coping by reference to the disfigurement itself:

- It is often assumed that the worse the disfigurement, the worse the psychological impact. However, this is unsupported by a large body of research[219]. As one Professor of Plastic Surgery remarked, '… the impact on a patient is not proportional to the magnitude of the disfigurement … as many tears may be shed in the doctor's surgery as when confronting a fatal illness"[220]. Some researchers have suggested that the anticipation of negative reactions can be worse for those with an objectively mild disfigurement, because such reactions are intermittent rather than constant[221], but this is a moot point[222].

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[217] Bethany A. Jones, Heather Buchanan and Diana Harcourt, 'The experiences of older adults living with an appearance altering burn injury: an exploratory qualitative study' (2017) 22 Journal of Health Psychology 364, 369.

[218] S. L. Versnel and others, 'Satisfaction with facial appearance and its determinants in adults with severe congenital facial disfigurement: A case-referent study' (2010) 63 Journal of Plastic, Reconstructive & Aesthetic Surgery 1642, 1646.

[219] Frances Cooke Macgregor, 'Social and Psychological Implications of Dentofacial Disfigurement' (1970) 40 The Angle Orthodontist 231, 232.

[220] D. A. McGrouther, 'Facial Disfigurement: The Last Bastion of Discrimination' (1997) 314 BMJ: British Medical Journal 991, 991.

[221] Frances Cooke Macgregor, 'Facial disfigurement: Problems and management of social interaction and implications for mental health' (1990) 14 Official Journal of the International Society of Plastic Surgery 249, 252.

[222] Marijke E. P. Van Den Elzen and others, 'Adults with congenital or acquired facial disfigurement: Impact of appearance on social functioning' (2012) 40 Journal of Cranio-Maxillofacial Surgery 777, 781.

- Despite a significant body of research suggesting that *visible* disfigurements (especially facial) are a more reliable indicator of psychological distress than those which can be hidden[223] (which is a principle reflected in the Guidance on the Equality Act – see 4.5.1) this is not universally accepted, with other studies finding no link between the visibility of the bodily location and greater distress[224]. Certain findings that disfigurements on the torso caused more distress for women[225] (perhaps due to ongoing anxiety about it being revealed[226], or the sexual significance of the female torso[227], or because hiding the problem prevents psychological adaptation[228]) also highlights an interaction between gender and disfigurement. So, the common assumption that facial disfigurements are the hardest to cope with is not always reliable.

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[223] See, for example, Kent and Keohane (n206) 30.

[224] Timothy P. Moss, 'Individual differences in psychological adjustment to perceived abnormalities of appearance' (PhD research thesis, Plymouth University 1997) 186.

[225] Ibid 187; Nichola Rumsey et al, 'Factors associated with distress and positive adjustment in people with disfigurement: evidence from large multi-centered study' (undated, unpublished) cited in Timothy P. Moss and Ben Rosser, 'Adult Psychosocial Adjustment to visible differences: physical and psychological predictors of variation' in Nicola Rumsey and Nicola Harcourt (eds), *Oxford handbook of the Psychology of Appearance* (Oxford University Press 2012) 276.

[226] Moss and Rosser (n225) 276.

[227] Ibid.

[228] Sue Cahners, 'Young women with breast burns: a self-help "group by mail"' (1992) 13 Journal of Burn Care and Rehabilitation 44, 44.

3.2.3 SUMMARY OF THE RELEVANCE OF PSYCHOLOGICAL SCHOLARSHIP TO THE RESEARCH QUESTION

The two key themes which emerge in this section are:

i) The (sometimes profound) psychological impact of a disfigurement on the affected person, which can in turn impact on the individual's social experience; and

ii) Variance in research findings makes assumptions about severity, visibility and other characteristics unreliable. A wide variety of factors may influence the experience of disfigurement, and generalisations (or portrayals of visible difference as universally negative) are often unhelpful.

3.3 LITERATURE REVIEW: SOCIAL CONSEQUENCES OF VISIBLE DIFFERENCE

3.3.1 RELATIONS WITH OTHER PEOPLE AND COMMUNICATION

Studies have shown that people living with disfigurements often have heightened concern over social interaction, avoiding social situations as a result[229]. Many people with a visible difference report implicit awkwardness such as ‘the guarded references, the common everyday words suddenly made taboo, the fixed stare elsewhere, the artificial levity, the compulsive loquaciousness, the awkward solemnity’[230]. Explicit negative reactions are reported too; various surveys and personal accounts confirm experiences of teasing, name-calling, staring and unsolicited comments, questions[231] and even hate-crime[232]. James Partridge, founder of the charity Changing faces, who has a burns injury himself, uses the acronym SCARED to summarise the reactions of others to disfigurement: Staring, Curiosity, Anguish, Recoil, Embarrassment, Dread[233]. Communication skills can also be impacted due to interference with non-verbal clues of facial expression[234], leading to awkward social exchanges.

While it could be argued that negative expectations of others may lead to self-fulfilling prophecies, studies have demonstrated that concerns about the reactions of others are often well-founded, with the general public tending to avoid interaction with people with disfigurements where possible, choosing to stand

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[229] Thompson and Kent (n204) 666.

[230] Fred Davis, 'Deviance Disavowal: The Management of Strained Interaction by the Visibly Handicapped' (1961) 9 Social Problems 120, 123.

[231] Ibid.

[232] Changing Faces, 'Disfigurement in the UK' (Changing Faces 2017) 20.

[233] James Partridge, *Changing faces: the challenge of facial disfigurement* (Penguin Books 1990) 65.

[234] Macgregor (n221) 253.

further away from them on the street[235], not to sit next to them on a train[236], and to be less likely to donate to a charity collection if the collector has a visible difference[237] (although in all of these studies, the disfigurement was simulated with make-up, which raises questions about whether it influenced the participants, even subconsciously). Negative reactions are also sometimes reported in the use of public facilities, with 19% of participants in one study asked to leave a restaurant, swimming pool or other public place because of their appearance[238]. Difficult psychosocial experiences can sometimes occur with temporary disfigurement too, such as hair loss during chemotherapy[239], although isolating appearance from the impact of other factors during a time of trauma or intense illness is difficult.

Personal relationships – both at the level of friendship and intimacy – can also be affected[240]. This may be exacerbated by social media which, while opening lines of communication and support for many people, can expose users to abuse; 92% of respondents in the Changing Faces survey who had used a dating app reported negative comments about their appearance from other users. (It is worth clarifying that, in research terms, I have treated the Changing Faces survey with cautious interest; as an online survey, it does not pretend to be nationally representative and arguably its response rate is biased towards certain categories of people, particularly those in contact with the charity, and those (generally younger and socioeconomically advantaged[241]) people with internet access. In addition, the phrasing of the questions is not included for review, making it hard to judge the openness of the methodology. That said, recognising those parameters, it provides

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[235] Nicola Rumsey, Ray Bull and Denis Gahagan, 'The Effect of Facial Disfigurement on the Proxemic Behaviour of the General Public' (1982) 12 Journal of Applied Social Psychology 137, 146.

[236] Vicky Houston and Ray Bull, 'Do people avoid sitting next to someone who is facially disfigured?' (1994) 24 European Journal of Social Psychology 279, 279.

[237] Ray Bull and Julia Stevens, 'The effects of facial disfigurement on helping behaviour' (1981) 8 Italian Journal of Psychology 25, 25.

[238] Iona Ginsburg and Bruce Link, 'Psychosocial consequences of rejection and stigma in patients with psoriasis' (1993) 32 International Journal of Dermatology 587, 587.

[239] Diana Harcourt and Hannah Frith, 'Women's Experiences of an Altered Appearance during Chemotherapy' (2008) 13 Journal of Health Psychology 597, 603.

[240] Robinson (n139) 103; Nicholas David Sharratt and others, 'Understandings and experiences of visible difference and romantic relationships: A qualitative exploration' (2018) 27 Body Image 32, 35..

[241] Martyn Denscombe, *The Good research Guide For small-scale social research projects* (5th edn, Open University Press 2014) 27.

useful and up to date information of the views of over 800 participants with a disfigurement).

3.3.2 ASSUMED LINKS BETWEEN APPEARANCE AND CHARACTER

A large body of scholarship suggests that people make character assumptions based on appearance, associating physical attractiveness with positive personality traits. This is summed up by Dion et al in the sociologically iconic phrase 'what is beautiful is good'[242]. (The veracity of this assumption has also been tested, with mixed results[243]).

Studies on disfigurement specifically produce similar conclusions[244]. A US study by Rankin and Borah[245] used a two-group comparative research design of photographs of people with disfigurements and 'normal' faces, which were then rated by adult volunteer evaluators. In comparison with the simulated conditions discussed above, in this study photographs of real disfigurements were used and then digitally retouched to create a 'normal' image, seemingly reversing the possibility of simulated scars negatively impacting results. Even so, the study found that most of the photographs with real disfigurements showing were rated as "significantly less honest […], less employable […], less trustworthy […], less optimistic […], less effective […], less capable […], less intelligent […], less popular […] and less attractive" than the same photographs after digital removal of the disfigurement[246]. This is consistent with research by Bull et al[247] which found learned associations of pictures of disfigured people with negative character traits from the age of 12. In addition, a recent US study used neural responses recorded during an MRI scan of

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[242] Karen Dion, Ellen Berscheid and Elaine Walster, 'What is beautiful is good' (1972) 24 Journal of Personality and Social Psychology 285.

[243] Judith H. Langlois and others, 'Maxims or Myths of Beauty? A Meta-Analytic and Theoretical Review' (2000) 126 Psychological Bulletin 390, 404.

[244] See, for example, Anja Jamrozik and others, 'More Than Skin Deep: Judgments of Individuals With Facial Disfigurement' (2019) 13 Psychology of Aesthetics, Creativity, and the Arts 117, 124: a "disfigured-is-bad" stereotype.

[245] Marlene Rankin and Gregory Borah, 'Perceived Functional Impact of Abnormal Facial Appearance' (2002) 111 Plastic & Reconstructive Surgery 2140.

[246] Ibid.

[247] Ray Bull, 'The General Public's Reactions to Facial Disfigurement' in Jean Ann Graham and Albert M Kligman (eds), *The Psychology of Cosmetic Treatments* (Praeger 1985) 188.

the participants' brains to identify an active subconscious 'disfigured is bad' bias when presented with photographs of visibly different people[248]. Regrettably, bias against people who are visibly different is one area where research paints a consistent picture.

3.3.3 FACTORS AFFECTING THE SOCIAL CONSEQUENCES OF DISFIGUREMENT

To understand the variability of social experiences, the extent to which factors such as the severity, visibility, or aetiology of the disfigurement determine the extent of social disruption experienced will now be considered briefly.

Severity:

In section 3.2.2, it was submitted that studies show little reliable relationship between clinical severity and psychological outcome. But, to the extent that they can be isolated from psychological factors, what about social consequences and clinical severity? Some studies have found a relationship[249] but this is contradicted by a greater body of research which has found little link between objective clinical severity and social consequences[250]. Macgregor tentatively attributed the more extensive psychological consequences resulting from minor (rather than severe) disfigurements to the fact that minor disfigurements were less likely to evoke pity from others[251]. The law needs to move beyond basic assumptions of 'more clinical severity equals more discrimination'.

Visibility:

The effect of the visibility (location) of the disfigurement is harder to measure objectively as any reactions to it will depend on whether it is hidden or visible at the time. But 'visibility' is not a static concept. Few people are able (or choose) to

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[248] Franziska Hartung and others, 'Behavioural and neural responses to facial disfigurements' (2018) PsyArXiv 1, 10.

[249] Pam Carroll and Rosalyn Shute, 'School peer victimization of young people with craniofacial conditions: A comparative study' (2005) 10 Psychology, Health & Medicine 291, 300; Ornella Masnari and others, 'Self- and parent- perceived stigmatisation in children and adolescents with congenital or acquired facial differences' (2012) 65 Journal of Plastic, Reconstructive & Aesthetic Surgery 1664, 1667.

[250] Rumsey and others (n189) 450; Van Den Elzen and others (n222) 781.

[251] Macgregor (n219) 232.

keep covered from neck to toe all year round, and reports are frequent about the difficulties experienced when a usually-covered disfigurement is exposed, such as when required to wear shorts[252], or when removing a cardigan in hot weather[253]. One patient with acne quoted in the All Party Parliamentary Group on Skin report explained:

> "Any activities that need uncovering myself at all, (I live covered from neck to toe, and with makeup on my face) are a no-no as I get stares and people cat calling or moving away from me, thinking I have something catching. This particularly includes swimming, dancing, gym, going to the beach or being out in the sun"[254].

Kent and Keohane, in a study of psoriasis patients, found that the extent of visibility only impacted quality of life in those patients who also demonstrated high social anxiety[255]. This neatly illustrates the difficulties in drawing firm conclusions where a variety of factors (internal and external, psychological and social, clinical and personal) interact.

Aetiology:

Researchers have also considered the extent to which the aetiology of the disfigurement (or, perhaps more accurately, society's perception of the aetiology of the disfigurement) affects the stigma attaching to it. People are stigmatised more where they are seen as personally responsible for their problems[256] (see the widespread lack of media sympathy for Daniella Westbrook's nasal disfigurement, for example, which resulted from drug use[257]). In a similar vein, Macgregor notes

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[252] Jowett and Ryan (n208) 428.

[253] Kent and Keohane (n206) 31.

[254] All Party Parliamentary Group on Skin, 'The Psychological and Social impact of skin diseases on people's lives' (London 2013) 18.

[255] Kent and Keohane (n206) 27. See also John Lawrence and others, 'Visible vs hidden scars and their relation to body esteem' (2004) 25 Journal of Burn Care and Rehabilitation 25, 30, which found a low to moderate association between burn scar visibility and self-appraisals of appearance.

[256] Eugene Stone, Diana Stone and Robert Dipboye, 'Stigmas in organizations: race, handicaps and physical unattractiveness' in Kathryn Kelley (ed), *Organizational Psychology* (North-Holland 1992) 433.

[257] Geraldine Bedell, 'Girl, Interrupted' *The Guardian* (London 5 May 2002) Culture <https://www.theguardian.com/theobserver/2002/may/05/features.review27 > accessed 15 August 2019.

that some aetiologies (car accidents or war injuries) are more socially acceptable than others[258].

However, the cause of a disfigurement is not always clear to an observer, and research has also noted that some types of disfigurement (such as burns scars) may be better understood, and consequently accepted, by society[259]. Applying this, while some causes of a visible difference may help reduce social awkwardness once explained, this is unlikely to alleviate initial reactions of strangers, and public ignorance of less well-known conditions may lead to increased stigmatisation despite their 'blameless' aetiology.

Social skills:

Various individual accounts of disfigurement[260], as well as research studies[261], suggest that social competency on the part of the visibly different person can mitigate negative reactions of other people. There is also promising evidence that social skills training can help those for whom this is not innate[262].

3.3.4 THE WORKPLACE EXPERIENCE WITH DISFIGUREMENT

The 'beauty is good' stereotype feeds through to the job market too[263], and people with facial disfigurements often report high levels of perceived discrimination looking for work[264]. Other data suggests that many participants avoid applying

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[258] Macgregor (n221) 251.

[259] Masnari and others (n249) 1669.

[260] Partridge (n233) 65; Katherine Lacy, 'Katherine Lacy's account' in Richard Lansdown and others (eds), *Visibly Different: Coping with disfigurement* (Butterworth Heinemann 1997) 24-26; Dawn Shaw, *Facial Shift* (Lightning Source UK Ltd 2016) 23.

[261] Nichola Rumsey, Ray Bull and Dennis Gahagan, 'A preliminary study of the potential for social skills for improving the quality of social interaction for the facially disfigured' (1986) 1 Social Behaviour 143, 145.

[262] Emma Robinson, Nichola Rumsey and James Partridge, 'An evaluation of the impact of social interaction skills training for facially disfigured people' (1996) 49 British Journal of Plastic Surgery 281, 286.

[263] Megumi Hosoda, Eugene F. Stone-Romero and Gwen Coats, 'The effects of physical attractiveness on job-related outcomes: a metal-analysis of experimental studies' (2003) 56 Personnel Psychology 431, 432.

[264] D.B. Sarwer, S.P. Bartlett and L.A. Whitaker, 'Adult Psychological Functioning of Individuals Born with Craniofacial Anomalies' (1999) 103 Plastic and reconstructive surgery 412, 415.

for a job because of fears of reactions to their appearance[265]; the impact of lowered expectations is a consistent theme[266].

Reported fears of workplace discrimination appear to be well-founded. Stevenage & McKay[267] conducted a mock recruitment study to ascertain the effect of facial disfigurement on hiring decisions. Based on participants reviewing mock job applications, they identified a significant negative perception of the applicant with a facial disfigurement (a port wine stain), as against both a non-disabled applicant and an applicant in a wheelchair. An applicant with both a physical disability *and* a disfigurement fared worse of all in the recruitment evaluations. Interestingly, although hiring decisions differed, the personality and job skills judgments made by HR professionals and college students were the same, which suggests that HR training does little to reduce underlying bias against visibly different people. The increased disadvantage of the visibly different applicant in the wheelchair also suggests that complex disfiguring conditions are a point of increased disadvantage. While this was a mock study, thereby lacking the real-life validity of decisions with consequences[268] and arguably tainted by participants' desire to be seen to do the 'right thing', a similar result was established by *Stone and Wright* in their real-world job application study.

Figure B:

Stone and Wright's real-life recruitment study[269]
Methodology

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[265] Changing Faces (n232) 16.

[266] See also F. Ayala and others, 'The impact of psoriasis on work-related problems: a multicenter cross-sectional survey' (2014) 28 Journal of the European Academy of Dermatology and Venereology 1623, 1626, which found that over 50% of participants with psoriasis reported that the condition had affected their career expectations, and a similar number believed their educational prospects had been limited.

[267] Sarah V. Stevenage and Yolanda McKay, 'Model applicants: The effect of facial appearance on recruitment decisions' (1999) 90 British Journal of Psychology 221.

[268] Some studies have suggested that in a simulated setting, results may differ from real world decisions with consequences e.g. Anna Stone and Toby Wright, 'When your face doesn't fit: employment discrimination against people with facial disfigurements' (2013) 43 Journal of Applied Social Psychology 515, 516.

[269] Ibid.

Applications were submitted in response to job advertisements which fitted specific parameters. The applications were different but validated as equal in calibre and appropriateness to the relevant job. For each job, three applications were submitted – one for a wheelchair user, one for someone with a congenital disfigurement, and one with no apparent disability. The applications contained a worded statement describing the relevant condition (if any), not a photograph. Responses from employers were rated.

Findings

Stone and Wright found discrimination against people with a facial disfigurement where the role applied for entailed high levels of customer contact (a theme consistent with other studies too[270]). Discrimination against the wheelchair user was consistent – the authors speculated that this may be due to concern about the cost of making adjustments for a mobility-impaired applicant. The authors mooted a possible explanation for the focus on customer contact in disfigurement discrimination; employers might be concerned about reactions of customers and a knock-on effect on their business.

Analysis

The study stopped (for ethical reasons) at the stage of offering interviews, and it therefore can't be assumed that bias would not have influenced the interview stage and ultimate job offer even for these behind the scenes roles. The authors also recognised the possibility that recruiters may have struggled to envisage the visible difference described, but not pictured, on paper, and reactions could therefore have changed had the candidate proceeded to interview.

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[270] Alexander Tartaglia and others, 'Workplace discrimination and disfigurement: the national EEOC ADA research project' (2005) 25 Work (Reading, Mass) 57, 63; William Drew Gouvier and others, 'Employment Discrimination Against Handicapped Job Candidates: An Analog Study of the Effects of Neurological Causation, Visibility of Handicap, and Public Contact' (1991) 36 Rehabilitation Psychology 121, 125.

It is reasonable to assume that this bias may continue at the job interview stage; studies have found that both the applicant's physical attractiveness, and the level of social comfort experienced by the interviewer, influence the interviewer's perception of the individual's performance [271] at interview, and that facial disfigurement makes co-workers more uncomfortable than most other disabilities[272].

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[271] Cynthia Nordstrom, Bill Huffaker and Karen Williams, 'When physical disabilities are not liabilities: the role of applicant and interviewer characteristics on employment interview outcomes' (1998) 28 Journal of Applied Social Psychology 283, 302. Facial disfigurement was ranked 7/20 for discomfort, though these rankings were made on the basis of brief information only – so verification would be beneficial.

[272] Gwen Jones and Dianna Stone, 'Perceived discomfort associated with working with persons with varying disabilities' (1995) 81 Perceptual and Motor Skills 911, 915.

3.3.5 SUMMARY OF THE RELEVANCE OF SOCIOLOGICAL SCHOLARSHIP TO THE RESEARCH QUESTION

The key themes which emerge in this section are:

i) Significant bias against people with disfigurements does exist, both in the workplace and beyond. The attitudes of other people towards visible difference have the power not just to isolate socially, but to prevent participation in certain activities, to compromise personal security and privacy, and reduce the ability to support oneself financially necessitating dependence on others; and

ii) Variability makes predictions about social experiences based on particular characteristics difficult; some people cope well and experience few social consequences, while many others are profoundly affected.

3.4 LITERATURE REVIEW: LEGAL

This section is divided into themes relevant to the Research Questions identified in Chapter 1. Given a paucity of research on disfigurement law, parallels with general disability law scholarship will be drawn where appropriate.

3.4.1 REVIEW OF LITERATURE RELEVANT TO TARGETING DISADVANTAGE (RESEARCH QUESTION 1)

Research Question 1 divides into two related issues. First, are visibly different people a disadvantaged group? As outlined in Chapter 1, disadvantage here focuses predominantly on socioeconomic disadvantage. Although no legal literature was identified which addressed this specific point in relation to visible difference, there is some (albeit limited) existing evidence about employment and pay rates of visibly different people from which likely conclusions can be drawn.

Research by the EHRC found the pay gap for people with 'skin conditions, allergies and severe disfigurement' relative to non-disabled people[273] not to be statistically significant, but they did not address severe disfigurement disaggregated from this group. Contradicting this, research from the US suggests that a good-looking employee is likely to earn around $230,000 extra averaged over a 40 year career than a below average-looking employee[274] (including someone with a disfigurement, although the distinction between unattractiveness and disfigurement could perhaps be delineated more clearly in this work). Similarly, the Changing Faces survey found that 60% of its 806 visibly different participants were paid at or below the national average wage. The collection of disaggregated national statistics would be beneficial, but the evidence on pay hints at possible socioeconomic disadvantage.

In relation to employment rates, the evidence presented at 3.3.4 above indicated bias against visibly different people in the work context, including during recruitment, and the data discussed at 3.4.4 below suggests this pattern is also

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[273] Simonetta Longhi, *The disability pay gap* (EHRC Research reports, 2017) 38.

[274] Daniel S Hamermesh, *Beauty Pays* (Princeton University Press 2011) 47.

reflected in wider labour market statistics. The avoidance of applying for jobs reported in other studies reinforces this (see 3.3.4), and the evidence at 3.3.2 suggests that this workplace experience fits into wider patterns of negative assumptions and stereotyping against people with a visible difference. Accordingly, in answer to Research Question 1(a), it is clear that visibly different people are a disadvantaged group.

The second issue is whether domestic equality law i) accurately defines and ii) targets this disadvantage. One piece of existing detailed evidence was found on this point: in 2015, the charity Changing Faces gave evidence to the parliamentary committee evaluating the impact of the Equality Act 2010 on disabled people. Expressing 'strong reservations […] about how well it works in practice", Changing Faces identified the following problems with the way that the Act applies to people with a visible difference[275]:

CHANGING FACES COMMENTARY	**REVIEW**
A lack of guidance in the Act or accompanying guidance about what is meant by the term 'severe disfigurement'.	Although there is some guidance about the concept of severity[276], it is vague (see 4.5) referring to the nature, size, prominence and location of the disfigurement. Disfigurement itself is also only loosely defined, leading to a lack of clarity.
The limit of severity is inappropriate as it creates a need to 'quantify the disfigurement and wrongly puts single emphasis on the physical	This thesis strongly supports this argument, which identifies societal reactions as disabling those people with disfigurements, recognising a

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[275] Changing Faces, 'Evidence (EQD0131) to the House of Lords Select Committee on the Equality Act 2010 and Disability' (House of Lords Stationery Office 2015) 294.

[276] Office for Disability Issues, 'Equality Act 2010: Guidance on matters to be taken into account in determining questions relating to the definition of disability' (HM Government 2011) 26.

aspects of a disfigurement'[277]*. It also does not reflect research which suggests that the severity of the disfigurement is not directly proportional to the amount of social and psychological distress caused by it. 'It is the bias and response of the general public that influence treatment of individuals with a disfigurement rather than the objective size or shape of disfigurement'*[278].	social model approach. See 3.2.2 and 3.3.3 for a summary of research debunking an assumed link between severity and both social and psychological distress; this suggests that the law's scope is not clearly aligned with the ambit of disadvantage.
The importance of smaller disfigurements affecting the communication triangle between eyes and mouth is underestimated.	Research agrees that communication can be disrupted by disfigurement [279] . However, this thesis argues that an exclusionary focus on visible (particularly facial) disfigurements is unnecessary – see 4.5.1.
The Act could expressly declare the rights to equality of opportunity in employment for people with disfigurements, but it fails to do so.	While advantageous for raising awareness (in line with Research Question 4), such statements are likely to be too generic to be legally enforceable beyond the specific provisions relating to severe disfigurement.
The deeming provision of Schedule 1 to the Act, which provides that people	It is submitted that this is already partially the case following

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[277] Changing Faces, (n275) 297.

[278] Ibid.

[279] Macgregor (n221) 253; 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, 76.

with a severe disfigurement do not have to demonstrate substantial adverse effects on their ability to carry out normal day to day activities, focuses the attention purely on the physical characteristics of disfigurement; a decision which is taken by the Tribunals and / or medical professionals, without taking into account structural negative prejudices towards people with disfigurements. While it is positive that people with severe disfigurements do not have to demonstrate functional impairment, the test should not be a purely medical one but instead should take into account the impact on the person's life instead of his day to day activities.	*Hutchison (3G) Limited v Edwards*[280] (see 4.5). However, such subjectivity must be carefully balanced to avoid penalising those claimants who have participated fully in society despite having a visible difference. There is insufficient case law available to ascertain the approach taken by Tribunals on this point. It is submitted that a better approach is the removal of the severity requirement (or, its replacement with a lesser one of substantiality – see 6.2.1).
A lack of case law under these provisions, together with survey data from 2015 confirming that only one quarter of the 150 respondents knew that legal protection against discrimination was available for someone with a disfigurement, demonstrates a lack of awareness as well, potentially, as reluctance to bring their cases forward. The 25% of awareness contrasts with the 66% in the same survey who believed they	A more recent survey carried out by the charity found that over 50% of participants were aware of the severe disfigurement protection under the Act. This is broadly consistent with the findings of my empirical research too, which is outlined in Chapter 5. This suggests some increase in awareness over the last couple of years, although, as noted earlier, the methodology casts doubt on how

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[280] [2014] UKEAT/0467/13/DM.

had experienced discrimination in the last five years.	representative such statistics are, and reported claims do not demonstrate such an increase.
PROPOSALS BY CHANGING FACES	**REVIEW**
The concept of severe disfigurement should be removed as a subset of disability discrimination and, instead, a new protected characteristic of 'facial disfigurement' should be created.	The creation of a new protected characteristic of disfigurement is discussed at 6.4.1.
An annual report by the EHRC containing statistics and activity regarding disfigurement.	Agreed. This is in-keeping with the EHRC's own call for interventions to be evaluated[281] and with Articles 31 and 33 of the CRPD which require data collection and monitoring to ensure compliance and efficacy.
An awareness campaign about the rights available to people with disfigurements under the Equality Act 2010.	Agreed. The charity notes that some public bodies (including the police) and regulatory bodies (particularly in the media) sometimes lack awareness or commitment to challenging disfigurement discrimination and prejudice, so institutional awareness is an issue to be tackled as well as public awareness.

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[281] Dominic Abrams, Hannah Swift and Lynsey Mahmood, *Prejudice and unlawful behaviour: Exploring levers for change* (EHRC Research Reports, 2017) 20.

	Campaigns must be careful not to increase pity stigma[282] inadvertently.

Expanding the literature search to include wider disability, the following criticisms of the way the Act defines the disadvantage of disability have been identified in extant literature:

- First, the definitional focus on the effects of the impairment moves attention from the behaviour of the alleged discriminator onto the disabled person[283]; it is the definition of disability which acts as gatekeeper rather than the treatment of the disabled person. The same can be said of severe disfigurement, which precludes examination of discriminatory treatment against those who cannot meet it;

- Second, linked with this, the level at which the gatekeeper definition grants access is too high and misses an opportunity to make 'disability discrimination claims available to people treated less favourably because of impairments with only very minor effects on their daily lives'[284]. This echoes the discussion at 1.3.1 as it questions at what point outside functional 'norms' equality law should engage. A parallel here with mild and moderate disfigurements is obvious, especially as the evidence at 3.3.3 confirms the absence of a clear link between the severity of the disfigurement and its social consequences. The definition of both disability and severe disfigurement create a misalignment between the ambit of disadvantage and the scope of legal rights, meaning that some people will be disadvantaged but not covered by the Act; and

- Third, the definition of disability under the Act (with its inward, medical-model focus on the effects of impairment on the individual) is inconsistent

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[282] Diana Harcourt and Nichola Rumsey, 'Using novel methods in appearance research' in Nichola Rumsey (ed), *The Oxford handbook of the Psychology of Appearance* (Oxford university Press 2012) 688.

[283] Anna Lawson, 'Disability and Employment in the Equality Act 2010: Opportunities Seized, Lost and Generated' (2011) 40 Industrial Law Journal 359, 362.

[284] Ibid 363.

> with the guidance provided by Article 1 of the CRPD[285], which has a greater external, social model focus.[286] Again, in targeting disadvantage based on narrow medical criteria, the scope of protection offered by the Act is misaligned with the aims of the CRPD.

So the literature on both disfigurement and (by extension) disability suggests that the Act does not accurately define the true scope of visible difference disadvantage, resulting in a potential mismatch between the scope of disadvantage and access to equality rights. However, given the relatively small amount of existing legal analysis, this argument will be supplemented in Chapter 4.

Research Question 1(b) then asks whether the law targets this disadvantage rather than 'aiming at neutrality' in its equality provisions. As this question concerns disability law in general, the available research on this point is much richer, and overlaps to some extent with the discussion of substantive equality in Chapter 1. Broadly speaking, the Act (and the Framework Directive which it implements[287]) incorporates more than one conception of equality. The 'like for like treatment' embodied by formal equality is apparent in direct discrimination[288] which targets sameness, not disadvantage. However, indirect discrimination focuses on equality of results[289], not treatment, which addresses the disadvantage of substantive equality. The asymmetrical approach is also identifiable in the duty of reasonable adjustment, which attempts to accommodate disadvantage in the workplace. Harassment, too, speaks to the recognition dimension of substantive equality as it requires no comparator and seeks dignity and inclusion over detriment. Ideals of transformative equality can be found in positive duties and positive action which aim to remedy disadvantage by employing (often unequal) targeted measures (though the detail of these is subject to much criticism in existing literature – see 3.4.5 below).

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[285] Sarah Fraser Butlin, 'The UN Convention on the Rights of Persons with Disabilities: Does the Equality Act 2010 Measure up to UK International Commitments?' (2011) 40 Industrial Law Journal 428, 432.

[286] Lawson (n283) 363.

[287] Marc De Vos, *Beyond Formal Equality* (European Commission 2007) 10.

[288] Barnard and Hepple (n78) 562.

[289] Ibid 564.

So, the Act does include provisions targeting disadvantage in line with substantive, rather than formal, equality. An important caveat to this, though, is that research demonstrates that the detail of the Act's drafting, and the way in which it is interpreted by the courts, can impact on its effectiveness in targeting disadvantage, with 'principle' often ceding to 'pragmatism'[290] in the form of exceptions and justifications[291], which have the potential to limit the effectiveness of the law overall in combating disadvantage despite its apparently substantive aims. A detailed analysis of how each form of discrimination works in practice, and limits its effectiveness in substantive equality terms, is beyond the scope of this thesis. However, specific forms of discrimination will be addressed where a relevant interaction with visible difference is identified (for example, in how the duty to make reasonable adjustments applies to visible difference).

SUMMARY OF PROGRESS AGAINST RESEARCH QUESTIONS

Progress towards research Question 1: targeting disadvantage	Research question 1(a) is confirmed: visibly different people are a disadvantaged group, and the scope of disadvantage is not limited to those whose disfigurements are 'severe'. The evidence concerning Research Question 1(b) suggests that the Act does not accurately define the disadvantaged group. However, existing evidence is weak. This will be further analysed in Chapter 4. Further in relation to Question 1(b), in broad theoretical terms, the non-discrimination and equality provisions in the Act, taken together, do target disadvantage rather than neutrality;

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[290] Colm O'Cinneide and others, 'Defining the limits of discrimination law in the United Kingdom' (2015) 15 International Journal of Discrimination and the Law 80.

[291] Jackie A. Lane and Rachel Ingleby, 'Indirect Discrimination, Justification and Proportionality: Are UK Claimants at a Disadvantage?(European Union)' (2018) 47 Industrial Law Journal 531, 533.

	the Act includes manifestations of both formal and substantive conceptions of equality.

3.4.2 REVIEW OF LITERATURE RELEVANT TO INTERSECTIONALITY (RESEARCH QUESTION 2)

It is tempting to assume that everyone with a disfigurement shares the same experience within society. This enables easy (but not necessarily accurate) generalisations. Sections 3.2 and 3.3 have already discussed how the experience can be altered by the disfigurement itself (clinical severity, aetiology and visibility) and by individual traits (coping mechanisms, resilience and social skills) creating a more nuanced picture. But the reality is also layered by personal characteristics.

To address Research Question 2, research about the interaction of disfigurement with gender, race and age will be summarised. The extent to which equality law has the potential to redress points of intersectional disadvantage will then be discussed. Unfortunately, most studies on disfigurement are not specific enough to elicit distinctions between additive discrimination and intersectionality (discussed at 3.4.2.4), but they provide useful background.

3.4.2.1 THE INTERSECTION OF DISFIGUREMENT AND RACE

Social intersectionality: Limited scholarship suggests interplay between disfigurement and race / cultural characteristics. Naqvi and Saul cite “cross-cultural superstitions, religious, and folk beliefs”[292] as contributing to perceptions of visible difference. For example, Jennifer Hughes’ study with South Asian communities living in Britain identified a number of views about the causes of

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[292] Habib Naqvi and Saul Krysia, 'Culture and Ethnicity' in Nicola Rumsey and Diana Harcourt (eds), *The Oxford Handbook of the Psychology of Appearance* (Oxford University Press 2012) 208. See also Ann Hill Beuf, *Beauty Is the Beast : Appearance-Impaired Children in America* (Philadelphia : University of Pennsylvania Press 2016) 27.

disfigurement, including karma or blame for past or present actions[293]. A woman with a disfigurement in the family was perceived by one participant as 'terribly embarrassing'[294], suggesting a further intersection with gender. On the positive side, extended families within some of the cultures studied sometimes resulted in greater community inclusion for those living with disfigurements within them[295].

Workplace intersectionality: There is some supporting international evidence relating to disability, if not disfigurement, which suggests that some ethnic groups are less likely to be accommodated for disability in the workplace [296] and disproportionately hindered in the job market[297], but the evidence here is piecemeal. Many studies on disfigurement fail to address race adequately in their methodologies. This is an area for further research.

3.4.2.2 THE INTERSECTION OF DISFIGUREMENT AND GENDER

There is more evidence available about gender intersectionality.

Psychological intersectionality: It is commonly assumed that disfigurement will be more difficult psychologically for a woman than a man. But studies don't always support that assumption[298].

Social intersectionality: Changing Faces argue that disfigurement hate crimes are more commonly suffered by women than men[299] (see the earlier discussion of the

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[293] Jennifer Hughes and others, 'South Asian Community Views about individuals with a Disfigurement' (2009) 6 Diversity and Equality in Health Care 241, 246.
[294] Ibid 247.
[295] Naqvi and Saul (n292) 208.
[296] Sharon L. Harlan and Pamela M. Robert, 'The Social Construction of Disability in Organizations. Why Employers Resist Reasonable Accommodation' (1998) 25 Work and Occupations: An International Sociological Journal 397, 414.
[297] Maria Pierce, 'Minority Ethnic People with Disabilities in Ireland', (The Equality Authority, 2003) 39; Marianne Pieper and Jamal Haji Mohammadi, 'Aleism and Racism - Barriers in the Labour Market' (2014) 3 Canadian Journal of Disability Studies 65, 74.
[298] Rumsey and Harcourt (n140) 88; Ngoc Tram Nguyen and others, 'Barriers and facilitators to work reintegration and burn survivors' perspectives on educating work colleagues' (2016) 42 Burns 1477, 1484.
[299] Henrietta Spalding, *Changing Faces* (BBC Radio 4 18 April 2018).

methodology of the survey on which this radio broadcast was based). Consistent with this finding, Gardiner et al[300] found disfigurement was rated by other people as having a significantly greater impact on the appearance of younger girls and women relative to both their male and older counterparts, hence young women with disfigurements appear likely to represent a disadvantaged intersection. (Until 2017, this perception was reflected in the law itself, with guidelines providing that awards to women for personal injury involving facial scarring should be significantly higher than for equivalent injuries in men. The new guidelines no longer differentiate in terms of gender but instead take into account the psychological effect on the victim[301]).

Workplace intersectionality: No studies were found about the gender / disfigurement intersection in the workplace. However, more generally, statistics show that disabled women are slightly less likely to be employed than disabled men, which suggests marginal intersectionality[302]. There is mixed evidence on whether gender impacts the granting of requests for reasonable adjustments[303], but studies suggest that women are more likely to request accommodations than men[304] (perhaps as women are often engaged in lower level jobs than men, affording them less flexibility to make small adjustments of their own volition[305]). Women are also less likely to be happy with the adjustments granted[306](though this study did not explore the 'reasonableness' aspect of any requested adjustment in legal terms, so the root cause of differential dissatisfaction is unclear).

Despite some variance in findings, some studies have found that men are likely to judge someone with a disfigurement more harshly[307], and be less comfortable working with them[308], than women. If this is accurate, it may mean that women

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[300] Gardiner and others (n279) 76.

[301] Judicial College, *Guidelines for the assessment of General Damages in Personal Injury Cases* (14th Edition, Oxford University Press 2017).

[302] Longhi (n273) 14.

[303] Helen Hartnett and others, 'Employment Accommodations for People with Disabilities: Does Gender Really Matter?' (2014) Disability Studies Quarterly <https://doaj.org/article/43916ed5f2a643dc8313782981053f9a> accessed 8 July 2019; Harlan and Robert (n296) 413.

[304] Harlan and Robert, ibid.

[305] Ibid 414.

[306] Hartnett and others (n303).

[307] Jamrozik and others (n244) 8; Gardiner and others (n279) 75.

[308] Jones and Stone (n272) 916.

with a visible difference working in male dominated environments (e.g. engineering) may be more likely to encounter hostile environments than those working in female-dominated roles, such as office support, and male managers are likely to be less accommodating to staff with disfigurements.

Overall, the available evidence on gender and disfigurement (and disability by extension) suggests that women with disfigurements are likely to be at increased disadvantage, but further research would be beneficial.

3.4.2.3 THE INTERSECTION OF DISFIGUREMENT AND AGE

Psychological intersectionality: It is often assumed that disfigurement will 'matter less' as you get older. Only to a limited extent is this supported by evidence[309] but for some the passage of time can lead to better adjustment and coping[310] (although a lack of good quality longitudinal research makes such judgments difficult to prove[311]).

Social intersectionality: Facial disfigurements were judged to have a greater negative impact on the attractiveness of younger women and girls than older women[312] (although this finding was based on photographs of faces only, thus lacking not only a real life context but also the impact of someone's overall bodily presentation and facial movements on such judgments[313]).

Workplace intersectionality: The intersection with youth is consistent with findings that workplace disfigurement discrimination is more prevalent against younger workers[314].

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[309] See for example Judith R. Porter and Ann Hill Beuf, 'Response of older people to impaired appearance: The effect of age on disturbance by Vitiligo' (1988) 2 Journal of Aging Studies 167, 177.
[310] Mary S. Knudson-Cooper, 'Adjustment to visible stigma: The case of the severely burned' (1981) 15 Social Science and Medicine Part B Medical Anthropology 31, 43.
[311] Robinson (n139) 106.
[312] Gardiner and others (n279) 75.
[313] Ibid 76.
[314] Tartaglia and others (n270) 62.

The age of the observer can also impact; bias against visibly different faces was found to be greatest amongst participants in the age range of 45-64[315], who are likely to have decision-making roles within the workplace.

In summary, it appears possible that young people with disfigurements may be disproportionately disadvantaged relative to their older counterparts.

3.4.2.4 THE LAW ON INTERSECTIONALITY

In legal literature, a number of terms are used to describe overlapping or multiple disadvantage. A distinction is drawn between two types:

- Additive discrimination, where someone experiences discrimination related to more than one characteristic, such as a woman told that she could not work in a DIY shop both because she is a woman and because she has a disfigurement. She would have claims both for sex discrimination (against a male comparator) and disability discrimination (against a comparator without a disability).

- Intersectional discrimination, where someone experiences discrimination related to two or more intimately interwoven characteristics. Take a gym instructor turned down for a job because, given the combination of her being over 40 and having a disfigurement, she doesn't meet the brand image. The woman finds herself at the intersection between two grounds; disadvantaged in a way which is qualitatively different from the separate disadvantages of age and visible difference. This overlap is difficult to recognise under separate protected characteristics.

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[315] COG Research on behalf of Changing Faces, 'Public Attitudes to Disfigurement in 2017' (*Changing Faces,* 2017) <https://www.changingfaces.org.uk/wp-content/uploads/2017/05/IAT2017.pdf> accessed 3 July 2019.

While much early scholarship focused on identifying and separating these intersections into distinct sub-groups of disadvantage, the impracticality of this was soon recognised as a 'Pandora's box'[316] of never-ending categories. Even once a new sub-group is created, that still assumes that the experiences of all people within that group are homogenous[317]. This argument has particular force for disability, which breaks down into many different 'types' of disability, each with different characteristics and disadvantages.

Instead, the work of Crenshaw et al has encouraged an understanding of intersectionality which focuses not on identifying specific groups but on structural intersectionality based on relative power and exclusion[318]; intersections reveal 'domination' rather than 'difference'[319]. Fredman expands on this idea, arguing that, because people have a position within multiple characterisations (e.g. gender, race, age etc) 'power relationships do not only operate vertically. They operate diagonally and in layers'[320]. So, while a white, heterosexual man with a disfigurement may be disadvantaged by his appearance, he may have other power advantages in terms of gender, sexual orientation and race. An intersectional approach provides context and recognises that a hierarchy of disadvantage can operate within groups which share a given characteristic. It therefore reinforces notions of substantive and transformative equality, which aim to redress disadvantage rather than trying to identify comparisons of sameness and difference[321].

Much scholarship has focused on models which allow increased fluidity and recognition of intersectional disadvantage. Dagmar Shiek[322], for example, proposes organizing grounds of discrimination around three central overlapping nodes – sex

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[316] Sandra Fredman, 'Double Trouble: Multiple Discrimination and EU law' (2005) European Discrimination Law Review 13, 14.

[317] Sandra Fredman, *Intersectional discrimination in EU gender equality and non-discrimination law* (European Commission 2016) 33.

[318] Sumi Cho, Kimberlé Williams Crenshaw and Leslie McCall, 'Toward a Field of Intersectionality Studies: Theory, Applications, and Praxis' (2013) 38 Signs 785, 797.

[319] Ben Smith, 'Intersectional Discrimination and Substantive Equality: A comparative and Theoretical Perspective' (2016) 16 The Equal Rights Review 73, 75.

[320] Fredman (n317) 33.

[321] Ibid 36.

[322] Dagmar Schiek, 'Intersectionality and the notion of disability in EU discrimination law' (2016) 53 Common Market Law Review 35, 52.

/ gender, race / ethnicity and disability / impairment. Iyiola Solanke's work on 'stigma as discrimination' suggests the renaming of protected characteristics as 'stigmatised characteristics'[323] and argues that the anti-stigma principle would address the synergy of intersectionality[324]. But it is not always clear how these can be incorporated into legal systems which require clarity, certainty and user-friendliness for self-representing claimants. While intersectionality theory recognises that the current law is over-simplistic in its single ground approach, the challenge is in remedying that without bringing the law further out of reach for those who need to access it.

Sandra Fredman suggests that spectrums of disadvantage could be recognised within a single protected characteristic[325]. Under this analysis, a disabled woman could bring a claim for either disability or sex discrimination, and her increased disadvantage could be recognised as justifying additional protection. However, questions remain, such as:

- what does an intersectional comparator look like? Should a black disabled woman compare herself to an able-bodied white man (the approach taken in s.14 of the Act, which was legislated but never brought into force), or should comparators be disposed of in favour of asking simply why she was treated the way that she was?[326]

- Is the existing burden of proof adequate in situations where there could be numerous different combinations of motivations underlying a particular act?[327].

- Does it matter whether her 'main' claim is race, sex or disability?[328]

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[323] Solanke (n3) 152.
[324] Ibid 151.
[325] Fredman (n317) 69.
[326] Gay Moon, 'Multiple Discrimination - Problems confounded or solutions found?' (2006) 3 Justice Journal 86, 92.
[327] Paola Uccellari, 'Multiple Discrimination: How Law can Reflect reality' (2008) 1 The Equal Rights Review 2436.
[328] Fredman (n317) 70.

- How can the different exceptions and justifications applicable to specific grounds be reconciled?[329]

- If all 'disadvantages' are not equal (for example, having a facial disfigurement may be more or less disadvantageous than being a woman or being black), how does the law measure and account for their relative impact?

- Should different remedies be applied to intersectional claims e.g. public apologies[330], to reflect the increased weight of stigma applied?

In addition, the scope to redress intersectional disadvantage within an individual complaints model is limited[331] unless respondents are to be held responsible for structural inequalities for which they are not individually to blame. If an employee is refused a reasonable adjustment and resigns, should the remedy be increased to reflect the fact that, as a black woman, it will take her longer to get another job than a white man with the same disability? Aside from arguments about fairness to employers, it may also work against disadvantaged minorities by increasing employer reluctance to hire staff who would be more expensive to fire; increasing backwards-looking remedies to redress intersectional disadvantage could actually aggravate forward-looking disadvantage. Fredman suggests that intersectionality may have a bigger part to play in the targeting of positive action (though the current wording of s.158, which refers to action based on '*a* protected characteristic', suggests that this point has yet to filter through to legislation).

Although Parliament's approach has remained static, existing research suggests that the gap left by the decision not to bring s.14 into force is being filled by the courts[332]. It has moved from the well-publicised case of Kamlesh Bahl[333], where the Court of Appeal held that race and sex had to be proved separately (i.e. being black and a woman) not combined (i.e. being a black woman), to cases such as De Bique, where the combined effect of sex and race was accepted as discrimination which

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[329] Ibid.

[330] Solanke (n3) 156.

[331] Fredman (n317) 71.

[332] Ibid 56.

[333] *Kamlesh Bahl v Law Society* [2004] IRLR 799.

"cannot always be sensibly compartmentalised into discrete categories"[334]. It is submitted, though, that the case law has not yet reached the point of providing complete clarity over when and how, the principles will apply. A 2012 research study by ACAS found many legal advisers were uncertain over exactly what intersectional discrimination claims were and how to argue them[335], with some admitting to having come across cases involving intersectional issues but instead advised the client to focus on whichever single ground appeared strongest[336]. Potential claims are being deterred as a result of this lack of clarity.

In summary, existing research suggests that, although the law is beginning to recognise intersectional discrimination in piecemeal fashion, the legal dimension of intersectionality lacks clarity and structure in UK law, which is hindering its potential to address disadvantage at the intersection of grounds.

3.4.2.5 SUMMARY OF PROGRESS AGAINST RESEARCH QUESTIONS

Progress towards research Question 2: intersectionality	In relation to **Research Question 2(a)**, existing research suggests that, as for disability, these characteristics are likely to intersect with disfigurement, but the evidence (particularly on race and age) is inconclusive. This is an area to be addressed in Chapters 4 and 5. In answer to **Research Question 2(b)**, to the extent that intersections of combined disadvantage are identified, at present existing research suggests that domestic law does not deal adequately with them, though this is

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[334] *Ministry of Defence v De Bique* [2010] IRLR 471, para 165. See also *Hewage v Grampian Health Board* [2012] UKSC 37.

[335] Maria Hudson, *Research paper: the experience of discrimination on multiple grounds* (ACAS Research Papers, ACAS 2012) 18.

[336] Ibid 25.

	starting to change through judicial interpretation.

3.4.3 REVIEW OF LITERATURE RELEVANT TO THE DUTY TO MAKE REASONABLE ADJUSTMENTS (RESEARCH QUESTION 3)

There are two aspects to Research Question 3. The first concerns the effectiveness of the reasonable adjustment duty in accommodating difference. The second requires an analysis of the duty with respect to visible difference specifically. These will be addressed in turn.

3.4.3.1 THE EFFECTIVENESS OF THE DUTY

The mechanics of the duty to make reasonable adjustments are set out at 4.7.2. In the employment context, the duty is limited to reacting to an individual disabled employee being put at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled. There is much criticism in literature of the fact that this imposes a reactive duty only[337]; it does not require the employer to anticipate such barriers (in contrast with the service provider duty). Research also highlights the fact that the requirement of a comparator is one which is not mirrored (at least to the same extent) in the CRPD[338]. The response required by the duty is also limited; once aware of the disadvantage, the employer is only under a duty to take reasonable steps to avoid it, not to remove it[339].

Linked with the aim of ensuring participation (Research Question 6), existing scholarship laments the lack of a separate obligation to consult the disabled employee as part of the reasonable adjustment process[340]; the emphasis is on whether the adjustments were ultimately reasonable, not whether an inclusive process was followed. Given specific consultation obligations in other areas of

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[337] Lawson (n283) 368.

[338] Rachel Crasnow and Sarah Fraser Butlin, 'Disabled Compared to Whom? An analysis of the Current Jurisprudence on the Appropriate Comparator under the UK Equality Act's Reasonable Adjustments Duty' (2015) 75, 85.

[339] Rachel Geffen, 'The Equality Act 2010 and the Social Model of Disability' (LLM thesis, Leeds University 2013) 15.

[340] Rupert Harwood, 'What Has Limited the Impact of UK Disability Equality Law on Social Justice?' (2016) 5 Laws 42, 6.

employment law (e.g. redundancy and business transfers), this is a surprising omission.

Research demonstrates that the duty can benefit both employees (enabling them to continue working, succeed in their jobs, reduce sick leave, and gain promotion[341]) and employers (in terms of retention, productivity, loyalty and positive cultural change within the organisation)[342]. However, it has also been suggested that employers may be discouraged from hiring disabled employees if extra responsibilities may be entailed[343].

There are common practical problems with the application of the duty to make reasonable adjustments (for disability generally), including:

- **Unclear scope:** Employers are uncertain of the scope of their duty because it is vague and broadly defined. The House of Lords Select Committee[344] called for clearer guidance on when the costs of an adjustment are reasonable, a further Code of Practice on making reasonable adjustments, and industry-specific guidance on reasonable adjustment. These recommendations have not all been followed[345], despite Article 5(3) of the CRPD requiring states to raise awareness about the existence and nature of reasonable adjustment duties[346];

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[341] Ibid 6.

[342] Anna Lawson, *Disability and equality law in britain : the role of reasonable adjustment* (Hart Publishing 2008) 246.

[343] David Bell and Axel Heitmueller, 'The Disability Discrimination Act in the UK: Helping or hindering employment among the disabled?' (2009) 28 Journal of Health Economics 465, 480.

[344] House of Lords Select Committee (n113) 70. The ECHR website does, however, now contain detailed guidance for both employers and employees – see ECHR, 'Employing People: Workplace Adjustments' (updated 14 May 2019) https://www.equalityhumanrights.com/en/multipage-guide/examples-reasonable-adjustments-practice accessed 13 September 2019.

[345] UK Government, *Government response to the House of Lords Select Committee on the Equality Act 2010 and Disability* (Publications Office 2016) 16.

[346] Lawson (n342) 32.

- **Difficult / inconsistent process:** The process of obtaining reasonable adjustments is often “painful and protracted”[347], with failures commonly caused by an “implementation gap rather than legislative failure’[348]. (It should be noted, however, that both disability and the reasonableness of the adjustments were self-defined in this study, therefore not necessarily adhering to the same legal principles as the Act). Requests were sometimes interpreted as confrontational[349], with adaptations to the nature of the role often the most problematic. The duty is sometimes applied inconsistently, with the goodwill of individual line managers ‘turning what should be a legal obligation into a personal lottery’[350] and UK employers more likely than their US counterparts to refuse a particular adjustment on the basis that it is unworkable[351], perhaps as a result of receiving less training[352];

- **Financial / organisational factors:** A variety of financial / organisational factors affect an employee’s experience of reasonable adjustment within the workplace; the size and funding source of the employer[353] (with non-profit workplaces faring worse than private and public sector workplaces)[354], the presence of a specialist equality champion[355], a shift towards organizational structures requiring

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[347] Laura C. William, 'The implementation of equality legislation: the case of disabled graduates and reasonable adjustments' (2016) 47 Industrial Relations Journal 341, 356.
[348] Ibid.
[349] Deborah Foster and Patricia Fosh, 'Negotiating ‘Difference’: Representing Disabled Employees in the British Workplace' (2010) 48 British Journal of Industrial Relations 560, 569.
[350] Deborah Foster, 'Legal obligation or personal lottery?' (2007) 21 Work, Employment & Society 67, 79.
[351] Susanne M. Bruyère, William A. Erickson and Sara Vanlooy, 'Comparative Study of Workplace Policy and Practices Contributing to Disability Nondiscrimination' (2004) 49 Rehabilitation Psychology 28, 30.
[352] Ibid 35. Increased training for employers on reasonable adjustment is an action point in the CRPD Committee’s 2017 report on UK progress – see Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the initial report of the United Kingdom of Great Britain and Northern Ireland' (United Nations, 2017) CRPD/C/GBR/CO1, 12.
[353] Kim Hoque and Mike Noon, 'Equal Opportunities Policy and Practice in Britain' (2004) 18 Work, Employment and Society 481, 497.
[354] Deborah Balser, 'Predictors of Workplace Accommodations for Employees with Mobility-Related Disabilities' (2007) 39 Administration and Society 656, 676.
[355] William (n347) 349.

employees to move between tasks and roles[356], external pressures and competing priorities (particularly budgetary)[357], and whether other colleagues are impacted by a proposed adjustment[358]. (On this point, it is pertinent to note that the CRPD includes obligations in relation to funding; 'it is not enough simply to pass legislation. [...] Laws and policies which are not funded are unlikely to be fully implemented'[359]. Despite this, there is little financial support available to employers to assist with the cost of making reasonable adjustments[360], suggesting that problems with the implementation of the duty for financial reasons may be attributable to the state as well as employers). The mere presence of an equal opportunity policy appears to count for little, these are often nothing more than an 'empty shell'[361] adopted for commercial reasons. This runs counter to the participative concept of the CRPD which requires genuine accountability in decision-making processes to avoid predetermined outcomes[362];

- **Employee reluctance:** Some employees were reluctant to request reasonable adjustments, either for fear of their jobs (exacerbated by welfare benefit cuts)[363], because they felt too unwell[364], were reluctant to identify as disabled[365], or were uncertain whether they were covered by

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[356] Deborah Foster and Victoria Wass, 'Disability in the Labour Market: An Exploration of Concepts of the Ideal Worker and Organisational Fit that Disadvantage Employees with Impairments' (2013) 47 Sociology 705, 714.

[357] Deborah Foster and Peter Scott, 'Nobody's responsibility: the precarious position of disabled employees in the UK workplace' (2015) 46 Industrial Relations Journal 328, 339; Rupert Harwood, ''The dying of the light': the impact of the spending cuts, and cuts to employment law protections, on disability adjustments in British local authorities' (2014) Disability & Society 1511, 1517.

[358] William (n347) 352.

[359] United Nations, (n47) 33.

[360] The cost of making some physical adjustments may qualify for tax relief, and the Access to Work scheme can provide grants to cover expenses, but only those which would not fall under the duty to make reasonable adjustments.

[361] Hoque and Noon (n353) 497.

[362] United Nations, (n47) 37.

[363] Harwood (n340) 11.

[364] Heather Mack and Ian Paylor, 'Employment Experiences of Those Living With and Being Treated For Hepatitis C: Seeking Reasonable Adjustments and the Role of Disability Legislation' 15 (2016) 555, 563.

[365] Foster and Fosh (n349) 565.

the duty[366]. The latter point has particular resonance for disfigurement as many people are unaware that severe disfigurement is a disability under the Act[367]. The employee's ability and willingness to advocate their needs clearly to the employer[368] was important, suggesting a role for a better state-run, reasonable adjustment mediation service; and

- **Timing:** *Williams-Whitt and Taras* found that the behaviour and perception of an employee prior to disability was a key factor in determining accommodations going forward[369]. People who have a disfigurement from an early age may therefore be more disadvantaged in the workplace than those who acquire them in adulthood having already have built up some goodwill.

In summary, the reasonable adjustment duty offers a powerful tool to accommodate difference, but has theoretical and practical limitations. While it is perhaps easy to blame some of the practical issues on employers failing to comply properly with the duty, widespread problems of implementation suggest underlying structural issues, such as a lack of clarity of the law, a failure to tackle deeply embedded societal prejudice, or inadequate funding structures. On the latter point, the government's Fit to Work scheme was praised for providing a route for employers to get free Occupational Health assessments to help return a sick employee to work. But the scheme was withdrawn in early 2018 due to inadequate referrals, which in turn have been blamed on a lack of publicity and awareness of the scheme[370]. This neatly encapsulates the need for concepts such as reasonable adjustment, awareness, and participation to be addressed holistically rather than individually.

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[366] Mack and Paylor (n364) 563.

[367] Changing Faces (n232) 37.

[368] Nina Nevala and others, 'Workplace Accommodation Among Persons with Disabilities: A Systematic Review of Its Effectiveness and Barriers or Facilitators' (2015) 25 Journal of Occupational Rehabilitation 432, 443; Nguyen and others (n298) 1481.

[369] Kelly Williams-Whitt and Daphne Taras, 'Disability and the Performance Paradox: Can Social Capital Bridge the Divide?' (2010) 48 British Journal of Industrial Relations 534, 544.

[370] Cigna, 'Assessing the Fit to Work service rollout ' (*Cigna Corporation,* 2015) <https://www.cigna.co.uk/downloads/2015/Fit%20for%20Work%20research%20article.pdf> accessed 4 July 2019.

3.4.3.2 THE APPLICATION OF REASONABLE ADJUSTMENTS TO VISIBLE DIFFERENCE

Turning to Research Question 3(b), a basic internet search reveals that a little practical advice on making adjustments for people with disfigurements is freely available if you search hard enough[371]. But very little research was identified about the extent to which visibly different employees are having, or want, reasonable adjustments made for them.

One qualitative Canadian study (see Figure C, below) considered the related issue of return to work arrangements for people with a burn injury, which overlaps with the concept of reasonable adjustment.

Figure C

Qualitative study by Nguyen et al concerning work reintegration for burns survivors[372]
Methodology Focus groups were conducted with burns survivors who had returned to work (or planned to) and burn care professionals. The sampling frame was the database of patients at a Canadian medical facility, enabling certainty that participants met the criteria for the study (albeit this did limit both the geographical representativeness of the study and the sample size). There was a team of four reviewers, allowing triangulation of results and limiting the potential for researcher bias.

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[371] Business Disability Forum, 'Factsheet for employers on disfigurement' (*Rhondda Cynon Taf Council,* Undated) <https://rct.learningpool.com/pluginfile.php/711/mod_folder/content/0/Saesneg%20-%20English/Factsheet%20on%20Disfigurement%2012_13.pdf?forcedownload=1> accessed 4 July 2019. See also Gemma Borwick, 'Disfigurement: Looking beyond face value' (*Personnel Today,* 2010) <http://www.personneltoday.com/hr/disfigurement-looking-beyond-face-value/> accessed 4 July 2019.

[372] Nguyen and others (n298).

Key findings

Recently returned employees felt that the legitimacy of their continued support needs were questioned once their scars became less visible. The presence / absence of support and adjustments were cited respectively as a facilitator or barrier to returning to work.

Burn survivors varied in the amount of information they wanted their employer to receive about their ongoing impairment; those returning to an old job felt it would help, those looking for new work were reluctant to disclose information. Participants agreed that information about rehabilitation needed to be disclosed, though those seeking work were keen for any information to have a positive focus.

The majority preferred their doctors to speak to their employers about their ongoing condition, abilities and support needs, but some preferred to handle this process alone. The participants wanted a training tool which could be personalised and delivered to the workplace to disseminate relevant information.

Analysis

The research noted an interesting contradiction: employees in work often felt that the legitimacy of their impairment was doubted and they were pressured to take on a normal workload before they were ready, whereas employees looking for work were denied it as they were presumed unfit to perform the duties of the role. This links to the recognition dimension encapsulated in Research Question 4, as there appear to be contrasting stereotypes in play – disabled people in work are perceived as work-shy (consistent with benefits cheat rhetoric[373]), and disabled people looking for work are perceived as incapable[374].

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[373] Libby McEnhill and Victoria Byrne, ''Beat the cheat': portrayals of disability benefit claimants in print media' (2014) 22 Journal of Poverty and Social Justice 99, 104.

[374] Katharina Vornholt and others, 'Disability and employment – overview and highlights' (2018) 27 European Journal of Work and Organizational Psychology 40, 46.

It also highlights the importance of education as part of the reasonable adjustment process, extended to the wider workplace if appropriate. (Only 4.5% of participants in another survey said their employer had implemented disfigurement training for colleagues[375]). The type of participation valued by the participants varied, suggesting that employees should themselves be involved in deciding how such educational processes should work.

Despite the participants highlighting the importance of adjustments to work reintegration, and ongoing stigmatization where these were not made effectively, the US study below suggests that numbers of reasonable adjustment failure claims by visibly different workers are disproportionately low compared with some other types of claim.

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[375] Changing Faces (n232) 17.

Figure D: Workplace discrimination and disfigurement: The national EEOC ADA research project by Tartaglia et al[376]

Methodology

This US study analysed data of the Equal Employment Opportunity Commission database on allegations and resolutions of discrimination. Disfigurement discrimination data was contrasted with that relating to missing limb discrimination. One strength of this methodology is that it analyses objective legal findings, rather than just perceptions, of discrimination, ensuring that (US) legal criteria are applied. The corollary of that is that it fails to capture those people who feel discriminated against but do not bring a claim.

Key findings

Most disfigurement discrimination claims focused on either harassment or non-wage benefits. There were proportionately fewer reasonable adjustment claims relating to disfigurement. The number of disfigurement discrimination allegations raised amounted to only 0.2% of the total disability claims raised. Numbers in the retail and service industries were proportionately higher than in other industries (which supports the customer contact anomaly discussed at 3.3.4). An intersection with both gender and age was identified; more disfigurement discrimination claims were brought by younger, female workers. No racial intersection was noted.

Only 15.6% of disfigurement discrimination claims were found to have merit, compared with 17.2% of missing limb discrimination complaints and 22% of other disability complaints. This suggests that disfigurement discrimination claims may be slightly harder to win. Although the difference is statistically marginal, the authors also note that more disfigurement than missing limb claims were closed (8% and 5% respectively) due to failure to show disability or other qualifying criteria, suggesting multiple hurdles. The authors moot that this may be because of the difficulty of proving that an appearance issue is an impairment (though US law on disfigurement is different from UK law so this finding lacks ready transferability).

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[376] Tartaglia and others (n314).

Analysis

The data tells half of a story, but, as the authors admit, leaves questions unanswered. Is the disproportionately low number of disfigurement reasonable adjustment claims because adjustments are being made or claims are not being brought? In either case, why? Or do visibly different people not want reasonable adjustments and why? Why are disfigurement discrimination claims harder to win? Is it due to the facts of the case or because inconsistent legal standards are being applied to disfigurement discrimination claims? Does the data relating to age and gender reflect a genuine intersectional issue or a tendency of younger women to enforce their rights more often? Would similar findings apply today in Britain? This thesis seeks to answer many of these questions.

SUMMARY OF PROGRESS AGAINST RESEARCH QUESTIONS

Progress towards Research Question 3: reasonable adjustments	Research Question 3(a) can be answered from existing research: although useful, the duty in general terms has some limitations which hinder its effectiveness. Research Question 3(b), concerning the application of reasonable adjustments to visible difference, is only partly addressed by existing research, which suggests that the duty can in theory be applied to visible difference, but the evidence is slight. This question will be explored further in Chapters 4 and 5.

3.4.4 REVIEW OF LITERATURE RELEVANT TO PARTICIPATION AND INCLUSION (RESEARCH QUESTION 6)

Research Question 6 considers whether UK equality law promotes the participation and inclusion of people who are visibly different in the workplace and labour market. Participation and inclusion is one of the General Principles[377] in the CRPD. Participation means 'nothing about us without us'[378]; its essence is involving disabled people in decision-making processes that affect them. At an individual level, this would most obviously mean consultation about, say, job duties and performance – the duty to make reasonable adjustments provides one likely context for this participation. Collectively, it means consulting visibly different people on policies which affect them and initiatives designed to support them. Inclusion means a mainstream, not segregated, approach to disability, where disabled people are not just put in the same space as non-disabled people (in the open market, rather than sheltered, workplaces) but enabled to participate on an equal basis. Given the open market focus in this thesis, sheltered workplaces will not be discussed further, but inclusion remains relevant on a micro level, in understanding whether visibly different people are included equally when seeking, and performing, work.

Research emphasises that participation is not always a simple process; where exercised collectively rather than individually, care needs to be taken that the right people are being consulted. Sherlaw et al point out that the interests of disabled people's organizations ("DPO"s) do not necessarily tally with those of their members, or of other DPOs[379], and a 'commonality of disability'[380] cannot be

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[377] CRPD (n44) art 3.
[378] United Nations, (n47) 37.
[379] William Sherlaw and Hervé Hudebine, 'The United Nations Convention on the rights of persons with disabilities: Opportunities and tensions within the social inclusion and participation of persons with disabilities' (2015) 9 European Journal of Disability research 9, 15.
[380] Vic Finkelstein, 'The commonality of disability' in V Finkelstein and others (eds), *Disabling Barriers, Enabling Environments* (1st edn, Sage Publications Ltd 1993) 14.

assumed. This is particularly salient for visible difference which is often overlooked as a form of disability.

In addition to research about bias against visible difference in the workplace, the evidence on the wider inclusion of visibly different workers in the labour market does not engender optimism. The most recent statistics found concerning employment rates of visibly different people across Britain are from the 2016 Labour Force survey[381], which listed the employment rate of those with severe disfigurements, allergies and skin conditions as being 67% (compared with an average 80% for non-disabled people). However, this category makes it difficult to disaggregate data relating just to disfigurements, plus the methodology of the Labour Force Survey has been criticised for producing results which are more optimistic than other surveys[382].

Evidence suggests that this exclusion is, once again, particularly acute in types of work involving high levels of customer contact (see 3.3.4). A study conducted in Japan (where admittedly labour market conditions may be different) found that some visibly different people are counselled away from visible careers by family members and schools too[383]. This highlights a lack of free choice within the job market (hence lacking the CRPD's criteria of 'work freely chosen'[384]). If visibly different people are channelled into (or away from) certain types of work, this also breaches the general principle of individual autonomy[385]. It suggests that structural interventions aiming to transform the workplace may need to begin earlier to prevent both career choices and educational qualifications being negatively affected.

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[381] Centre for Social Justice, 'Rethinking disability at work' (Centre for Social Justice 2017) 34.

[382] Ben Baumberg, Melanie Jones and Victoria Wass, 'Disability prevalence and disability- related employment gaps in the UK 1998–2012: Different trends in different surveys?' (2015) 141 Social Science & Medicine 72, 78.

[383] Miki Nishikura, 'Three employment-related difficulties: understanding the experiences of people with visible differences', *Creating a Society for all: disability and economy* (The Disability Press 2011), 94; Zali O'Dea, 'The Ayes have it!' (2018) 23(10) The Qualitative Report 2313, 2319.

[384] CRPD (n44) art 27(1).

[385] Ibid art 3(a).

Once in work, discriminatory promotion procedures can hinder equal 'career advancement'[386], and the evidence outlined at 3.4.1 shows that many visibly different people may be paid less than average, suggesting that many are either remaining in lower grade jobs (often in less well-paid industries), or receiving unequal pay, both of which point to segregation. Inclusion in the workplace can also be hindered socially, such as the visibly different employee asked not to attend the staff photo when royalty visited because his / her image "'didn't fit' with the company profile"[387] – the link here with the attitudinal change required by Research Question 4 is clear.

In summary, existing evidence suggests that the effective participation and inclusion of visibly different people may not yet have been achieved. In assessing whether this failure can be attributed to the law's failure to promote it, there is overlap with other research questions: Research Questions 4 and 7 consider the ability of positive legal measures to promote equality and inclusion collectively, and Research Questions 3 and 5 consider measures to promote individual inclusion.

SUMMARY OF PROGRESS AGAINST RESEARCH QUESTION

Progress towards Research Question 6: participation and inclusion	Existing evidence suggests that the effective participation and inclusion of visibly different people in the labour market may not yet have been achieved, but this will be explored further in Chapter 5.

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[386] Ibid art 27(1)(e).

[387] Changing Faces (n232) 16.

3.4.5 AWARENESS-RAISING (RESEARCH QUESTION 4) AND POSITIVE MEASURES (RESEARCH QUESTION 7)

There is significant overlap between Research Question 4 (awareness-raising) and 7 (positive measures), because the concepts of attitudinal change and structural change are closely linked. For this reason, they are considered together in this section.

Turning first to Research Question 4, it has already been established that visibly different people are disadvantaged by the attitudes of other people, both in the work context and beyond. A number of theories have been put forward to explain these attitudinal barriers, including:

i. a stigmatized social identity for those who fall outside the normal ranges (of appearance or behaviour) scoped by society (Goffman[388]);

ii. a 'just world hypothesis' where disfigurement is assumed to be in some way be deserved by the individual[389];

iii. fears of contagion caused by a lack of knowledge[390]; and

iv. avoidance resulting from conflict between the desire to stare, and the understanding that staring is wrong[391]; a natural reaction to the unusual[392] or an uncertainty over how to behave.

To create attitudinal change, article 8 of the CRPD requires 'immediate, effective and appropriate measures' to raise awareness of the rights, dignity and capabilities of disabled people, including public awareness campaigns and awareness-training

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[388] Goffman (n17) 14.

[389] David W. Novak and Melvin J. Lerner, 'Rejection as a consequence of perceived similarity' (1968) 9 Journal of Personality and Social Psychology 147, 151.

[390] N Bernstein, '*Emotional care of the facially burned and disfigured' (*1976 Boston: Little Brown) cited in Thompson and Kent (n204) 665.

[391] Ellen J. Langer and others, 'Stigma, staring, and discomfort: A novel-stimulus hypothesis' (1976) 12 Journal of Experimental Social Psychology 451, 460.

[392] Partridge (n233) 93.

programmes (the UK was recently chastised for not having implemented this cross-cutting obligation adequately)[393]. A detailed breakdown of individual awareness-raising campaigns is beyond the scope of this work, but equality law plays a role in awareness-raising in other ways, discussed below.

The concept of structural change (Research Question 7) recognises that inequality can be perpetuated not just by attitudes but also by environmental and institutional factors, including law. For example, as bias against visible difference is known to lead to discrimination in recruitment practices, there is a role for awareness-raising to reduce the bias. There may equally be a role for structural changes to recruitment procedures (e.g. such as 'blind' interviews to prevent judgments based on appearance). Structural change has the potential to challenge stereotypes too. Increased regulation of the media could help tackle the common disfigured 'baddy'[394] stereotype, and changes to the way that charities are funded could prevent images of disabled people being used to inspire donations through pity[395], which contradicts the social model's focus on empowerment. Attitudinal change and structural change are therefore symbiotic in many respects.

Although the CRPD doesn't refer to 'structural change' expressly, it embraces the idea[396] both in its willingness to turn the spotlight onto society rather than the individual, and the requirement of positive measures to accommodate difference.
UK equality legislation contains two main strands of positive measures. The first is the Equality Duty imposed on public bodies by s.149 of the EA 2010 (subsequently amended) ("PSED"), and the second is positive action measures which enable employers to take positive steps to achieve equality. These will be discussed in turn to assess their potential for both attitudinal and structural change.

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[393] Committee on the Rights of Persons with Disabilities, (n352) 5.

[394] Claire Wardle and Tammy Boyce, 'Media Coverage and Audience Reception of Disfigurement on Television' (Cardiff University / The Healing Foundation 2009) 3.

[395] Nichola Rumsey and Diana Harcourt, 'Where do we go from here?' in Nichola Rumsey and Diana Harcourt (eds), *The Oxford Handbook of the Psychology of Appearance* (Oxford University Press 2012) 688.

[396] Jenny E. Goldschmidt, 'New Perspectives on Equality: Towards Transformative Justice through the Disability Convention?' (2017) 35 Nordic Journal of Human Rights 1, 6.

3.4.5.1 PUBLIC SECTOR EQUALITY DUTY

The duty on public bodies consists of:

1. a general duty to have due regard to the elimination of discrimination, harassment, victimisation and related conduct, the advancement of equality of opportunity and the need to foster good relations between persons who share a relevant protected characteristic and those who do not[397];

2. Specific duties to publish equality information[398] and objectives[399]. (Public authorities in Wales[400] and Scotland[401] have additional specific duties, including equality in procurement exercises).

The identified limitations of this duty in existing research fall into two camps: implementation and scope. In terms of implementation, no research was identified which considered the extent to which the PSED is being used in relation to disfigurement specifically, though research does demonstrate that very limited effective action is happening in relation to disability[402], so it seems unlikely that disfigurement prejudice as a subset is being widely addressed under the duty. There is, though, evidence that some schools are doing so where disfigurement affects a particular student[403], and evidence of the potential for interventions to be effective if they were to be widely adopted[404].

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[397] Equality Act 2010 s.149 (1)

[398] The Equality Act 2010 (Specific Duties) Regulations 2011, Reg 2.

[399] Ibid Reg 3.

[400] The Equality Act (Statutory Duties) (Wales) Regulations 2011, Reg 18.

[401] The Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012, Reg 9.

[402] See e.g. Angharad E. Beckett and Lisa Buckner, 'Promoting Positive Attitudes towards Disabled People: Definition of, Rationale and Prospects for Anti-Disablist Education' (2012) 33 British Journal of Sociology of Education 873, 881; Equality and Human Rights Commission, *Hidden in Plain Sight: Inquiry into Disability-related harassment* (ECHR 2011) 112.

[403] Lindsay Dell and Jess Prior, 'Evaluating a Schools' Service for Children with a Facial Disfigurement: The Views of Teaching and Support Staff' (2005) 20 Support for Learning 35, 37.

[404] Tony Cline and others, 'Educational Research Volume 40 Number 1 Spring 1998 The effects of brief exposure and of classroom teaching on attitudes children express towards facial disfigurement in peers' (1998) 40 Educational Research 55, 60.

Several limitations of the general duty have been highlighted in scholarship. First, the obligation is only to 'have due regard to' equality objectives, not necessarily to do anything about them. Sandra Fredman argues that a requirement to take action would be more effective[405]. The House of Lords Select Committee agreed[406], concluding that the ability for a public authority to 'make no progress towards the aims of the general duty and yet be judged compliant with it by the courts' was fundamentally flawed. However, their recommendation to amend s.149 to require "all proportionate steps" was not implemented.

Second, the duty has been criticised for encouraging a tick-box compliance approach, focusing on the process of decision-making rather than the content. Manfredi et al point to a number of unsuccessful judicial review claims using the PSED which have failed due to the low, procedural standard required[407].

Third, the duty applies only in the public sector, leaving the private sector without any positive duty regarding equality[408]. It is submitted that excluding broadcasting decisions about content[409] from the duty is another significant limitation, which misses a chance to mainstream positive images of visibly different people in ordinary life in the media.

Changes to the specific duties have also been criticised. Predecessor duties provided for the publication of equality schemes after consultation with interested people and representative groups. These requirements were dropped from s.149 in order to cut red tape. Anna Lawson[410] highlights the conflict between this lack of an engagement (or even consultation) requirement in the PSED with the participation provisions in the CRPD. Bob Hepple's work, too, views the changes as a backwards

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[405] Sandra Fredman, 'The Public Sector Equality Duty' (2011) 40 Industrial Law Journal 405, 427.

[406] House of Lords Select Committee (n113) 99.

[407] Simonetta Manfredi, Lucy Vickers and Kate Clayton-Hathway, 'The Public Sector Equality Duty: Enforcing Equality Rights Through Second-Generation Regulation' (2018) 47 Industrial Law Journal 365, 386.

[408] Bob Hepple, 'The New Single Equality Act in Britain' (2010) 5 The Equal Rights Review 11, 22.

[409] Equality Act 2010, sched 19, pt 1.

[410] Lawson (n283) 381.

step[411], signifying the undermining of a more 'reflexive' approach to regulation based on self-regulation and the involvement of interest groups, rather than top-down 'command and control' regulation. More cautiously, Manfredi et al question the usefulness of enforced consultation, where the inequality of bargaining power between the public authority and the consulted stakeholders creates a "veneer of equality which hides the deepening inequality beneath"[412].

The other problem with the PSED is that, because it applies across protected characteristics, it does not explicitly recognise the differing stereotypes and challenges facing individual groups. Promoting the equality of disabled people in general, or those with mobility impairments, may not assist those with a visible difference where the nature of the underlying stigma is different. While it is implicit that the duty must take such differences into account, the focus of a thinly spread duty is likely to fall on the more well-known impairments, increasing the visibility of some types of disability and the relative invisibility of others.

In summary, therefore, the duty under s.149 of the Act could provide a framework for limited positive measures in a number of respects. The duty to have due regard to fostering 'good relations' provides the ability to contribute positively to raising awareness and respect, and to combatting stereotypes (Research Question 4). The requirement to have due regard to advancing 'equal opportunity' has the potential to promote the inclusion of people with a visible difference in the labour market (Research Question 6) and to promote structural change for the benefit of people with a visible difference (Research Question 7). But there is no evidence that it *is* contributing positively to the experiences of people with a visible difference at group-level, and the technical drafting of the duty provides significant leeway for public authorities to meet the duty without achieving any of the substantive equality aims underlying it.

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[411] Bob Hepple, 'Enforcing Equality Law: Two Steps Forward and Two Steps Backwards for Reflexive Regulation' (2011) 40 Industrial Law Journal 315, 326.

[412] Manfredi, Vickers and Clayton-Hathway (n407) 25.

3.4.5.2 POSITIVE ACTION

The Act allows "positive action" by employers in favour of disabled people. Positive action is voluntary, although some have suggested that the interplay between the duty under s.149 on public bodies and the ‘permitted’ positive action provisions may place public bodies under an obligation to consider using positive action measures where appropriate[413].

Positive action is different from positive discrimination. Positive action involves the use of special measures to assist people in disadvantaged groups; it is about seeking to level the terms of competition by addressing disadvantage. Christopher McCrudden’s work[414] provides some useful examples of relevant measures. He identifies five types of positive action:

> 1) measures to eradicate discrimination - in the context of visible difference, this could include reviewing dress codes and recruitment procedures to remove discriminatory criteria;
>
> 2) purposefully inclusive policies which target disadvantage rather than protected characteristics, but which have an indirect benefit for the latter (e.g. measures aimed at people living beneath the poverty line, for example, or long-term unemployed, which are likely to benefit disabled people due to their increased exclusion in the labour market);
>
> 3) outreach programmes – campaigns designed to seek more applications from disabled people, perhaps advertised through charities or internet support sites for visibly different people;
>
> 4) preferential treatment, such as quota systems specifying that certain roles or percentage of jobs have to be filled by disabled people; and

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[413] Chantal Davies and others, 'Bridging the gap' (2016) 16 International Journal of Discrimination and the Law 83, 91.

[414] C. McCrudden, 'Rethinking positive action' (1986) 15 Industrial Law Journal 219, 223.

5) redefining merit by re-evaluating the criteria used for making decisions to ensure that disadvantaged groups are better able to participate. E.g. removing criteria linked to online visibility on professional networking sites, which may disadvantage some visibly different people.

As these categories date back to 1986, they do not reflect the present boundaries of what is permitted by law (and indeed number 4 would probably be classified today as positive discrimination[415]), but the categories provide a useful reminder that positive action can take a variety of forms.

Positive discrimination is more contentious than positive action[416] and means favourably taking into account the protected characteristic in making decisions, perhaps via tie-break, threshold or quota systems. Although positive discrimination is usually unlawful under UK law, direct discrimination in favour of a disabled person is permitted[417] (save where it discriminates between different types of disability). However, the more lenient approach afforded to positive disability discrimination appears to be little known about among employers and consolidating disability with other protected characteristics may have served to hide this express asymmetry[418].

The Act contains two separate positive action provisions. S.158 applies where an employer reasonably believes that people who have a particular protected characteristic (e.g. disability) suffer a disadvantage, have specific needs or are disproportionately under-represented. The action taken by the employer must be proportionate. In disability matters, there is a significant overlap with reasonable adjustment; the key differences are that positive action is group-based, anticipatory and optional, whereas reasonable adjustments are individual, reactive and compulsory. In addition, s.159 contains a tie-break provision which applies in situations of recruitment or promotion where two candidates are equally qualified. Again, the action must be proportionate.

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[415] Davies and others (n413) 86.

[416] See Mike Noon, 'The shackled runner: time to rethink positive discrimination?' (2010) 24 Work, Employment & Society 728, 730 for a summary of criticisms of positive discrimination, although Noon advocates its increased use.

[417] Equality Act 2010, s.13(3).

[418] House of Lords Select Committee (n113) 23.

So the law permits certain types of positive action. But the CRPD and dimensions of substantive equality on which the Research Questions are based require more than legal presenteeism; measures taken need to be effective and appropriate to achieve equality. This is a bigger challenge, because evidence shows that the many positive action measures in disability contexts are rarely used[419]. Chantal Davies' research identified a willingness by employers (particularly large public sector employers) to engage in high profile outreach programmes, but 'when looking for evidence of employers crossing the rubicon between 'outreach' and preferential treatment, the narrative dries up'[420]. Her qualitative study identifies a number of reasons for this; the permissive (rather than compulsory) nature of the positive action provisions, worries about getting it wrong, and possible credibility issues for those perceived as having benefited from positive action.

There is also an inherent contradiction in telling employers on the one had not to take into account certain characteristics when making decisions, and on the other, to drill down on those characteristics and take action toward them[421]. Accordingly, only 30% of those employers who responded to Davies' research had used the positive action provisions, even in the more limited form of outreach. Consistent with this, the CRPD Committee's 2017 report on the UK deemed existing affirmative action measures 'insufficient'[422].

While some of these issues could perhaps be rectified with clearer guidance and simplified drafting, less palatable reasons may lurk behind some refusals to use positive action; research suggests that many employers hold stereotypical views of disabled people[423], such as perceived differences in productivity and performance, perceived costs of making reasonable adjustments, and an overstated fear of litigation by disabled employees[424]. So, although positive action offers an

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[419] Davies and others (n413) 92.

[420] Ibid.

[421] Lizzie Barmes, 'Equality law and experimentation: the positive action challenge' (2009) 68 CLJ 623, 642.

[422] Committee on the Rights of Persons with Disabilities, (n352) 12.

[423] Mark L. Lengnick-Hall, Philip M. Gaunt and Mukta Kulkarni, 'Overlooked and underutilized: People with disabilities are an untapped human resource' (2008) 47 Human Resource Management 255, 269; Nguyen and others (n298) 1481; Vornholt and others (n374) 45.

[424] Lengnick-Hall, Gaunt and Kulkarni, ibid 259.

opportunity to increase equality, where negative attitudes prevail permitted positive action offers little scope to change them.

Some scholars have mooted making positive action compulsory (or extending positive duties to the private sector[425]), but in the current economic and political climate, this appears unlikely. In the meantime, there is some evidence that equality is becoming 'mainstreamed', with initiatives like Athena-SWAN[426], and the Investors in People programme[427], 'infecting' the receiving organisations (both public and private sector) with equality processes[428]. The gender pay gap reporting requirements, too, may force organisations to consider equality more generally in formulating policies. Against this background, it is interesting to note that a number of large employers, from both the private and public sectors, had signed up as members of the 'Face Equality at Work'[429] campaign run by the charity, Changing Faces, committing to strive to create a workplace where people are judged on ability and potential rather than appearance. The scheme was recently discontinued, however.

In summary, therefore, despite much scholarship highlighting the potential benefits of positive action, current statutory positive action measures seem to play little part in fostering awareness and respect for visibly different people and their rights, dignity, capabilities and contributions (Research Question 4). Nor do they presently play a significant role in practice in promoting the full and effective participation and inclusion of visibly different people in the workplace (Research

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[425] B. A. Hepple, *Equality : a new framework : report of the independent review of the enforcement of UK anti-discrimination legislation* (Hart e-books, Oxford; Portland, Or.: Hart Pub. 2000) 57; Colm O'Cinneide, 'Taking equal opportunities seriously: the extension of positive duties to promote equality' (Equality and Diversity Forum, 2003) 86.

[426] Athena SWAN is an initiative of the Equality Challenge Unit which offers recognition to higher education institutions for embedding principles of gender equality. See Advance HE, 'Athena SWAN charter' (*Advance HE,* undated) <https://www.ecu.ac.uk/equality-charters/athena-swan/> accessed 5 July 2019.

[427] Investors in People is an accreditation standard for better people management. See https://www.investorsinpeople.com.

[428] Manfredi, Vickers and Clayton-Hathway (n407) 392.

[429] Changing Faces, 'Achieving face equality in the workplace' (undated) www.changingfaces.org.uk/education/work accessed 10 October 2019.

Question 6) or achieving structural change to accommodate difference (Research Question 7).

SUMMARY OF PROGRESS AGAINST RESEARCH QUESTIONS

Progress towards Research Questions 4 and 7: recognition and structural change	No research was found concerning the use of positive measures to achieve structural change **(Research Question 7)**, or increased awareness and respect **(Research Question 4)** for visibly different people specifically. Although wider literature suggests that the current law is limited in its potential for effective positive measures, Chapter 5 will explore this theme further by analysing the experiences of affected people.

3.4.6 REVIEW OF LITERATURE RELEVANT TO ACCESS TO JUSTICE (RESEARCH QUESTION 5) AND REMEDIES (RESEARCH QUESTION 8)

The focus of this section is on whether visibly different people have effective access to justice in challenging discrimination, and if not, why not, (Research Question 5) and the related issue of whether domestic equality law provides 'forward-looking, non-pecuniary' remedies for discrimination against visibly different employees (Research Question 8).

Turning first to **Research Question 5**, there appears to be a mismatch between studies which show that many people with disfigurements believe they have been discriminated against[430], and the number of reported discrimination claims based on severe disfigurement.

Statistics show that:

- In the 2017-2018 year, 109,706 ET claims were issued of which 5,354 related to disability discrimination[431]. 3,627 of these disability discrimination claims were finalised during that year, of which approximately 566 either went to a full-hearing or were dismissed at a preliminary hearing[432].

- None of these 566 (approx.) claims were based on severe disfigurement. (This assertion is based on a search of the ET decisions database; it is not possible to search ET1 forms digitally, only decisions. Earlier statistics are not available as the ET system only introduced a keyword searchable database in Feb 2017).

While recognising that data showing the number of claims across a longer period of time would be useful, this statistic is particularly surprising when one considers that there are an estimated 1.3 million people in Britain living with a disfigurement[433] (although no statistics were found on how many of these might be considered 'severe' under the Act).

How can this apparent enforcement gap be explained? Changing Faces highlighted a lack of awareness that severe disfigurement was classed as a disability under the Equality Act[434] and reported that some people chose not to bring a claim as they felt helpless. To some extent, low enforcement levels are consistent with wider findings; Clements and Read refer to the 'disabling process of litigation' in identifying a

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[430] Changing Faces (n232) 17, suggested that 26.2% of participants believed they had been discriminated against by colleagues and 17.8% by their manager.

[431] Ministry of Justice, 'Tribunal statistics' (*UK government,* 2018) <https://www.gov.uk/government/collections/tribunals-statistics> accessed 6 July 2019.

[432] Ibid.

[433] Changing Faces (n232) 2

[434] Ibid (n232) 37.

similarly low level of disability-linked claims being brought to the ECHR[435], and Meager et al found that only 5% of those participants who had experienced problems at work had brought a claim[436]. However, there is a clear gap in research to establish the reasons for low enforcement among people with a visible difference specifically; this thesis seeks to fill this gap.

In relation to disability, some evidence exists. A study conducted by the Institute for Employment Studies[437] identified the following concerns among claimants (and potential claimants):

DRC concerns identified	Comments on relevance to disfigurement law
Lack of knowledge and understanding of the equality legislation (at that time, the DDA)	This is particularly plausible for visible difference where knowledge of the severe disfigurement provision is low[438]. Other studies suggest that awareness of employment rights is lower among the more disadvantaged groups, including women and those in temporary work[439], suggesting that there may be an intersectional aspect to enforcement patterns.

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[435] Luke Clements and Janet Read, 'The dog that didn't bark: the issue of access to rights under the European Convention on Human Rights by disabled people' in Anna Lawson and Caroline Gooding (eds), *Disability rights in Europe: from theory to practice* (Hart 2005) 33.
[436] Nigel Meager and others, 'Awareness, knowledge and exercise of individual employment rights' (Employment Relations Research Series, DTI 2002) 190.
[437] J Hurstfield and others, 'Monitoring the Disability Discrimination Act (DDA) 1995: Phase 3' (Disability Rights Commission, Department for Work and Pensions and the Equality Commission (Northern Ireland) 2004) 72.
[438] Changing Faces (n232) 37.
[439] Meager and others (n436) 22.

Cost barriers in obtaining representation and funding cases.	Legislative changes since this study was conducted are likely to have exacerbated this; the Legal Aid, Sentencing and Punishment of Offenders Act 2012 has restricted the functioning of Conditional Fee Arrangements ("CFA") and After the Event Insurance ("ATE") in England and Wales. The 2016 House of Select Committee in 2016 specifically noted this as a bar to enforcement. Lawson and Ferri also note a widespread (but mistaken) belief that, following cuts to legal aid, funding is no longer available to challenge disability discrimination in employment cases[440], although additional steps have been imposed on legal aid claims which have made funding harder to obtain[441]. Research also suggests that lack of legal representation in the early stages of a claim

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[440] Delia Ferri and Anna Lawson, *Reasonable accommodation for disabled people in employment* (European network of legal experts in gender equality and non-discrimination, 2016) 89.

[441] Law Centres Network, 'Equality Act 2010 and Disability Committee, House of Lords: Evidence from the Law Centres Network' (2015) 8.

	compromises chances of success[442].
Unwillingness to be labelled ‘disabled’	Claimants with a disfigurement face an even deeper paradox here; to enforce their rights they have to acquire two labels: ‘severely disfigured’ and ‘disabled’.
Difficulty satisfying the burden of proof to meet the definition of disability	While some disfigurements may be ordinarily visible (e.g. facial disfigurements), ‘hidden’ disfigurements are likely to have to provide more substantial evidence (e.g. medical and / or photographic) in order to satisfy the burden of proof, which can be emotionally intrusive for the Claimant[443]. See discussion of Hutchison 3G Ltd v Edwards at 4.5.
Difficulty providing medical evidence in support of a claim, which often proved costly, upsetting and stressful	The 2017 Changing Faces survey also highlighted common frustrations with GPs and the NHS for failing to understand particular conditions and the psychosocial impact of disfigurement. One participant summarised the

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[442] Rupert Harwood, 'Can International Human Rights Law Help Restore Access to Justice for Disabled Workers?' (2016) 5 Laws 17 22.

[443] Lawson (n283) 361 points to the human discomfort of having one’s impairment and its effect scrutinised in a public court room.

	GP's attitude as 'it's all cosmetic and we don't do cosmetic'[444]. Reluctance to request, and difficulty obtaining, sufficiently detailed medical evidence in such situations is plausible.
A lack of documentation available to the claimant, particularly in recruitment cases.	The abolition of discrimination questionnaires is likely to have exacerbated this[445]. This has changed the process for claimants to request documents and explanations about their treatment at an early stage, replacing formal questionnaires, complete with specified reply periods, with an informal process[446]. The HL Select Committee recommended that the questionnaire procedure should be reinstated, but the government refused[447].
The formal and legalistic tribunal process / the stress of the Tribunal process, and uncertainty about the outcome of a potential claim.	The CRPD Committee requested procedural accommodations in the justice system to facilitate the participation of people with

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[444] Changing Faces (n232) 32.

[445] House of Lords Select Committee (n113) 116.

[446] See ACAS, 'Asking and responding to questions of discrimination in the workplace' (undated) <https://www.acas.org.uk/media/3920/Asking-and-responding-to-questions-of-discrimination-in-the-workplace/pdf> accessed 20 October 2019.

[447] UK Government (n345) 27.

	disabilities[448]. This could include simple adjustments such as providing clear guidance to claimants in disfigurement claims about what to expect, or greater privacy options on the disclosure of medical evidence relevant to proving disability. Given that many respondents choose to challenge the issue of disability strategically to achieve a withdrawal or low value settlement[449], another option is increased Tribunal willingness to award costs against the employer for unreasonably contesting disability.

(It is worth noting, however, a big methodological constraint which limits the effectiveness of these findings: the researchers in this study admitted to a particular practical problem in identifying potential (rather than actual) claimants to participate, and therefore the findings in relation to those people who had not yet brought a claim were limited to five case studies in the employment context, as opposed to the 81 case studies about cases which had been brought). A different study included more people who chose not to claim, and highlighted additional reasons why, including feeling too ill / stressed, and concerns about being victimised for bringing a claim[450].

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[448] UN CRPD Committee (n352) 6.
[449] Hurstfield and others (n437) 121.
[450] Harwood (n340) 7.

Since the Institute of Employment Studies research was conducted, fees for bringing an Employment Tribunal claim were introduced, and later abolished. The introduction of fees resulted in a drop of around 68% for single claims and 75% for multiple claims and therefore may have influenced recent statistics, although the trend seems to be reversing since fees were scrapped[451].

In summary, the evidence suggests various reasons why people may not be bringing claims in respect of disfigurement discrimination. But this will be considered further in Chapter 5.

Research Question 8 questions whether the remedies provided by the Act in respect of discrimination claims include measures which are forward-looking and non-pecuniary, as required by the CRPD[452].

The traditional remedies under the Act are specified under s. 124 (2) as compensation, a recommendation, and / or a declaration as to the rights of the parties. Compensation is obviously an individual remedy designed to compensate financially for discrimination. Declarations, too, are individual remedies, restricted to the parties to the dispute, although could be argued to have a minimal forward-looking aspect in that they clarify a particular status or right going forward. Prior to 2015, recommendations could have impact beyond the parties to the claim; Tribunals had the power to make recommendations to a losing respondent which could benefits others, such as equality training for employees or managers of the respondent organisation. The Deregulation Act 2015 changed this; the law now requires that any recommendation relates only to the claimant which, in practice, this means that recommendations will be used less frequently, as they will not apply if the claimant has left the business. The House of Lords Select Committee recommended that the power to issue wider recommendations be reinstated (the government refused[453]). In addition, Employment Tribunals have no power to grant

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[451] Jo Faragher, 'Tribunal claims up 90% since fees abolished' (Personnel Today, 8 March 2018) < https://www.personneltoday.com/hr/employment-tribunal-claims-autumn-2017-up-since-fees-abolished/ accessed 13 September 2019.

[452]UN Committee on the Rights of Persons with Disabilities, (n107) 6.

[453] UK Government (n345) 28.

injunctions or to enforce awards, meaning that only 49% of Tribunal awards were found to have been paid in full[454].

These remedies are the product of a model of enforcement based on individual complaints; individual claims encourage individual remedies. But many academics argue strongly that the individual-complaints model does little to tackle structural discrimination[455]; often it isn't possible to find one person to blame for an embedded inequality, let alone someone prepared to bear the risk of challenging it.

As noted earlier, it is arguable that positive action could be reinforced by making it compulsory and introducing sanctions for those who fail to meet it. In some European countries, fines or tax penalties are imposed on businesses who fail to meet quotas for employing disabled people, although evidence suggests that many business prefer to pay the fine in any event[456], which underscores the challenge faced by the recognition dimension of substantive equality in changing negative attitudes towards disabled people.

Enforcement is possible against public bodies who fail to comply with obligations under the s.149 duty, but it is primarily through the EHRC in the form of assessments[457], notices[458] and agreements[459] (which often include an action plan to prevent future breaches). Whilst this is both non-pecuniary and forward-looking, applying separation of powers principles, there are questions to be answered around the effectiveness of an enforcement mechanism which exists between publicly funded bodies (even though the EHRC is a statutory arm's length body, it is funded by the government). Individual enforcement of the duty is possible through judicial review proceedings, but as well as the cost implications of doing so, and the difficulties establishing standing, such claims are often unsuccessful[460]. The weakness of the enforcement process is another reason why the public sector equality duty is often deemed ineffective.

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[454] IFF Research on behalf of Department for Business Innovation and Skills, 'Payment of Tribunal Awards' (Department for Business Innovation and Skills 2013) 6.
[455] Fredman (n405) 408.
[456] Vornholt and others (n374) 44.
[457] Equality Act 2010 s.21.
[458] Equality Act 2010 s.32.
[459] Equality Act 2010 s.23.
[460] Manfredi, Vickers and Clayton-Hathway (n407) 22.

In summary, therefore, the Act provides a number of remedies, some more forward-looking than others, but its main limitation is the individual-complaints model of enforcement which ensures that the remedies used the most are pecuniary and backwards-looking.

SUMMARY OF PROGRESS AGAINST RESEARCH QUESTIONS

Progress towards research Questions 5 and 8: access to justice and remedies	The evidence suggests reasons which may be affecting access to justice in challenging disability discrimination. Likely parallels can be drawn with visible difference, but this will be investigated further in both Chapter 4 and Chapter 5. **Research Question 8** is answered as follows: the available remedies under UK equality law for discrimination against someone with a visible difference do not include effective 'forward-looking, non-pecuniary' remedies.

3.5 CHAPTER 3 SUMMARY

In this Chapter, I have broken down the extent to which existing literature provides an answer to the eight Research Questions. Research Questions 1(a), 2(b), 3(a) and 8 have been answered from existing literature in this Chapter, and will therefore not be examined in further detail. The remaining Research Questions will be addressed in Chapters 4 and 5.

4. DOCTRINAL RESEARCH

4.1 CHAPTER INTRODUCTION

Chapter Four[461] divides into four parts:

- First, section 4.2 sets out what we know about the meaning of disfigurement, and how interpretive approaches can ascribe a clearer meaning to the relevant statutory provision. It considers how disfigurement differs from the concepts of appearance and disability, and identifies several respects in which the current statutory provision seems to fall short of the implicit logic which drove its inclusion in the Act. It is argued that 'disfigurement' should be read as encompassing a broader range of appearance-altering conditions than has, to date, been recognised. It will be argued that protection should extend beyond conditions such as scarring to include other visible differences.

- Second, section 4.5 onwards addresses the 'severity' threshold which someone with a disfigurement is required to meet before qualifying for protection against discrimination. It is argued that this threshold has no justification in either wider social and psychological research, or international law, and should be removed.

- Third, section 4.6 discusses the legal dichotomy facing people discriminated against because of complex disfiguring conditions, who are not allowed to combine functional and aesthetic effects in determining whether the severe disfigurement provision is met.

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[461] Most of the contents of this Chapter feature in a recently published journal article and a separate conference paper delivered during my PhD, and adapted here for inclusion in this thesis. See Hannah Saunders, 'The invisible law of visible difference : disfigurement in the workplace' (2018) Industrial law journal; Hannah Saunders, 'Disfigurement: A visibly different approach to equality?' (Society of Legal Scholars Annual conference, Preston, 6 September 2019).

- Fourth, section 4.7 discusses the application of the legal concepts of perceptive discrimination and reasonable adjustments to people with a visible difference, to evaluate the extent to which they can mitigate the shortcomings identified earlier.

4.2 DISFIGUREMENT: DEFINING AN APPEARANCE DISABILITY

Discrimination against people with visible differences is, at least to some extent, prohibited by disability provisions in the Act. The definition of disability is contained within Section 6 of the Act:

> ‘A person (P) has a disability if—
>
> (a) P has a physical or mental impairment, and
>
> (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.’

While someone with a visible difference, without other functional limitations, would be unlikely to satisfy this definition, Schedule 1[462] deems that an impairment which consists of a severe disfigurement is to be *treated as* having a substantial adverse effect on the ability to carry out normal day-to-day activities. This removes the need for the individual to demonstrate the functional disadvantage required by the standard definition, albeit that she still has to demonstrate that the impairment is long-term (meaning that it has lasted, or is likely to last, for at least 12 months, or for the rest of the life of the person affected[463]).

However, a lack of clear statutory guidance and case law on the meaning of the term ‘disfigurement’ mean that the parameters of this section of the Act remain uncertain. The first question which this Chapter seeks to answer, therefore, is this:

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[462] EA 2010, sched 1, pt 1, s 3.

[463] EA 2010, sched 1, pt 1, s 2.

with the law as it currently stands, what types of condition are likely to fall within the severe disfigurement provision?

Given the much-debated definition of disability in the Act, it is strange that there is no equivalent definition of severe disfigurement. S.3, Schedule 1 simply provides that:

> "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."

EU law yields no definition of disfigurement either; the disfigurement provision in the Act does not stem from EU law expressly. The Convention on the Rights of Persons with Disabilities provides no definition either, although its wide description of disability as a social construct would include those with a visible difference[464] (see 1.4.1). There is a partial explanation of the concept of severe disfigurement in the Equality Act guidance[465]. This provides:

> 'Examples of disfigurements include scars, birthmarks, limb or postural deformation (including restricted bodily development), or diseases of the skin. Assessing severity will be mainly a matter of the degree of the disfigurement which may involve taking into account factors such as the nature, size, and prominence of the disfigurement. However, it may be necessary to take account of where the disfigurement in question is (e.g. on the back as opposed to the face).'

The guidance does not pretend to be comprehensive – the types of disfigurement listed are examples only. Scars and birthmarks are perhaps the most commonly envisaged type of disfigurement which (provided they meet the severity threshold) fall readily within the scope of the provision, as do some skin conditions, such as severe psoriasis[466]. The other examples given, however, are a more curious choice. Without question, limb deformation (to use the terminology of the Guidance) can

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[464] UN Convention on the Rights of Persons with Disabilities (n44) Article 1.
[465] Office for Disability Issues (n276) para B25.
[466] *Cosgrove v Northern Ireland Ambulance Service* [2007] IRLR 397.

affect others' perceptions of someone's appearance. In 2009, for example, the BBC received numerous complaints from viewers about the appearance of a children's TV presenter whose arm stopped at the elbow[467]. But the inclusion of limb deformation as one of only five listed examples of severe disfigurement is surprising because most limb deformities will also produce functional effects on what the affected person can do; a deformation of the hand will often impact on tasks involving manual dexterity, while a deformation of the leg or foot may impair mobility.

The same argument can be made for many postural deformities; people with these conditions unable to demonstrate a substantial adverse effect on their ability to carry out normal day to day activities may be in a minority of people with similar conditions. For example, in the case of *Hutchison 3G UK Ltd*[468], the EAT upheld the Tribunal's finding that the Claimant's chest deformity caused by Poland syndrome was both a severe disfigurement and a physical impairment which had a substantial and long-term effect on the Claimant's ability to carry out normal day-to-day activities.

So, without doubting that limb and postural deformations conditions merit equality rights as disabilities (whether by virtue of their functional effects or their aesthetic impact), their express inclusion in the guidance on severe disfigurement in place of many other disfiguring conditions misses an opportunity to expressly extend, rather than overlap with, the scope of protection provided by s.6.

There have been relatively few reported cases under the severe disfigurement provision, but those reported have not really moved much beyond the examples given in the Guidance. For example, *Hutchison*, cited above, concerned a postural deformity of the chest cavity; *Cosgrove*[469], *Blyth*[470] and *Whyte*[471] concerned skin

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[467] ITV News, 'Ex-CBeebies presenter: 'Parents criticised my decision not to wear prosthetic arm', (2017) <https://www.itv.com/news/2017-05-04/ex-cbeebies-presenter-cerrie-burnell-parents-rang-up-complaining-about-my-arm/>accessed 31 January 2019.

[468] *Hutchison* (n280).

[469] (n466). Note that *Cosgrove* is a decision of the Northern Ireland Court of Appeal.

[470] *Blyth v Historic Scotland* [2001] Xpert HR, <https://www.xperthr.co.uk/law-reports/psoriasis-not-severe-disfigurement/66497/> accessed 29 April 2019.

[471] *Whyte v First Capital East Limited* [2005] UKEAT/0686/04/DM.

conditions (psoriasis and folliculitis); *Johansson*[472] and *Hand*[473] (both decisions of the Northern Ireland Industrial Tribunals[474] applying similar severe disfigurement wording) and *Griffiths*[475] all concerned facial scarring.

Principles of statutory interpretation can also be used to understand the scope of the severe disfigurement provision in Schedule 1 of the Act. In the case of *Goodwin v Patent Office*[476], the EAT stated (of the Disability Discrimination Act 1995, which preceded the Act) that "with social legislation of this kind, a purposive approach to construction should be adopted. The language should be construed in a way which gives effect to the stated or presumed intention of Parliament, but with due regard to the ordinary and natural meaning of the words in question."[477] The EAT specifically urged Tribunals to consider the relevant code of practice and guidance. In this instance, however, neither document is instructive on the definition of the term disfigurement, beyond the loose parameters in the guidance quoted above.

The extent to which wider Parliamentary records can be taken into account in the search for Parliament's intended meaning is debatable[478]. However, that debate need not trouble us here, as extensive searches of Hansard have not revealed any detailed debates about the meaning of disfigurement itself, beyond oft cited examples of scars and birthmarks. Ironically, one MP remarked during a standing committee debate that 'there are many types of severe disfigurement and we can all imagine what they might be"[479]. The debates do, however, reveal a concern that the severe disfigurement provision should be 'comprehensive'[480], and not unjustifiably watered down in due course (for example by excluding from protection purportedly 'blameworthy' disfigurements such as a burns injury resulting from solvent abuse, or scars from self-harm). A purposive analysis of Parliamentary

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

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

[474] Northern Irish decisions are persuasive in Britain but not binding.

[475] *Griffiths v Lancashire County Council* [2009] (unreported) (ET).

[476] *[1999] IRLR 4, para 2.*

[477] Ibid para 2.

[478] In *Pepper v Hart [1992] 3 WLR 1032*, the House of Lords appeared to relax the rules about using explanations from parliamentary records in statutory interpretation. However, see also Johan Steyn, 'Pepper v Hart; A Re-examination' (2001) 21 Oxford Journal of Legal Studies 59.

[479] House of Commons Standing Committee E debate, 7 February 1995, per David Hanson.

[480] Ibid.

records therefore perhaps brings with it a small glimmer of optimism, if not clarity, as to the intended comprehensiveness of the severe disfigurement provision.

A literal interpretation, on the other hand, involves assessing the natural and ordinary meaning of the Act: what the words of the statute actually mean. The Oxford dictionary defines disfigurement as "something that spoils the appearance of someone or something; a blemish"[481], whereas Black's legal dictionary defines it as "the result of an accident or an injury that impairs the beauty, symmetry and appearance."[482] The focus on accidents and injuries in the Blacks definition perhaps arises because disfigurement in legal terms usually occurs in a personal injury context, where someone or something is to blame. The case law under the Act is not limited in this way, however; disfigurements present from birth and natural causes are recognised as well as those acquired later. Setting this causation aspect aside, however, both dictionary definitions have at their core the idea of impaired appearance.

This idea of 'impaired appearance' is interesting because it is a semantic hybrid of two concepts: disability (through the concept of impairment[483]) and appearance. In theoretical terms, disfigurement can be thought of as occupying a middle position between the concepts of appearance and disability, as portrayed in the diagram below.

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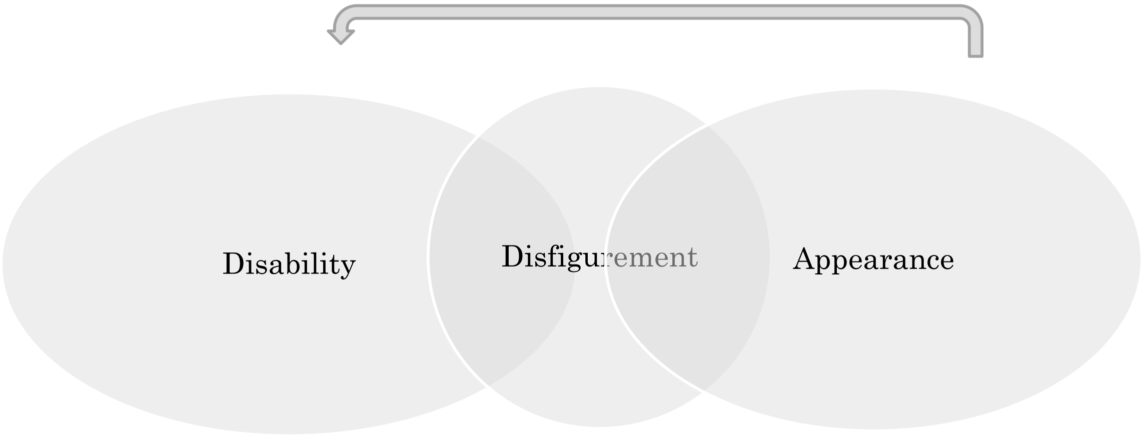
[481] See Oxford Dictionaries online, <https://en.oxforddictionaries.com/definition/disfigurement> accessed 29 April 2019.

[482] Blacks legal dictionary online, <https://thelawdictionary.org> accessed 29 April 2019. In *Blyth v Historic Scotland*, the Tribunal noted that "Disfigurement is variously defined in recognised dictionaries as a blemish, defacement, defect, deformity, or something which mars or spoils the appearance"; see *Blyth (n470).* A similar focus can be found in some US case law; in *Superior Min. Co. v. Industrial Commission (1923) 309 Ill. 339, 141 N.E. 165* the court defined disfigurement as "that which impairs or injures the beauty, symmetry, or appearance of a person or thing; that which renders unsightly, misshapen, or imperfect, or deforms in some manner".

[483]The relationship between impairment and disability is influenced by models of disability, discussed further at 4.3 below.



In legal terms, being able to differentiate these three concepts is vital because they have different legal consequences - people with a disability or a severe disfigurement (represented by the overlap between disability and disfigurement) are granted equality rights. People who have an imperfection of appearance, or a moderate disfigurement, are not. Understanding the relationship between these concepts is therefore key to defining where disfigurement (and disability) stop, and appearance begins.

4.2.1 THE RELATIONSHIP BETWEEN DISFIGUREMENT AND DISABILITY

The relationship between disability and disfigurement stems from two related factors; first, models of disability, and second, legislation.

Turning first to models of disability, as outlined at 1.2.2, many people with a visible difference would not be disabled under medical model principles, because disfigurements often don't hinder the individual in doing particular activities. They are, however, hindered by social attitudes towards someone who looks different. This simple distinction encapsulates the essence of the medical / social model distinction, and Chapter 3 has already discussed the societal barriers faced by many people with a visible difference. The social model therefore explains the overlapping conceptual relationship between disability and disfigurement: attitudes facing someone who looks different can be disabling.

This conceptual overlap is reinforced by the law. The Act categorises severe disfigurement as a deemed disability. Its definition of disability in section 6 is functional; the disadvantage which it seeks to capture and respond to is rooted in a medical model analysis. The severe disfigurement provision, on the other hand, seeks to capture another type of disadvantage. The Act is not express about the nature of this but, implicitly, appearance-related disadvantage is its target, rooted in a social model analysis and the attitudes of society towards people who look different. (It is worth clarifying here that the 'disadvantage' referred to should perhaps more accurately be termed 'difference'. Some writers have argued powerfully against assumptions that any departure from physical 'normality' should necessarily be seen as disadvantageous or inferior rather than simply different[484]. Concepts of disadvantage are, however, intricately bound up in the Act's medical model-led definition of disability, with its focus not on difference but 'adverse' effects, which explains the use of the term 'disadvantage' here.)

In the case of both the definition of disability in section 6 and the severe disfigurement provision, the relevant type of disadvantage must result from impairment. This means that those who are placed at serious functional disadvantage, perhaps by having a lower than average IQ or a personality trait of low self-confidence, do not fall, without more, within the protection of the Act. Similarly, it is clear that the Act does not intend to protect pure differences of appearance (without impairment) even where these produce severe disadvantage. This is so despite evidence showing that people can face attitudinal barriers because of the way they look *without* having an impairment. Appearance and disfigurement are part of a spectrum, and beautiful people have a better chance at leading beautiful lives[485]. They are likely to be perceived by others not just as more attractive, but also more socially adept, and more successful[486]. The implicit

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[484] Ron Amundson, 'Biological Normality and the ADA' in Leslie Pickering Francis and Anita Silvers (eds), *Americans with Disabilities* (Routledge 2000) 103.

[485] See, for example, Langlois and others (n243) 403.

[486] Dion, Berscheid and Walster (n242) 288 .

corollary of this is that we less than beautiful people – who don't have a disfigurement but are prone to a few spots, whose ears stick out more than we'd like, or who are carrying an extra stone in weight - are relatively disadvantaged because of it. Impairment thus acts as a filter, separating the 'unlucky' disadvantage of appearance and function from the actionable disadvantage of appearance and function resulting from impairment.

It could be argued that the scope of the law is wrong; that disadvantage (or, stepping back from the law's assumptions of inferiority, difference) should be the sole determinant of equality rights, and that extra 'filters' such as impairment, and criteria as to duration and substantiality / severity, are unwarranted. These theoretical arguments are discussed further at 1.3.1. The focus in this section, however, is more immediate. Rather than addressing what the law should, as a matter of principle and legal theory, protect, this Chapter begins by evaluating an even more basic requirement: whether the Act's current drafting *achieves* its underlying choices. If, as suggested above, the aim of the severe disfigurement provision is to counter appearance-related disadvantage which meets specific thresholds, the relevant question can be framed as follows: do all people who experience severe, long-term appearance-related disadvantage resulting from impairment receive equality rights under the Act?

4.3 THE RELATIONSHIP BETWEEN DISFIGUREMENT AND APPEARANCE

As noted above, disfigurement and appearance are part of a spectrum but equality law engages with one part of that spectrum only: an impairment which consists of a severe disfigurement[487]. The first step in understanding the relationship between disfigurement and appearance is therefore to analyse the filter of impairment.

The term 'impairment' is included in the Act's provisions on both functional and appearance-related disadvantage (disability and severe disfigurement respectively). Impairment is not defined in the Act but case law determines that a

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[487] Equality Act 2010, Sched 1, S.3.

physical impairment means “something wrong with them physically”[488], and it is an undemanding threshold which is to be given its ‘ordinary and natural meaning’[489].

The Guidance on the definition of disability is clear that, in determining whether an impairment exists, it is not necessary for tribunals to identify its cause[490]. In most situations, this benefits claimants, who are relieved from the obligation of proving why they have a particular impairment – they simply have to prove its existence, which can often be helped by a consideration of the effects of the alleged impairment on the ability to perform day to day activities. Sometimes Tribunals have adopted a ‘back to front’ approach by identifying the effects on day to day activities first, and assuming that "as a matter of common-sense inference" any effects found must point to the presence of an impairment producing them[491]. Accordingly, someone can still be disabled even when doctors cannot identify a cause for the problem they are experiencing. Although this sounds simple, closer examination of the legal concept of impairment reveals fault lines beneath the surface.

The first fault line is that a binary distinction between impairment and non-impairment (i.e. physical norms) is often too simplistic. Numerous degrees of human functioning exist, making an assessment of what is ‘normal’ or ‘impaired’ tricky. Mary Crossley argues that “the immense variety found in human bodies makes it quite difficult to draw a bright line between those bodily characteristics that are considered impairments and those that are not”[492]. A second, related, fault line appears where an issue falls close to the dividing line between appearance and disfigurement. The binary distinction between impairment and physical ‘normality’ is joined by a third category: imperfections of appearance. These are both undefined and unprotected. So how does the law differentiate what is ‘wrong’ (i.e. impairment), both from what is ‘normal’ (i.e. unimpaired) and from what is unimpaired but looks different?

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[488] *Rugamer v Sony Music Entertainment UK Limited* [2001] IRLR 644 para 34.

[489] *McNicol v Balfour Beatty [2002] IRLR 711, para 17.*

[490] Equality and Human Rights Commission, *Employment Statutory Code of Practice*, (The Stationery office Limited, 2011), Schedule 1 Para 7.

[491] *J -v- DLA Piper LLP* UKEAT/0263/09/RN, para 38.

[492] Mary Crossley, 'Impairment and Embodiment' in Leslie Pickering Francis and Anita Silvers (eds), *Americans with Disabilities* (Routledge 2000) 112.

The challenge of separating appearance from impairment sometimes encourages Tribunals to fall back on the physiological cause underlying a condition[493]. Although this sits uncomfortably with the Guidance which, as outlined above, places the emphasis on the effect of an impairment rather than its cause, a focus on biomedical causation is clearly identifiable in case law under the Act. In *Hussain v Sky In-Home Services Ltd*[494], a male claimant who was 4'8" (without a proven, relied-on, medical cause) was held not to have a physical impairment. Yet someone of a similar height due to restricted bodily development appears likely to qualify for protection given the express inclusion of this condition in the Guidance on the meaning of 'severe disfigurement'[495]. The Employment Tribunal made a particular point of noting that the Claimant's short stature had not been expressly argued as resulting from a hormone deficiency, despite a suggestion of this in a doctor's letter. The physiological cause of a characteristic *is* therefore sometimes relevant to its status as an impairment.

Judging impairment by reference to biomedical causation is not always clear cut, however. As the boundaries of medical knowledge expand, we are increasingly able to identify underlying physiological reasons for aspects of the way we look and age as well as for conditions more traditionally viewed as impairments. Physiological causation can't always delineate the two concepts. The issue of hair loss illustrates this. In the Scottish case of *Campbell v Falkirk Council*[496], the claimant (a 61-year-old man) complained of unfair dismissal and disability discrimination. His disability claim relied on the fact that he was balding. Mr Campbell's claim was actually made under the standard definition of disability rather than the severe disfigurement provision, but this made little difference as both require the presence of an impairment, which the Tribunal found was not satisfied. The Tribunal commented that "if baldness was to be regarded as an impairment then perhaps a physical feature such as a big nose, big ears or being smaller than average height might of themselves be regarded as an impairment under the DDA."[497]

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[493] See also Wasserman (n22) 149 on this point.

[494] ET/2300908/16

[495] Restricted bodily development is generally interpreted as a final adult height of 4'10" or less; see Restricted Growth Association, (undated), <https://rgauk.org/about-restricted-growth> accessed 29 April 2019.

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

[497] Ibid para 15.

The reason for the claimant's hair loss in this case is not expressly referenced in the judgment, but male pattern baldness (also known as androgenetic alopecia) commonly occurs as a part of the ageing process. Statistics suggest that up to 50% of men aged over 50 experience male pattern baldness[498], and on that basis, the Tribunal's finding that hair loss was not an impairment (and therefore a matter of appearance but not disability or disfigurement) is unremarkable. Yet there is an identified physiological cause for male pattern baldness: both genetic and hormonal factors tend to play a part, inducing the hair follicles to shrink permanently, making them unable to support hair growth[499]. Why is this biomedical reason less valid than that underlying other types of impairment? A biomedical causative approach doesn't always explain why the law finds impairment in some aesthetic characteristics but not in others.

The distinction in *Campbell* becomes more complex still when we consider other causes of baldness. Alopecia areata, for example, affects only 2 in 1000 people in the UK and can cause partial or total hair loss of the head and body at any stage of life, but predominantly in those under thirty[500]. It is believed to result from an autoimmune condition and, unlike male pattern baldness, it tends not to occur gradually over years but suddenly, repeatedly and in clumps. It is commonly associated with stress and can be very traumatic for those affected, as well as very visible to other people. If different types of hair loss should be treated differently by the law (and it is submitted here that those suffering from alopecia areata *do* satisfy the criteria of impairment), clarity on the issue of non-functional impairment is crucial to ensuring that the boundaries of protection are properly drawn[501].

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[498] William Cranwell and Rodney Sinclair, 'Male Androgenetic Alopecia' (2016) *Endotext* https://www.ncbi.nlm.nih.gov/books/NBK278957/ accessed 31 January 2019.

[499] Alopecia UK (undated), <https://www.alopecia.org.uk/Pages/FAQs/Category/types-of-alopecia > accessed 30 January 2019).

[500] Anonymous, 'Hair loss reversed in alopecia areata sufferers', *BBC* <https://www.bbc.co.uk/news/health-28834058> accessed 30 January 2019.

[501] Because alopecia affects the hair follicles, which are part of the skin, it can arguably be thought of as a skin condition, and skin conditions are listed in the Guidance as a potential form of severe disfigurement. The International Classification of Functioning, Disability and Health also lists baldness as a 'problem of skin function' – see World Health Organisation, 'A practical manual for using the International Classification of Functioning,

So, the presence of a physiological cause underpinning a particular condition doesn't always offer a reliable way of sifting impairment from imperfections of appearance. But an additional filter is perhaps implicit: prevalence. Male pattern baldness was (at least within Mr Campbell's demographic) extremely common. The prevalence of a condition does not necessarily reduce the social barriers or stigma that it engenders[502], and it is often associated with distributive arguments about opening the floodgates[503]. But prevalence perhaps becomes an even greater obstacle when it comes to conditions which only impact appearance; it is harder to argue that an aesthetic characteristic is a physical 'wrong' (i.e. an impairment) when it is shared with a significant proportion of the relevant population. Prevalence blurs with appearance 'normality', making it harder to prove impairment, and accordingly less likely to fall within the Act's scope.

Case law suggests that prevalence is being used as a blunt tool. In *Hussain*, for example, the Employment Tribunal, as part of its reasoning for finding that the (adult male) Claimant's short stature was not an impairment, relied on the fact that women and children are often short too[504]. The implicit logic appears to be that a man is not impaired on the basis of short stature because being short is prevalent among a lot of other people – including children. But clearly a normal height range for a man is different from a normal height range for a child, and perhaps also for a woman. The Tribunal's blunt comparison fails to take into account the relative nature of appearance which must be salient if taking prevalence into account to differentiate appearance from impairment.

By way of further example, consider again the issue of hair loss. Despite placing particular importance on facial disfigurements due to their visibility, the

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Disability and Health (draft)', https://www.who.int/classifications/drafticfpracticalmanual2.pdf?ua=1 accessed 29 April 2019, para 2.3. This argument may help anyone seeking to claim that alopecia is a severe disfigurement.

[502] Obesity is one example of this. See 4.4 below.

[503] For an example of a recent case where the issue of prevalence has been expressly acknowledged as a policy argument in restricting the definition of disability, see *Taylor v Ladbrokes Betting and Gaming Limited* [2017], UKEAT/0353/15/DA, para 9.

[504] (n494) para 32.

Guidance[505] is silent about (often very visible) hair conditions. Remembering *Campbell*[506], the decision (that baldness – presumably male pattern baldness - was not an impairment) implies a keenness to distinguish (unprotected) issues of appearance from (protected) issues of disability and disfigurement. The comparative examples cited by the Tribunal (a big nose, big ears or being smaller than average) are common physical appearance traits. But while male pattern baldness may be a common feature of appearance for men of Mr Campbell's age, it is much less common in young women. An 18-year old woman with severe male pattern baldness (despite the name, it can happen to women too) would stand out to a much greater degree from her peers for this reason. Yet, neither the Act nor the Guidance expressly situate the threshold of impairment or severe disfigurement within the context of the personal characteristics of the person affected.

Hair loss is not the only example of a condition which can fall either side of the cusp of impairment according to personal context. Consider, for example, a man with enlarged breast tissue, which would be considered aesthetically normal for women[507]; or significant facial hair growth on a woman, which would be considered a common feature of appearance for men; or wrinkled skin[508] or varicose veins on an adolescent, which may be a prevalent appearance trait in older people. The need for context applies to the concept of severe disfigurement, too, as well as impairment. It is submitted that a condition such as vitiligo, which causes patches of bleached skin to appear, may readily meet the threshold of impairment irrespective of personal context, but a relative approach may help some people with vitiligo (especially those with darker skin tones) to meet the threshold of severe disfigurement.

Just as disability is individually determined (by assessing the effects of an impairment on that specific person's ability to carry out normal day to day

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[505] (n276).

[506] (n496).

[507] Gynecomastia is swelling of the breast tissue in men due to hormonal imbalance.

[508] Genetic and Rare Diseases Information Center, 'Wrinkly skin syndrome' 2016) <https://rarediseases.info.nih.gov/diseases/273/wrinkly-skin-syndrome> accessed 1 February 2019.

activities, rather than the typical impact of that condition on people generally[509]), so potential disfigurements should be assessed individually relative to *that* person's appearance. Disfigurement (and impairment as one aspect of the legal test) should not be viewed as a universal standard irrespective of context, but as a measure of the extent to which that person's appearance is impaired by 'something wrong with them physically'[510]. This personal context allows the law to recognise that a condition which may be relatively commonplace within a particular demographic (such as baldness in men over 60) can be a physical wrong and have a much greater negative aesthetic impact on the appearance of someone with different personal characteristics.

It is worth clarifying that the contextual approach presented here is not based on misplaced assumptions about appearance 'mattering more' to certain groups of people. The law has, until recently, been coloured by such an assumption in relation to personal injury, with the JC Guidance prior to 2017 [511] providing that damages for a woman who sustained a facial disfigurement should be greater than those for a man sustaining a similar injury. This appears to have been based on an erroneous assumption that the extent to which appearance 'matters' to someone will be affected by their gender (an assumption which has been challenged by a considerable body of research in the social sciences[512]). Instead, the proposition argued here is that a characteristic which is a commonplace appearance characteristic for a person of one demographic (such as thinning hair for an older man, or acne for a teenager) may be an impairment for another.

So, in assessing whether the law achieves its aim of protecting all people who experience severe, long-term appearance-related disadvantage resulting from impairment, the concept of impairment comes under particular strain. This results in some people being excluded from protection even where the characteristic in question has an underlying physiological cause, and makes the person stand out

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[509] *Paterson v The Commissioner of the Police of the Metropolis* [2007] UKEAT 0635/06, para 39.

[510] *Rugamer* (n488).

[511] Judicial College, *Guidelines for the Assessment of General Damages in Personal Injury Cases* (13th Edition, OUP, 2015) 81.

[512] See, for example, Thompson and Kent (n204) 668. Interestingly, the most recent 14th edition of the Judicial College guidelines still includes an uplift of damages for younger people.

within their demographic, creating social barriers for that reason. The concept of impairment, as it applies to non-functional limitations, is in urgent need of review.

Setting the issue of impairment aside, the meaning of 'disfigurement' is also problematic. The apparent logic behind the severe disfigurement provision is, as identified above, one of appearance-related disadvantage. Yet the Act doesn't use the word 'appearance', but 'disfigurement'. The two concepts are connected (especially when linked by impairment) but it is arguable that common usage of the word 'disfigurement' creates a narrower subset of appearance-related disadvantage than 'appearance'. Instinctively, 'disfigurement' is usually associated with certain types of appearance-related impairments, such as scars and birthmarks, at the expense of others, such as stained and missing teeth, hair loss, or other impairments which have the potential to create appearance disadvantage. This creates a mismatch between the underlying logic of the law and its scope.

Whereas the noun of (severe) disfigurement suggests that there is a static, self-contained 'thing' (such as a scar, a birthmark or similar) to be judged, the logic of appearance-disadvantage plus impairment would include an impairment which has a *disfiguring effect*, without the condition itself *being* a disfigurement.

The example of facial movement impairments illustrates this point. A facial movement impairment is any condition which affects the way that the face moves, voluntarily or involuntarily. Tourette syndrome, for example, can cause involuntary facial tics and fleeting contortions of the face. While some sufferers also experience other symptoms such as vocal tics (which would be likely to meet the usual definition of disability because of the impact on speech), for others the disruption of facial expressions is the defining feature of the condition[513]. Similarly, synkinesis can cause involuntary grimaces to be trigged by voluntary movements, such as smiling, and facial palsy means paralysis in part of the face which can prevent or affect normal facial movements such as smiling.

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[513] In *Vatcher v Kelly Services (UK) Ltd [1999] UKEAT 595_99_0510*, the Claimant had facial tics of Tourette's syndrome which did not meet the standard definition of disability. The EAT refused to hear his contention that this amounted to a severe disfigurement for procedural reasons: they determined that the argument had not been made at the original hearing.

There are strong arguments suggesting that the law should not treat facial movement impairments differently from other types of visible difference, because the case law on disfigurement places importance on a number of factors present in facial movement disorders.

First, case law demonstrates that an impairment which hinders facial expressions (as facial movement disorders often do) is more likely to meet the definition of severe disfigurement. In *Johansson v Fountain Street Community Development Association*[514], for example, the fact that the Claimant's facial expressions were found to be 'normal and appropriate'[515] contributed to a finding by the Northern Ireland Industrial Tribunal that the Claimant's disfigurement was not severe.

Second, impairments affecting facial movement often create (intermittent or ongoing) facial asymmetry. Consistent with a strong body of research demonstrating the importance of facial symmetry to judgments about appearance[516], the limited case law on severe disfigurement shows that Tribunals are often prepared to take facial asymmetry resulting from an impairment into account in determining whether the threshold is met[517].

Third, facial movement impairments are not easy to disguise with make-up, and very likely to be visible at a distance. This is another factor that features strongly in reported case law. In *Griffiths*[518], for example, the Tribunal placed importance on the fact that, when the Tribunal clerk was asked what the Claimant looked like, she described him as a 'balding man with glasses and moustache' without noticing his facial scar. Similarly, in *Hand*[519], the Tribunal noted that the scarring was visible both when the Claimant came to the front to give evidence, and when she sat further back in the room, and decided that she had a severe disfigurement.

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[514] (n472).
[515] Ibid para 7.
[516] See Domagoj Svegar, 'What does facial symmetry reveal about health and personality?' (2016) 47 Polish Psychological Bulletin 356, for a summary of some recent research on this issue.
[517] *Hand* (n473) para 2(b).
[518] *Griffiths v Lancashire CC* (n475).
[519] *Hand* (n473) para 2(b).

These three practical arguments suggest a degree of commonality between facial movement disorders and other types of disfigurement, which may be useful to anyone wishing to argue a facial movement impairment as a severe disfigurement. Yet, despite this commonality, instinctively some facial movement impairments (particularly those which cause excessive facial movements rather than facial paralysis) feel like an awkward fit with the severe disfigurement provision as it is currently drafted.[520] When preparing this argument, not one person who was consulted informally on the issue[521] instinctively aligned conditions such as Tourette syndrome and synkinesis with the concept of severe disfigurement.

It is submitted that the reason for this disconnect is linguistic. The phrase 'which consists of a severe disfigurement' in the Act implies an unchanging state. This doesn't lend itself easily to conditions which can alter from one moment to the next. This is reinforced by the examples given in the Guidance of which almost all (with the exception of a small proportion of skin conditions) would usually be permanent and unchanging. We might tend to describe a scar as a disfigurement but a condition which causes involuntary additional facial movements as a *disfiguring condition*; the latter description focuses more on the appearance-altering power of the condition rather than the appearance of the condition itself. A definition which allowed greater focus on disfiguring *effects*, rather than disfigure*ment*, may resolve this disconnect. This focus may benefit people with conditions beyond facial movement disorders too – the severe dandruff-like skin flakes in the eyebrows and scalp produced by seborrheic dermatitis, or the visual impact of excessive facial perspiration are examples of conditions which are a difficult fit within the word disfigure*ment* because of their processual, ongoing nature, but which surely produce a disfiguring effect and appearance-related disadvantage.

In summary, common usage of the word 'disfigurement' highlights a narrow subset of appearance-related impairments, which risks making other appearance-related impairments (such as facial movement disorders, and conditions which can produce

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[520] It is submitted that facial movement impairments which prevent, rather than create, facial movement – such as facial palsy – are an easier fit within the implicitly static concept of 'disfigurement'.

[521] No attempt is made to suggest that these informal consultations were academically rigorous, but simply informal discussions with colleagues and a practising lawyer on the general principles.

varying degrees of disadvantage according to the personal characteristics of the person concerned) legally invisible.

4.4 THE RELATIONSHIP BETWEEN DISABILITY AND APPEARANCE

Given the positioning of the concept of disfigurement, one might not expect significant overlap between the areas of disability and appearance without the engagement of disfigurement too. However, obesity is one area where this overlap occurs, and will now be discussed.

Some obese people will experience functional effects from their size, such as restricted mobility or joint pain. If sufficiently substantial and long term, these functional effects would bring them within the reach of disability law. But some people are obese without it affecting what they can do. This was alleged to be the case in the recent ECJ decision of *Kaltoft*[522], where the claimant argued that he had been dismissed from his job because he was obese, but that his size did not prevent him from fulfilling his role[523]. His case was that he was discriminated against because he was fat, not because his weight impacted on his activities.

On this point, there is strong evidence that people who are overweight are stigmatised because of it[524]. This can take a number of forms; from stereotypes of laziness and low self-control, to health policy-induced stigma designed to encourage people to lose weight. Under a social model analysis, there clearly are barriers hindering overweight people even when their ability to carry out day to day activities is not affected. Research from the US suggests that those who feel stigmatised because of their weight are more at risk of a variety of adverse psychological and physical health consequences, including further increases in

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[522] Kaltoft (n72).

[523] Bruno Waterfield and Justin Huggler, "I don't feel my weight is a big problem,' says Dane in EU obesity ruling' *The Telegraph* (24 May 2019) <https://www.telegraph.co.uk/lifestyle/wellbeing/diet/11302442/I-dont-feel-my-weight-is-a-big-problem-says-Dane-in-EU-obesity-ruling.html> accessed 24 May 2019.

[524] World Health Organisation, 'Weight bias and obesity stigma: considerations for the WHO European region' (Copenhagen, undated), <http://www.euro.who.int/__data/assets/pdf_file/0017/351026/WeightBias.pdf> accessed 24 May 2019.

obesity levels[525]. Weight stigmatisation therefore seems to have a complex interaction with disability.

In *Kaltoft*, the ECJ considered when obesity could be a disability. They began by reaffirming a definition of disability from the earlier case of *Ring*, which partially reflects a social model understanding of disability:

> 'a limitation which results in particular from long-term physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers '[526].

This definition locates disability in the interaction between impairment and external barriers (which could presumably include attitudinal barriers and stigmatisation). However, the ECJ then progressed to narrow its analysis by suggesting that this definition would be fulfilled only in cases of functional limitation, such as "reduced mobility or the onset, in that person, of medical conditions preventing him from carrying out his work or causing discomfort when carrying out his professional activity"[527]. The examples given appear to suggest that the ECJ's interpretation of a 'limitation' is a functional one such that obesity will only be a disability if it produces functional limits or hindrances on what the person can do, such as walking upstairs, or performing daily work tasks without getting out of breath. If this was their intent, the decision appears to take a significant step back from the social model of disability, as it fails to recognise the stigma barriers faced by Mr Kaltoft on account of his size[528]. This implicit inconsistency perhaps indicates that further clarification of the law on obesity is likely in the future.

Despite apparently strong reasons for recognising non-functional obesity as a disability, it is possible that one complication in doing so, as touched on earlier, is the issue of prevalence. Obesity is very common (it is estimated that over 25% of the UK adult population is obese, and around 3% of us are morbidly obese with a

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[525] Rebecca M. Puhl and Chelsea A. Heuer, 'Obesity stigma: important considerations for public health.' (2010) 100 The American Journal of Public Health 1019, 1023.

[526] *Kaltoft* (n72) para 53.

[527] Ibid para 60.

[528] Waddington (n68) 587.

BMI over 40[529]). Indeed, some studies predict that morbid obesity levels in the UK are set to double over the next twenty years[530]. Extending equality rights to people with all degrees of obesity would represent a significant expansion of the numbers (on paper, at least) of disabled people. This could give rise to (possibly ill-founded[531]) policy concerns about opening the floodgates, both in terms of numbers of potential claims and other duties on employers such as the need to make reasonable adjustments. Although not expressly mentioned in *Kaltoft*, the prevalence of (non-functional) obesity does perhaps makes it more likely to be viewed by some as an issue of appearance rather than impairment.

There is already a considerable body of scholarship which considers whether, and how, obesity should trigger equality rights, but the legal relationship between disfigurement and obesity merits further exploration. *Kaltoft* was not a UK case so the claimant would not have been able to argue that the severe disfigurement provision in s.3 of Schedule 1 applied. However, regardless of the jurisdictional aspect, this probably would not have helped him in any event; to suggest that obesity could be a severe disfigurement seems to stretch the statutory wording beyond breaking point linguistically, even with the aid of a definition focused on appearance disadvantage. It is also extremely doubtful whether many people who are overweight would self-identify as having a severe disfigurement.

But the ongoing tussle over equality rights for people who are obese has an important ramification for disfigurement law; if obesity is not recognised, this creates inconsistency with a number of other conditions which may be more likely to fall under the severe disfigurement provision. Conditions such as lipoedema, lymphedema and elephantiasis, for example, all cause bodily swelling, usually just in the legs and ankles, (and, for lipoedema, the arms). These conditions are not caused by overeating (lipoedema is thought to be hereditary fat cell deposit problem affecting women, primary lymphedema is caused by a genetic problem in the lymphatic drainage system, and elephantiasis is a reaction to mosquito bites) and they can all affect people irrespective of their prior BMI. Like obesity, sometimes

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[529] Carl Baker, 'House of Commons Briefing Paper No 3336' (20 March 2018).

[530] Bethany Minelle, 'Morbid obesity in Britain to double within twenty years', (2018), *Sky* <https://news.sky.com/story/morbid-obesity-in-britain-to-double-within-20-years-11385734> accessed 30 January 2019.

[531] Wasserman (n22) 154.

they limit what the person can do. They can be painful and can reduce mobility, but not in all cases. They are much less common than obesity among the population (both elephantiasis and primary lymphedema are rare, and lipoedema is thought to affect up to 1 in 9 women[532], of whom only a much smaller percentage would be severe cases potentially qualifying as a severe disfigurement), which helps to avoid suggestions that these conditions are common matters of appearance only, rather than impairments. Yet observers (and sometimes even medical professionals) often mistake conditions such as lipoedema for obesity[533], which suggests that the experiences and social barriers faced by all groups are likely to be similar.

A further inconsistency could arise in respect of formerly obese people who, having lost weight, may be left with excess skin. Despite a lack of case law on this point, it is arguable that this excess skin could be viewed as a type of skin condition resulting in (severe) disfigurement, leading to the slightly illogical conclusion that, while obesity is not treated as a disability in the absence of functional consequences, the visible effects of *former* obesity may be. Failing to give equality rights to obese people could therefore create inconsistencies or exclusions which are hard to justify.

To summarise, the boundaries between the concepts of appearance, disfigurement and disability are blurred at the edges, leading to likely uncertainty and the potential for inconsistency in situations falling close to these boundaries. This creates tension as the courts grapple with a desire not to open the scope of disability so wide that they are protecting issues of appearance through the back door and imposing a disproportionate burden on employers. The tension stems, perhaps, from trying to impose binary legal categories (disabled or not, severely disfigured or not) onto spectrums which include both appearance and impairment, and the stigma which can accompany them. The areas where this tension is most apparent are those where the protected areas under the Act (disability, and severe disfigurement as a subset of that) meet issues of appearance. At these transition boundaries, we find inconsistency.

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[532] Donald W. Buck and Karen L. Herbst, 'Lipedema: A relatively common disease with extremely common misconceptions' (2016) Plastic Reconstructive Surgery Global Open 1043, 1043.

[533] Ibid.

Comparison of the Act's wording with its implicit logic of protecting those who experience severe, long-term appearance-related disadvantage resulting from impairment reveals a mismatch, suggesting that the Act is not meeting its own aims. Chapter 6 addresses the extent to which this mismatch can be addressed by law reform.

4.5 HOW SEVERE IS 'SEVERE'?

Turning now to the severity threshold located within s.3 of Schedule 1 to the Act, there is no further definition within the Act on what constitutes a severe disfigurement, but it will be remembered from paragraph 4.2 that the Guidance provides that:

> 'Examples of disfigurements include scars, birthmarks, limb or postural deformation (including restricted bodily development), or diseases of the skin. Assessing severity will be mainly a matter of the degree of the disfigurement which may involve taking into account factors such as the nature, size, and prominence of the disfigurement. However, it may be necessary to take account of where the disfigurement in question is (e.g. on the back as opposed to the face).'[534]

The Act makes no distinction between congenital or acquired conditions, though tattoos which have not been removed, and piercings, are expressly excluded.[535]

The open scope of this concept has, to some extent, been addressed in case law, but with little resultant clarity. In *Hutchison 3G UK Ltd v Edwards*[536], the claimant worked in a mobile 'phone shop, and was asked to wear a company polo shirt. He suffered from Poland syndrome which caused a significant asymmetry of his chest cavity which, he felt, would have been obvious when wearing a polo shirt. His condition also made some movements (e.g. pushing / pulling) more difficult. The first instance Tribunal decided that Mr Edwards had a severe disfigurement, but this was appealed, with the respondent arguing that the Tribunal did not have

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[534] Office for Disability Issues (n276) Para B25.

[535] The Equality Act 2010 (Disability) Regulations 2010 (n11), reg 5.

[536] (n280).

enough evidence in front of it on which to reach this conclusion. The Employment Appeal Tribunal ('EAT') expressed discomfort about being asked to make visual judgments on the extent of a disfigurement evidenced photographically or in person, recognising that 'the protection is afforded to those for whom issues of appearance are likely to be particularly sensitive'[537]. The EAT concluded instead that it was entitled to take into account 'the impact of the disfigurement on the claimant'[538] in assessing the severity of a disfigurement – in other words, the claimant's perception of, and behavioural response to it. By promoting 'a degree of sensitivity'[539] in the evidential requirements for establishing severe disfigurement, the EAT introduced both flexibility for claimants and uncertainty for respondents, accepting that different forms of evidence may suffice in different cases. The EAT did, however, conclude that the test for severe disfigurement could not be wholly subjective; 'not simply what the claimant believed to be the case'[540].

Prima facie, this decision is favourable to claimants, allowing more people to meet the evidential threshold and balancing the Act's requirements of process with 'respect for inherent dignity'[541] of the claimant. However, it could conceivably disadvantage claimants whose disfigurements are borderline in their severity, but who have not allowed their life choices to be inhibited. Tribunals must guard against this, as it threatens to remove access to justice for those who have exercised a 'full and effective participation in society'[542]; the antithesis of what disability law policy, enshrined in the principles of the CRPD, seeks to achieve.

4.5.1 THE BODILY LOCATION OF DISFIGUREMENT

Returning to the Guidance[543], it is clear that the bodily location of the disfigurement is one factor to be taken into account in deciding whether the severe disfigurement threshold test is met. In *Blyth v Historic Scotland*[544], for example, the Tribunal

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[537] ibid para 56.
[538] ibid para 55.
[539] ibid para 57.
[540] ibid para 60.
[541] CRPD art 3(a).
[542] CRPD art 1.
[543] Office for Disability Issues (n276).
[544] (n470).

noted that the claimant's psoriasis was mainly on her torso and legs; parts of her body which she covered up. The Tribunal found her not to have a severe disfigurement. In *Whyte v First Capital East Ltd*[545], again the EAT found that the claimant's folliculitis on his back was not a severe disfigurement, commenting that 'location is important as it affects ordinary people's judgment about its severity…protection against discrimination … is more necessary when it is visible on the face than when it is invisible on the backside'[546] [sic].

This focus on invisibility suggests that the rationale for the guidance lies at least partly in how likely the disfigurement is, given its location, to be seen by others. On one level, this seems both logical and in line with the social model of disability, reflecting the frequency with which attitudinal barriers would be expected to be encountered. But, while recognising that facial disfigurements can be particularly challenging for those affected, on closer analysis the possibility that this guidance will be used to exclude non-facial disfigurements from equality protection is troubling in two respects.

First, it creates an expectation that a disfigurement which *can be* covered, *should* be covered; or, at least, that legal redress may be limited where it *could have been* covered. While the Guidance which accompanies the Act provides that:

> '[a]ccount should be taken of how far a person can reasonably be expected to modify his or her behaviour, for example by use of a coping or avoidance strategy, to prevent or reduce the effects of an impairment on normal day-to-day activities'[547],

the emphasis of these coping mechanisms is on small, practical activity choices, such as avoiding skiing, but not shopping, to alleviate back pain. The issue of coping mechanisms is not directly relevant to severe disfigurements which, as discussed above, do not need to satisfy the substantial adverse effect test. But linking the bodily location of a disfigurement with its severity imports a similar expectation; that a person will cope by hiding their difference. Far from being a small, practical

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[545] (n471)

[546] ibid para 34.

[547] Office for Disability Issues (n276) para B7.

activity choice, this goes to the root of the individual's self-identity and body image. The respect for difference and human diversity[548] emphasised in the CRPD reflects a move away from the 'care or cure' approach to disability, embodied in the medical model, towards an approach which values disability not as 'a "mistake" of society but an element of its diversity'[549]. Restricting access to justice in situations where diversity can be covered up is a retrograde step which shifts the focus away from the employer's alleged discriminatory behaviour back to the specifics of individual impairment.

The second concern with the focus on the visibility of the bodily location stems from the risk of conflating visibility and knowledge. While a disfigurement in a visible place, such as the face, is very likely to become known to others, the converse is not necessarily true; disfigurements in places of the body often covered by clothes can also become 'known'. They could, for example, be disclosed voluntarily, gleaned from a sick note, or visible in hot weather. So, while facial disfigurements are likely to be noticed and at risk of stigmatisation, thus meriting legal redress, it isn't the case that disfigurements on the torso are immune from such stigma or undeserving of legal remedy if they do give rise to discrimination.

It is submitted that, instead of using the likelihood of a disfigurement being noticed to exclude some people from the definition of disability, the better approach (and one which reinforces the CRPD's focus on hindered participation) is for the employer's actual knowledge and conduct to be assessed on the facts of each case in determining whether discrimination has taken place.

4.5.2 PROGRESSIVE CONDITIONS

Although the Act makes provision for progressive conditions generally[550], (the Act provides that a person with a progressive condition is protected as a disabled person from the first time when his impairment has some adverse effect, provided that the

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[548] CRPD art 3(d).
[549] United Nations, (n 47) 13.
[550] EA 2010 Sched 1, Pt 1, s 8.

adverse effect is likely to become substantial in the future) similar protection has not been afforded to people with progressively disfiguring conditions, such as neurofibromatosis type 1[551] or vitiligo[552], which are likely to lead to severe disfigurement.

The progressive condition provision under the Act was introduced to combat stigma before the condition reached a stage where the substantial adverse effects test was satisfied; a recognition of social barriers pre-empting functional barriers. HIV, multiple sclerosis and cancer are expressly included as disabilities[553], rather than being left to fall under the progressive conditions provision, because they were identified as conditions which could be diagnosed and lead to stigmatisation while the affected person was asymptomatic, thereby also failing the progressive condition test. There is an obvious parallel here with progressively disfiguring conditions, which may *never* produce an adverse effect on day-to-day activities, but which can lead to stigmatization from an early stage.

The CRPD does not discuss progressive conditions, because it does not need to; its concept of disability is not limited by reference to a given level of impairment. Someone with a progressively disfiguring condition would be covered by the CRPD from the moment that the condition, in interaction with various barriers, has the potential to hinder full participation in society. The failure to extend the progressive condition protection to disfigurement is therefore out of step with the CRPD. It is arguable that, if this point were tested in court, this gap could be easily filled without sacrificing the integrity of the Act's existing provisions. However, the lack of clarity may discourage such claims being brought in the first place.

The discussion in this section so far has raised several concerns which are, directly or indirectly, related to one thing: the threshold test of severity. The real question is therefore not how severity should be determined, but whether the severity threshold should exist at all.

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[551] Neurofibromatosis Type 1 is a genetic condition which can cause (usually benign) tumours to grow over time along the nerves, both inside the body and on the skin. In some people, it also causes other symptoms such as scoliosis, high blood pressure and learning difficulties.

[552] Vitiligo causes patches of skin to lose pigmentation, often progressively.

[553] EA 2010 Sched 1, Pt 1, s 6(1).

4.5.3 WHY HAVE A SEVERITY THRESHOLD?

When the severity threshold for disfigurement was first introduced (in the Disability Discrimination Act 1995 ('DDA'), which preceded the Act), Parliamentary records show that the rationale was a presumed assumption that more serious disfigurements will always elicit worse discrimination. This was questioned during the passage of the Bill through the Lords, as follows:

> 'The Government protect those with severe disfigurement; but, as the charity Changing Faces makes clear, discrimination is not related to the severity of disfigurement or to the severity of disability. Small wounds can be very disfiguring, whereas a large burn carried by an airman may be worn with pride as a sign of war. Alternatively, mild facial palsy is, for example, very isolating. Therefore, it is not size, it is not seriousness and it is not the conspicuousness of disfigurement which affects the person's ability to cope: it is another person's perception of it. Yet, such a person would not be protected under the provisions of the Bill.[554]'

However, the amendment proposed to resolve the issue was one of perceived disability rather than one directed specifically at disfigurement. At the time, perceived discrimination was not provided for within the DDA (although it has subsequently been incorporated into the Act) and the amendment was not passed. Arguments that 'if the definition of disability is too narrowly drawn, there may well be people who are disabled but who are not protected'[555], were overridden to prevent the net being drawn so widely that '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[556]'. However, with the benefit of twenty years of hindsight, the binary distinction in the Act between severe and non-severe disfigurements still appears hard to justify for the following reasons:

1. Studies in the field of psychology (see 3.2 and 3.3) continue to confirm that this assumption of clinical severity leading to worse consequences is wholly unreliable: reactions to minor or moderate disfigurements, in terms of the

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[554] HL Deb, 1995, vol 564, col 1642 Baroness Hollis of Heigham.
[555] ibid, vol 564, col 1650.
[556] ibid, vol 564, col 1650, Lord Mackay of Ardbrecknish.

psychosocial impact on the individual, can often be as damaging as those experienced by people with severe disfigurements[557] and, despite variability, there is evidence that some people with relatively minor disfiguring conditions experience higher levels of both depression and social anxiety than their more severely disfigured counterparts[558].

2. The severity threshold for disfigurement is inconsistent with the threshold test for disability in the Act, that of 'substantial adverse effect'. 'Substantial' is defined in the Act as 'more than minor or trivial'[559] which has, in turn, been interpreted as a relatively low standard. An ordinary reading of the word 'severe' denotes a higher threshold than 'substantial' (as evidenced, for example, by national security threat levels where severe is a more serious level than substantial). This suggests that functional impairments are treated by the Act as more disabling than the social barriers of disfigurement, necessitating staggered thresholds for the law to engage. Once again, this sits uncomfortably with a body of evidence which demonstrates that people with a disfigurement are as likely to suffer discrimination in the workplace as people with other types of disability. As mentioned above, studies have found that a person with a disfigurement is at least as likely to be discriminated against in the job application process as someone in a wheelchair[560], although interestingly one of the studies found this was only prevalent in sectors involving a high degree of customer contact[561], perhaps indicating that employers are fearful of the reactions of customers. Similarly, a study in the US asked workers about their levels of discomfort in working with people with different disabilities, and a facial disfigurement featured highly in the rankings of reported discomfort[562]. There appears, therefore, to be little justification for imposing a higher threshold for equality rights based on disfigurement than on other types of disability.

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[557] See e.g. Macgregor (n219), 232.
[558] Rumsey and others (n250), 450.
[559] EA 2010 s 212(1).
[560] Stevenage and McKay (n267); Stone and Wright (n268) 521.
[561] Stone and Wright, ibid.
[562] Jones and Stone (n272) 915.

Accordingly, it is submitted that the 'severity' threshold for disfigurement is unjustified and inconsistent. In contrast to the CRPD, in which 'the challenge facing a person with a disability is measured in terms of the existing barriers and not on the category or percentage of the impairment'[563], the severity threshold represents a familiar retreat to the ideology of the medical model, pushing the focus back onto the level of impairment. Given the sensitivity of issues of appearance (as recognised by the EAT in *Hutchinson 3G Limited*), requiring a person to prove that he is 'severely disfigured' as a precondition to challenging discrimination runs counter to the principles of respect for difference[564] and the inherent dignity of the person[565], and inhibits effective access to justice[566] as required by the CRPD. For these reasons, it is submitted that the severity requirement should be removed or at least reduced to the level of substantiality in line with s.6.

4.6 THE LEGAL DICHOTOMY BETWEEN FUNCTION AND AESTHETICS

A further hurdle arises in the interpretation of a disability which '*consists of*' severe disfigurement. In *Cosgrove –v- Northern Ireland Ambulance Service*[567], the claimant had psoriasis which amounted to a severe disfigurement but which the parties agreed would not, but for the 'deemed disability' provision of severe disfigurement which existed under the DDA 1995 at the time (and which was similar for this purpose to the current provisions under the Act), have satisfied the definition of disability. He was denied a job as an ambulance person due to the risk of irritants aggravating his condition at work, an increased risk of infection for him through broken skin, and an increased risk of cross-infection for his patients. Mr Cosgrove argued that this amounted to disability-related discrimination but his argument hinged on whether the impairment was the psoriasis as a whole (argued by Mr Cosgrove) or merely the disfiguring aspect of the psoriasis. This interpretation was crucial because, while the refusal of the job was causally connected to the symptoms

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[563] United Nations, (n47) 18.
[564] CRPD art 3(d).
[565] CRPD art 3(a).
[566] CRPD art 13.
[567] (n466).

of psoriasis, particularly broken skin, it was not connected to the disfiguring appearance of the psoriasis.

The Court of Appeal (NI) decided that '[a]n impairment 'consisting of' disfigurement means, in common parlance, that the impairment relates solely to the cosmetic aspect of the condition'[568]. Although the claim was decided in relation to disability-related discrimination, it appears likely that it would also apply in relation to other forms, such as discrimination arising from a disability.

It is questionable whether this narrow interpretation of a disability consisting of a severe disfigurement made much practical difference to a claimant in Mr Cosgrove's medical context, as the treatment could perhaps have been objectively justified, subject to a meaningful risk assessment process being carried out. However, the narrow interpretation could make a greater impact in other contexts. Had Mr Cosgrove applied for an office job, for example, the identified risks would presumably have been much reduced and, as a consequence, the withdrawal of the offer much less likely to be objectively justifiable. But his claim would still have failed as the withdrawal of the job offer would not arise from the disfiguring aspect of his condition.

The real problem with Cosgrove stems from the statutory wording ('a disability which *consists of* a severe disfigurement'), but the court's literal interpretation missed an opportunity to tackle this; they commented that if someone in Mr Cosgrove's situation was intended to be included with the embrace of the relevant section, 'a phrase such as "includes severe disfigurement" could have been used'[569]. The decision leaves many people who have a complex disfiguring condition (by which I mean one which includes an element of disfigurement and some other symptoms or effects) in an 'either/or' position; if aiming to prove disability under the standard test in s.6 of the Act, the aesthetic aspect of the condition is irrelevant, but if applying the deeming provision for severe disfigurements, the non-aesthetic aspects of the condition are not protected against discrimination. This runs

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[568] Ibid para 16.
[569] Ibid.

contrary to the way in which other disabilities under the Act are dealt with, where a cumulative approach to minor functional impairments is taken[570].

Cosgrove encapsulates the conflict between the social and medical models; its graceless approach implies that someone can be disabled either by attitudes towards people who look different or by functional effects of their impairment – but not both. By implication, the law declares that Mr Cosgrove encountered 'the wrong type of barrier', which is a far cry from the more complex 'interaction with various barriers'[571] envisaged in the CRPD. As a Northern Irish decision, *Cosgrove* is persuasive but not binding in England and Wales, which may allow an opportunity for the limitations of the decision to be departed from.

Having set out the limitations of the Act's approach to disfigurement, there are two avenues which, though not featuring significantly in the reported case law on disfigurement discrimination, may contribute to mitigating these limitations: perceptive discrimination, and reasonable adjustments.

4.7 MITIGATING THE ACT'S LIMITATIONS

4.7.1 PERCEPTIVE DISCRIMINATION

Someone with, say, a moderate disfigurement, who does not satisfy the 'severe' threshold test, may be able to base a claim of direct discrimination or harassment on the respondent's *perception* that he has a severe disfigurement. Perceptive discrimination claims recognise that discrimination can occur on the basis of a protected characteristic which the victim does not have. By way of example, in *English v Thomas Sanderson Ltd*[572], Mr English brought a successful harassment claim when he was subjected to a campaign of homophobic verbal harassment, despite the fact that he was heterosexual. Perceptive discrimination embodies the

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[570] Office for Disability Issues (n276) para B4-B6.
[571] CRPD art 1.
[572] (2009) ICR 543.

social model of disability, in that it recognises that disability can be externally created, not inherent within the individual.

Claims based on perception are permitted under the Act because the wording of both s. 13 (direct discrimination) and s.26 (harassment) is wide enough to allow a claim to be brought where the claimant does not actually have the protected characteristic (in this case, disability). Assume the example of an employee with a small facial haemangioma who is called an offensive nickname at work and told that he cannot be promoted to a client-facing role because of his face. The law's perception of his level of disfigurement may be different from those of his employer and colleagues, in that a Tribunal may find his disfigurement to be only moderate, so not disabling. But a claim that he has been discriminated against and / or harassed because of his employer's perception may enable this gap to be bridged.

However, discrimination because of perceived disability claims are not straightforward because disability (unlike, say, race or sex) has a threshold test (set out in s.6 of the Act) which a claimant has to meet. To what extent does the decision-maker have to know of, or put his mind to, the elements of that specific legal test before he can be said to perceive disability? In the recent case of *Coffey*, the EAT (subsequently confirmed by the Court of Appeal[573]) confirmed that:

> '[T]he answer will not depend on whether the putative discriminator A perceives B to be disabled as a matter of law; in other words, it will not depend on A's knowledge of disability law. It will depend on whether A perceived B to have an impairment with the features which are set out in the legislation.'[574]

Although *Coffey*'s confirmation of the application of perceptive discrimination to disability is welcome, the case is in other ways disappointing; it is likely to lead to a series of denials by decision-makers about the scope of their perception. However, this hurdle may be easier for people with disfigurements to overcome than for people with some other types of disability. This is because a moderate disfigurement, which is perceived by the employer to be severe, should be able to

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[573] *The Chief Constable of Norfolk v Coffey* [2019] IRLR 805

[574] *The Chief Constable of Norfolk v Coffey* [2018] IRLR 193, para 51.

bypass the 'substantial adverse effect' test contained in s.6; severe disfigurements (presumably including *perceived* severe disfigurements) are *treated as* satisfying that definition. Does this make a difference? Seemingly, yes. It means there is nothing for the respondent to put his mind to save for whether the claimant has a severe disfigurement. Comments like those envisaged in our fictional scenario would seem to make it difficult for the respondent to deny this perception. A perceived disability claim may prove a useful alternative where the severity of the disfigurement is contested.

Perceptive discrimination claims can also apply where the perpetrator knew the victim not to have the characteristic which formed the basis of the harassment[575]; in *English*, for example, the people harassing Mr English knew him not to be gay but harassed him with homophobic abuse anyway. One of the judges in that case noted as 'barely perceptible'[576] the distinction between someone harassed because he is believed to be gay and someone harassed *as if he were* believed to be gay. Although the facts of the case are perhaps unusual – claims where people are harassed as if they had a severe disfigurement even when they are known not to have one will be few and far between – the court's approach has important implications for disability law in two respects. First, the court placed the focal point of its analysis firmly on the discriminatory conduct, not on the characteristic of the victim. This affirms the social model's external focus and contrasts with the Act's approach to severe disfigurement, where the threshold test excludes many claims at the hurdle of proving disability. Second, in *English*, Sedley LJ recognised that sexual orientation is a matter which many people may prefer to keep private[577], so the law should not require its disclosure in order to challenge discrimination. Given the 'gruelling and personally invasive'[578] process of having one's impairment publicly scrutinised in a disability claim, this recognition of needing to balance privacy with principles of legal process is welcome; requiring someone to undergo a public analysis about whether they are both severely disfigured and disabled is a doubly unreasonable impediment to accessing justice.

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[575] EHRC (n490) para 7.10.

[576] *English* (n572) para 38, per Sedley LJ.

[577] Ibid para 39.

[578] Lawson (n283) 361.

Where the claim relates to discrimination on the basis of actual, rather than perceived, disability, it is hard to conceive how to prove disability (as it is currently defined in the Act, at least) without the intrusion of some enquiry. But the CRPD requires procedural accommodations to ensure that justice is accessible[579]. The Employment Tribunals have the power to make anonymity orders and restricted reporting orders but the requirements for these orders to be made are stringent. This is an area which could be further developed to prevent worthwhile claims being deterred.

A different type of perception connected with appearance is also conceivable; perceptions formed because of the way someone looks can also relate to assumed impairments of other kinds. For example, an employer may assume that a member of staff must be having cancer treatment because she has suddenly lost her hair. Or that a colleague with a red, bulbous nose caused by the skin condition rhinophyma must be an alcoholic. Or indeed that someone who is extremely thin must have an eating disorder.

These examples do expose an inconsistency in the perceptive discrimination concept, though; although the hair loss example might qualify for legal protection (because cancer is a disability under the Act), the rhinophyma/ alcoholism example may not because alcoholism is excluded from protection as a disability under the Act[580]. Although the policy reasons for excluding alcoholism would not apply to the person with rhinophyma who was disadvantaged by the perception, it is hard to imagine how the courts would resolve this given the wording of the Act. A similar issue could arise from scars perceived to relate to illegal drug use – also an excluded condition under the Act[581].

In summary, although perceptive discrimination provides a useful legal tool in some situations, it is not enough on its own to solve the apparent shortcomings in the severe disfigurement provision.

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[579] The UN's 2017 recommendations to the UK included a variety of measures to make justice more accessible for disabled people, including increased availability of legal aid and reasonable adjustments in the justice system. See UN Committee on the Rights of Persons with Disabilities (n352) para 33.

[580] The Equality Act 2010 (Disability) Regulations 2010 (n11), s.3.

[581] Ibid.

4.7.2 REASONABLE ADJUSTMENTS

The second area worthy of specific mention, but perhaps overlooked in its potential to assist people with disfigurements, is the duty to make reasonable adjustments. Unlike the issues discussed already, the duty does not affect whether someone with a disfigurement is deemed to be disabled, but how they should be treated once that threshold is assumed to have been met. The concept of reasonable accommodation is also provided in the CRPD[582].

The duty to make reasonable adjustments under the Act applies to the following scenarios:

1. where a provision criterion or practice ("PCP") puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled;
2. where a physical feature (of premises) puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled; and
3. where a disabled person would, but for the provision of an auxiliary aid, be put at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled.

The requirement is to take such steps as are reasonable to avoid the disadvantage (in the case of the first and second requirements) or provide the auxiliary aid (for the third requirement).

The application of the duty to disfigurements is not initially obvious in the way that it would be for a disability with a clear functional consequence. While a ramp may provide a neat solution to the disadvantage of an office entrance step for someone in a wheelchair, the mechanics of adjustment are perhaps more obscure where the

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[582] CRPD art 5(3). For a discussion on the CRPD duty generally and how it compares to the duty under the Act, see for example, Fraser Butlin (n285) 435.

impairment is a disfigurement. I would argue, however, that the duty can be applied practically for the benefit of many people with a visible difference, and a number of potential applications will now be put forward.

Auxiliary aids are unlikely to be relevant for someone with a 'pure' disfigurement without functional limitation. Physical features of premises, too, often represent no problem for people with a disfigurement, though there are some exceptions; for example, both cold and dry air can exacerbate psoriasis symptoms, and artificial and natural light can aggravate photo-dermatological skin conditions, potentially requiring adaptions to air conditioning settings, workplace lighting, or seating arrangements. Such issues need to be assessed on a case by case basis.

PCPs, though, have broader relevance. One example of a formal PCP is company 'look policies' and dress codes. Although prescriptive policies setting out how members of staff should present themselves are unusual, many employers have some kind of uniform requirement; the company polo shirt is, after all, what led to Mr Edwards' claim. Rigid enforcement of such a dress code may place employees with a severe disfigurement at a substantial disadvantage. In *Riam Dean v Abercrombie and Fitch*[583], for example, the employee had been allowed to wear a cardigan on the shop floor to hide the join of her prosthetic arm. When a manager asked her to remove the cardigan and she refused, she was told to work in the stock room as she didn't comply with the company's look policy. The Tribunal upheld her claim of harassment and found that there had been a withdrawal of a reasonable adjustment relating to the cardigan, as well as a wrongful dismissal. Although the claimant on this occasion preferred to cover up, it is submitted that the opposite situation – had she been *asked* to cover up by wearing a cardigan, for example - would also have been unlawful.

PCPs relating to performance evaluation may prove problematic given the subconscious tendency to associate negative character traits with visibly different people (which was discussed at 3.3.2). Policies which involve making judgments about staff may need to be adjusted to remove the possibility of any hidden discriminatory bias. A particular area of concern is soft skills such as 'teamworking ability', 'attitude' or 'ambition' which are almost invariably subjective and could

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[583] Unreported (August 2009).

easily be influenced by unfounded assumptions of how popular, employable or capable someone is likely to be. Ongoing training for managers about implicit bias and its effects seems to offer potential for improvements[584] by making subconscious bias and its effects conscious, but evaluation scoring systems can also be made clearer and linked to objectively verifiable criteria.

PCPs sometimes relate to the nature of the role itself. Returning to the psychological consequences identified earlier, some people with a visible difference report feeling particularly uncomfortable meeting new people[585]. A role requirement to give external presentations or attend networking events, for example, could therefore put an employee at a substantial disadvantage compared with someone who is not disabled. Even where the employer is aware of the disfigurement, though, the employee may need to expressly explain the nature of this substantial disadvantage in order to trigger the duty to make reasonable adjustments[586] as, unlike the 'wheelchair and office step' scenario envisaged earlier, it may not be reasonable for an employer to investigate such an adjustment without knowledge of this impact on the employee.

Once aware of the disadvantage relative to people who are not disabled, the employer is under a duty to take reasonable steps to prevent the PCP creating that disadvantage. Possible reasonable adjustments could include role support, such as mentoring and social skills training, or a variation of role duties. Open communication is important, to prevent requests for alterations to the work itself being 'interpreted … as an employee "being awkward"'[587] and to prevent unjustified assumptions.

A final category of PCP worth particular mention in this context, given the social difficulties complained of by some, relates to employee relations. In *Smith v HM Prison Service*[588], the employer was found to have failed to make reasonable

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[584] See, in the context of implicit racial bias: Patricia G. Devine and others, 'Long- term reduction in implicit race bias: A prejudice habit-breaking intervention' (2012) 48 *Journal of Experimental Social Psychology* 1267.
[585] Robinson (n139) 103.
[586] Mark Bell, 'Mental Health at Work and the Duty to Make Reasonable Adjustments' (2015) 44 Industrial Law Journal 194, 208.
[587] Foster (n350) 77.
[588] Unreported, August 10, 2004. See IDS Diversity at Work 9 (March 2005) 22.

adjustments for an employee with a severe facial disfigurement by failing to prevent continued bullying. It is pertinent here that the bullying was directed not just at the Claimant but also some of her colleagues; there was negative equality of treatment. But the Tribunal recognised the claimant's heightened sensitivity to bullying in the light of her condition (which the employer should also have been aware of) which placed her at a substantial disadvantage in comparison with people who were not disabled.

Reasonable adjustments for people with a visible difference are discussed further in the empirical findings at 5.6.2.

4.8 CHAPTER 4 SUMMARY

The analysis in this Chapter contributes to the remaining Research Questions as follows:

Progress towards Research Question 1: targeting disadvantage	**Research Question 1(a)** has already been answered at 3.4.1: visibly different people are a disadvantaged group. In relation to **Research Question 1(b**), this chapter has demonstrated that the Act does not accurately identify the true scope of disadvantage of visible difference; its narrow scope excludes many people who are disadvantaged because of aesthetic conditions which place them outside of relevant appearance norms but which do not meet these threshold concept of impairment, disfigurement or severity. Post-*Cosgrove*, the Act also probably excludes some who *do* meet the severity threshold but are discriminated against because of a minor functional (rather than aesthetic) impact of their disfigurement, thus again failing to target all relevant disadvantage as required by **Research Question 1(b)**. While the concept of perceptive discrimination may sometimes prove useful in closing a gap between the Act's scope and the true scope of disadvantage of visible difference, the concept is limited in some respects, preventing it from remedying all of the above problems (as discussed at 4.7.1)

	Research Question 1(b) will be returned to in Chapter 5.
Progress towards Research Question 2: intersectionality	In relation to **Research Question 2(a),** section 4.3 identifies a slightly different manifestation of intersectionality. The law fails to take into account the way that some aesthetic conditions (such as baldness, for example) intersect with personal characteristics (such as gender or age) to make the person ‘stand out’ (e.g. someone suffering from pattern baldness as a young woman). This results in a rigid concept of ‘severe disfigurement’ which fails to grant equality rights despite the increased social barriers found at these intersections between characteristics. Intersectionality will be further discussed in Chapter 5. **Research Question 2(b)** was answered at 3.4.2.4.
Progress towards research Question 3: reasonable adjustments	**Research Question 3(a)** was answered at 3.4.3.1. Under **Research Question 3(b),** section 4.7.2 (on reasonable adjustments) demonstrates that, despite the duty to make reasonable adjustments being limited in some respects, it still has the potential to be applied for the benefit of some people with severe disfigurements. The extent to which it is being applied *in practice* will be addressed in Chapter 5.
Research Question 5: access to justice	It is submitted that a lack of certainty over the scope of the severe disfigurement provision, and the need for potential claimants to prove that they

	are both severely disfigured and disabled in order to claim, with the loss of privacy entailed by evidential Tribunal procedures, are likely to inhibit effective access to justice. This will be explored further during Chapter 5.
Research Questions 4,6, 7 and 8: recognition, structural change and remedies	Research Question 8 was answered at 3.4.6. Research Questions 4, 6 and 7 will be addressed in Chapter 5.

5. EMPIRICAL RESEARCH

5.1 CHAPTER INTRODUCTION

Five themes were identified from the participant interviews. These are:

Theme 1: *Me* and visible difference – a complex equation of how I feel
Theme 2: Me, *you* and visible difference – balancing coping and explaining against privacy
Theme 3: Me, visible difference and *work* – my health needs and my job in conflict
Theme 4: Me, visible difference and *society* – feeling that I fall between the cracks
Theme 5: Me, visible difference and *rights* – solidarity vs wariness

5.2 THEME 1: *ME* AND VISIBLE DIFFERENCE – A COMPLEX EQUATION OF HOW I FEEL

5.2.1 THEME 1 SUMMARY

Theme 1 shows that issues of confidence are interwoven into the participants' experiences with other factors in a way which is impossible (and probably undesirable) to completely detangle. Almost all participants expressed feelings of low confidence and / or self-consciousness, probably related to visible difference, at different times of their life. But there are various factors which some participants believed impacted on the way they felt - such as fluctuations in the severity of their condition, self-acceptance, gender, age and level of job experience. There was not one unified picture amongst participants of 'what helps' and 'what hinders'. What these accounts do suggest, though, is that visible difference cannot be understood as an isolated, sole determinant of people's experiences; the importance of other aspects of life - such as friends and family, pride in the job and in my own skills, a role helping others – are also integral to the experiences recounted.

5.2.2 THEME 1 DETAIL

This multi-faceted theme is broken down into three sub-themes which help to explain its complexity:

A: Feeling self-conscious, low in confidence and worrying about being judged
B: A jigsaw of factors affect how I feel
C: There's more to me than visible difference.

Theme 1 Sub-theme A: Feeling self-conscious, low in confidence and worrying about being judged.

In terms of understanding the impact of visible difference on the person's state of mind, almost all of the participants mentioned what I understood to be some degree of feeling self-conscious or low in confidence, either at specific times of their lives, or for some, as an ongoing issue throughout life. Participant G explained that:

> PARTICIPANT G: "You're a different person when you’ve got something that’s very obviously recognisable as a difference. So the person I am today is not the person I was then, 20 years ago, because I was confident before that. Then it takes away your confidence. So you don’t actually fight back. You don’t defend yourself, because you feel that it’s indefensible. Well, I personally did, and I'm looking at a lot of the stories of people with facial palsy and they certainly feel the same way. Because it takes away a person’s confidence in themselves. It makes people feel insecure."

This accords with the body of research reported at paragraph 3.2.2, which suggests that many people with a visible difference suffer psychological effects from their condition.

Many participants indicated that interactions with others had the potential to affect their self-confidence too; while some interactions are felt as positive and supportive (such as Participant I's recollection of colleagues who were 'movingly wonderful' when he/she developed a facial difference overnight), other interactions were damaging to the way the individual felt about himself/herself:

> PARTICIPANT R: “It's weird, we've discussed this on the Facebook group, there's one, '[message board]' and we say, ‘It's always on the day where you're having a really good day, you feel quite good about yourself and then somebody just comes out with something.’ Then all your confidence goes or you get close to tears.”

> PARTICIPANT E: “Or I’ve had a few people who actually say ‘do you realise you have a lump on your neck, do you think you need to have that looked at’ and things like that. So then that makes me feel very, very self-conscious and slightly upset because then I feel the need to say ‘no I know what the lump is’.”

Apparently well-intentioned comments can have this effect sometimes too:

> PARTICIPANT B: “The only time I really get comments actually are when people say ‘oh your skin is looking really good at the moment’. [...] Which of course the counter to that is [laughs] God, it must’ve looked awful before…”

which highlights a fine line between what is felt by participants as emotional support and what is felt as upsetting.

Feeling 'judged' often accompanied the discussion of feeling self-conscious. This was felt to be either on the basis of perceived intellect or personality:

> PARTICIPANT Q: “Just because I know, when I first started going out and about, when I was looking at my worst, people sometimes did judge you in a way where they thought maybe you were a bit slow or you had something going on with your brain ..."

> PARTICIPANT K: “They think I'm no good because I look different”.

While this tallies with the body of research discussed at paragraph 3.3.2, which focuses around the theme of 'beauty is good' and the judgments people make based on appearance, it is also worth noting that several participants questioned the extent to which their feelings of being judged are influenced by their own expectations, making it hard to be certain where the balance lies between others' views and anticipations of particular views. For example:

> PARTICIPANT B: "Erm…and, but it's, it's kind of playing off between the paranoia of 'have they noticed, what do they think' and the actuality of 'are they making a judgment about me…?'"

This highlights the complexity of untangling emotions when so many internal and external factors may play a part: for some there is a conscious uncertainty whether I am being judged or just *feeling* that I am being judged.

Particular situations, too, were cited as giving rise to an increase in self-consciousness in some, especially giving presentations, speaking in public, being filmed or photographed, or interviewed by strangers:

> PARTICIPANT C: "…and the main thing has never been for me, 'Oh, I'm going to have to do a presentation,' because, God, I've done a million of them. [...] It's, 'Oh, God, what am I going to look like? What angle are they going to have the camera on? Is that going to affect… When they play it back and they see me, are they just going to focus on my palsy rather than listening to what I'm saying?'"

> PARTICIPANT N: "I think that's the other thing. Erm…if you have the confidence to (.) go for an interview then that's half the battle, no matter how you look, because I think that comes across as being, it's not an issue how I look. That's not an issue, [...] I don't worry about it, so don't you worry about it."

> PARTICIPANT H: "The interviews generally will involve presentations [...] and I really struggle standing up in front of a group of people talking for ages because my face just becomes like a big neon light in my head, you know what I mean? I just think people are just staring at that and then my confidence just goes out the window."

This partly links with a large body of scholarship, such as that summarised at paragraph 3.3.1, which connects negative reactions of the public with social anxiety in some people with a visible difference. But the dislike of public speaking was not common to all participants in this study, with some expressly mentioning feeling comfortable in these kinds of situations. Equally, while it might commonly be assumed that people with outgoing personality types would tend to be more confident and less self-conscious, I did not always find this reliably in the data - some participants, for example, who describe themselves as outgoing and loud, explained feelings of intense self-consciousness at times:

> PARTICIPANT H: "I come across as very confident, very gobby, chatty, you know…[...] quirky, and therefore I think people don't ever consider how, I'm going to swear, fucking hard it is for me just to walk out the door sometimes. So I guess it's my own bloody fault for being so good at hiding it [laughs]."

Theme 1, Sub-theme B: A jigsaw of factors affect how I feel

Despite the sub-theme of self-consciousness being very apparent to me in the data, the accounts also revealed quite a number of factors which were perceived as influencing the participants' self-perceptions.

First, there was mixed evidence here on whether self-consciousness and low confidence were linked to the participants' self-rated severity. Some participants appeared to feel a clear correlation (i.e. the less severe my visible difference, the more confident I feel). For example:

> PARTICIPANT Q: "…I think, at the beginning, I would say 'severe', to the point where I kind of had to make myself go out in public because I was so self-conscious of my face. [...] Yes, I would say 'mild' now because it doesn't affect me that much, and very severe at the beginning, really life changing then in terms of how I felt about seeing people."

Whereas others gave compelling accounts of moments of self-consciousness despite rating their own severity as 'mild'. For example:

> PARTICIPANT M: “Kids stare at- even, you know, last weekend, a little girl was staring at me in the way that hasn’t happened, actually, for quite a while. [...] I just, kind of, half stared back, and I wish they wouldn’t. Again, I don’t have a strategy. I still haven’t worked that one out.”

This finding supports existing research detailed at para 3.2.2 which suggests that there is not always a straightforward correlation between self-rated severity and psychological distress.

The impact of both getting older and accepting oneself was highlighted by some participants as affecting how they felt, with many indicating that coming to terms with their visible difference as they got older decreased their levels of self-consciousness or appearance-related concern:

> PARTICIPANT M: “I’ve decided I don’t want my appearance to change, actually. They could, if I wished, but I don’t think it’s that bad any longer [...] And I don’t want to not be me, but it’s been hard in the past, being me.”

> PARTICIPANT D: “And, like, so, my surgeon is like, "I can do something to your lip. I can make it look better." And I'm like, "For who? Is that something you want to do or something that I've asked you to do? I haven't come to you and said that that's an issue. You're saying you can do that." Whereas previously, I might (.) have, like, jumped at that opportunity in a way that now I'd be like, "I can't really be bothered".

> PARTICIPANT P: “I would never have spoken about it openly at all, say, up to- I’m going to say up until the age of 40.”
>
> INTERVIEWER: “Right. Why do you think that is?”
>
> PARTICIPANT P: “I think I didn’t feel confident enough. I hadn’t accepted it myself, so I didn’t feel comfortable myself talking about it. I think I tended to have the, sort of, bury your head in the sand, if you don’t discuss it, then no-one notices it…"

However, the participants' medical experiences were very varied in this regard; some had had a visible difference from birth, others had acquired a difference later on. Some had almost recovered from a temporary visible difference, while others felt theirs had got worse over time, and some were still facing the prospect of further surgery and potentially further changes to their appearance. 'Acceptance', therefore, was not something which could be assumed to have occurred in the same way for everyone as they aged, or something which, once achieved, was necessarily permanent, and some perceived no correlation at all between ageing and confidence in their appearance. As Participant M explained:

> PARTICIPANT M: "Everything has been pretty much fine for 45 years, but my current dentist has now discovered there may be a problem with my upper jaw [...] And as a result of this- this has happened just since Christmas, I have started acknowledging that I am cleft person, having denied it for all these years."

There was also a concern expressed by some (though not all) participants that young people face more appearance pressure generally, which can make coping with a visible difference as a young person much harder:

> PARTICIPANT B: "Yeah, I would say more the aesthetic pressures on me as a 20-year old were very different to me as a [late thirties] year old."
>
> INTERVIEWER: "Mmm – greater when you were younger or less extreme?"
>
> PARTICIPANT B: "Greater."

As set out at paragraph 3.4.2.3, this is a moot point in existing scholarship, so the fact that the participants in this study disagreed about the impact of youth on their experience of visible difference tends to support a lack of a clear relationship on this point.

In addition, some in this study perceived this pressure to have increased in recent years as society has developed - with societal expectations of beauty, and social media, being perceived to have increased the pressure on today's young people:

> PARTICIPANT C: “If I’d been – if I was 16, 17, 18 now, in the age of social media, with a facial palsy, that would be even more horrendous than when I was a child. Then, it was bullying and the pressure to look perfect is so much more now than when I was younger.”

The evidence on this latter point is very limited, though, because most of the participants in this study were not in the 0-30 age bands. There was only one participant below the age of 30, and a sense of appearance pressure or low confidence did not feature strongly in his/her account:

> PARTICIPANT A: "I don’t let my condition be part of, don’t be me, and it’s something that I've got, but I'm not (.) that condition. [...] I'm someone with that, but I'm also this person and that person, and this, so I'm quite lucky that I've just gone out and I've been able to be quite confident about it."

In some accounts, there was also a suggestion that the age or other personal characteristics of the beholder may be relevant to the interaction – and that older people are less likely to be judgmental:

> PARTICIPANT C: “Older people just don't give a monkey's. They don't care what you look like at all and they don't care what they look like, particularly. I think all that, sort of, social thing about what you look like just seems to disappear as you get older. People are more concerned about, ‘How can I help them?’ and, (.) I don't know, they just don't care about what you look like, really.”
>
> INTERVIEWER: “Which is actually quite interesting, because that's not just your age but their age impacting.”
>
> PARTICIPANT C: “I do think people in their teens, 20s and 30s, possibly into their 40s are far more judgemental about how people look. Then, once

> you get to a certain age, you're more accepting, I think, and you've got bigger fish to fry, really”.

> PARTICIPANT K: “The manager on the panel of the job interview I haven't got is not exactly God's gift. She's my age. She's probably about my age. You know, so…She looks normal, but she's 50. She's not going to discriminate against somebody else, is she?”

This doesn’t accord with the existing scholarship discussed at paragraph 3.4.2.3, which identified people within the age band of 45-64 as *more* likely to be biased against people who look different. But it does perhaps reinforce the interpretivist focus on the wider context of interactions as being crucial to a true understanding of the participant’s subjective reality.

In addition to age, a few participants felt that gender impacted on the way they felt about themselves:

> PARTICIPANT Q: "I know I stood in front of the mirror and thought, "What do I do? Do I put make-up on and risk my mascara running down my face because my eyes are [...] watering all the time? Do I put lipstick on and then it makes it look ridiculous because my mouth can't smile on both sides? I couldn't go to a business meeting and not do that, on the other hand, because that would feel wrong as well. So, I think from that point of view, maybe a lot of it is how you feel about yourself [...] rather than anybody else's expectations. Yes, I do think it is slightly different that maybe a man might feel he could go back into that scenario a bit sooner…"

> PARTICIPANT G: “It’s almost like being treated differently in a setting of women. A kind of feeling of being picked out as, ‘Well, you're not the pretty one,’ or, ‘You’re not the fun one,’ because others are more like that. Because if you're laughing you would kind of put your hand over your mouth. Or you might not join in so much with certain things, or be quite as sociable, because you don’t want to be. Or that it makes you feel more tired. It affects your general health. It’s kind of very subtle (.) but it’s there.”

> PARTICIPANT R: “I think being a woman with all this… You know what it's like these days, everyone's got to be gorgeous and beautiful and there are all these selfies and, you know, everywhere, isn't it? I think it is harder as a woman with society's conformity on being perfect. When you're absolutely nowhere near it, you kind of just think, ‘Oh, great’”.

There is a suggestion in these extracts that the internal view - how one sees oneself - is very much linked with how we think other people see us, and these expectations can be influenced by macro societal expectations that women should be beautiful. However, a caveat should be included that 15 out of 17 participants in the data set were female, and so it does not provide adequate gender balance to enable this idea to be fully explored.

Theme 1, Sub-theme C: There’s more to me than visible difference

The third sub-theme picks up an important thread which ran through almost all the interviews: there’s more to me than visible difference. It acknowledges that visible difference is just one part of a personal equation. This sub-theme broadly aligns with the research set out at paragraph 3.2.2, which highlights the importance of positive factors which help to ‘buffer a person against the stresses and strains of living with a visible difference’[589].

First, many of the participants demonstrated real pride in their skills and abilities in the workplace, and in education. In wanting employers who focus on what they can do not what they look like, many participants placed significant emphasis on their achievements, their potential, and their experience, and in some cases, wanted greater focus on this:

> PARTICIPANT A: “It was one of the tutors, like your personal tutor, but she was kind of quite adamant. She went, ‘Oh, no, a grade C is okay.’ I was like, ‘No, no, I want to get a grade A. I worked really hard for this, I want to get my grade.’ She went, ‘Well, I don’t think you….’ I said, ‘No, no, I’ll do it. Just

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[589] Rumsey and Harcourt (n140) 86.

> watch, I'll do it.' I've always kind of been very lucky that I've always been able to just, if people say that, I just kind of go, 'Well, okay, whatever'".

> PARTICIPANT G: "I've pushed myself to do a lot of things to prove to myself that I can do things".

> PARTICIPANT J: "You know, I knew I was a good [job type], I could do the job, I could do the job better than most of the lads, and I was confident with what I was doing. [...]So did it affect me? Yes, but in a way I knew I was good at my job and I knew I was a good [job type]. For me, the way I saw it as well, you know, the public are paying me to do a job. They're paying me a good salary. They don't care what I look like as long as I do my job well."

Often participants valued the support they received from friends, family, and colleagues - either on matters relating to visible difference or in more general terms:

> PARTICIPANT B: "I'm lucky in…where I am at the moment, everyone is incredibly compassionate about my skin"

> PARTICIPANT M: "I'm very happily married. [Husband] has been a star. He's known about everything from the very beginning, but he's the only one who I've ever shared it with".

And some wanted to express positive experiences at work, where they have felt that visible difference has either been irrelevant, or been dealt with appropriately:

> PARTICIPANT D: "Well, one of the reasons why I was like, 'I'll sign up to this,' is because I haven't felt any discrimination. I think often people that self-select to be involved in research like this have got a bone to pick. Axe to grind, that's the word I was looking for. Which I totally don't. I really don't feel like it has held me back in career at all, which is sort of why".

Some were proud of their employer for being inclusive and fair - and others were proud of their job. Many participants also acknowledged one or more of the daily pressures of life unconnected with visible difference, such as balancing childcare with work, ensuring financial independence, achieving a good work life balance, and wanting greater job security. All of these impacted on their experiences and perceptions of different jobs and workplaces. So, while important for many, the accounts suggest that visible difference is often best viewed within a greater patchwork of connected factors, needs, and experiences.

5.3 THEME 2: ME, *YOU* AND VISIBLE DIFFERENCE - BALANCING COPING AND EXPLAINING AGAINST PRIVACY

5.3.1 THEME 2 SUMMARY

Theme 2 relates to how people cope with having a visible difference in their daily lives. I found that a variety of proactive and reactive coping strategies exist - such as explaining, hiding one's difference or insecurity, and taking support from relevant charities and others in a similar position. Sometimes coping strategies seemed to me to focus more on self-protection - such as applying for manageable roles or avoiding jobs where appearance matters. While explaining is a common strategy, it is not always simple; participants factor in various different things when deciding whether to 'explain'. Some participants seemed to feel a conflict between a desire to explain and a resentment about having to, with the privacy sacrifice this involves for them.

5.3.2 THEME 2 DETAIL

This theme divides into 3 sub-themes:

A: How I cope with visible difference
B: To explain or not to explain?
C: Balancing explaining and my privacy

Theme 2, Sub-theme A: How I cope with visible difference

Many participants had found ways to help them cope with what they found to be difficult situations - sometimes pre-emptively, and sometimes reactively. Some were able to use social skills as a way of diffusing or preventing awkwardness:

> PARTICIPANT C: “I think I've probably compensated [...]…because I've always been very jovial and made jokes and been the centre of attention and always been the joker in the room. I've done that since I was a child and I think it's, kind of, a deflection thing, since a lot of people with disabilities or differences do that. They either become very shy and introverted or they are the complete opposite and become very extroverted and I went down that route, really, down the extrovert route”.

and using humour to describe one's condition was, for some, a way of breaking the ice. This accords with the research outlined at paragraph 3.3.3, which highlights the role of social skills in coping with visible difference. Not wanting others to see them upset was also a commonly expressed way of coping, even if the upset came out once the participant got home. A few people made reference to attempts to cope by hiding their difference - sometimes possible with clothing or make-up or, for men, by growing a beard (male facial hair was a commonly cited reason why some facial differences are sometimes perceived as being easier for men to cope with). Avoiding photographs where possible was another way of hiding, or at least preventing close scrutiny of, a difference. One participant commented that he/she always tried to dress stylishly, which I interpreted as a way of distracting from his/her visible difference.

Helping others was a thread which, I felt, was strong in some of the interviews - with several participants taking an active role in charities, or supporting other people on an individual basis. I perceived that this role helped them to cope. Quite a few participants also used the support offered by charities - particularly on message boards and social media - to help them connect with others, and as a source of coping. However, it should be acknowledged that the recruitment in this study occurred through charities, which may have influenced this finding by attracting more of those already involved with the charity.

Some coping strategies focused more on managing reality and avoiding difficult situations where possible. Avoiding applying for jobs where appearance was perceived to matter, or where the participant anticipated the potential for personal conflict, was a common theme in many accounts. Sometimes it acted to prevent the participant from pursuing career options that he/she was attracted to:

> PARTICIPANT C: "...what I really wanted to do was go into the arts. You know, acting, you know, theatre, that kind of thing, or perhaps go and work for the BBC. I was really interested in journalism and I knew that I'd never be put in front of a camera [...] so I think it would have held me back, in that respect. [...] Those jobs, you have to look good, don't you? That's the perception that you have, it's all to do with how you look if you're put on camera or on stage or whatever. So, it did affect, very markedly, the direction I took in life, really. [...] I didn't follow my dreams, if you know what I mean."

> PARTICIPANT R: "I didn't have confidence to go and, say, like, work in a bar on a Friday night and that sort of thing, because I just can't be doing with, like, drunken people, if I'm out or behind a bar. [...] People do behave differently after a few drinks. I mean, going back to when I was younger again, I was probably about 18, I was in a chip shop one night on a Friday, I'd been out with my friends. There were some guys behind me and they kept, like, you now, touching my bum and that. So, in the end, I turned around and said, 'What are you doing?' and the guy just ripped into me, 'Look at the state of you, you're not fucking speaking to me,' and he just absolutely ripped into me and tore shreds off of me".

Others avoided applying for particular jobs because of the recruitment process:

> INTERVIEWER: "when you apply for a job, do you disclose your condition at all?"
>
> PARTICIPANT D: "No. No, I don't. And actually I probably have, in the past, been put off from applying for jobs that require a video to be sent in. [...] So, I remember when I was looking for a job and I was thinking about…I was looking at this theme called [NAME]. I mean it doesn't really matter but

> basically it's quite a niche thing that they do and they have quite an interesting recruitment process. You have to have an idea like for a social enterprise you might want to have. Yeah that did put me off. I don't like, I wouldn't want to - I think I come across quite well in person. I feel quite confident going to an interview but I wouldn't want to send in a video of myself."

The idea that recruitment processes may actually deter people from applying is one that highlights the limits of the process of reasonable adjustment (which, being reactive, would not engage until the employer became aware of the applicant being placed at a substantial disadvantage in the recruitment process because of a disability). Possible ideas of best practice to counter this deterrent effect are discussed in Chapter 6.

Theme 2, Sub-theme B: To explain or not to explain?

Perhaps the most common theme which occurred in the data in relation to coping was that of explaining to deal with the reactions of other people. Not all participants had discussed their condition at work - with some feeling that it had never been an issue so had not been necessary, and some preferring to ignore the issue as a way of showing to others that it wasn't a problem. Whereas for other participants, explaining was almost a default strategy:

> PARTICIPANT A: "Just I'm very open. I'll talk to anyone about it. I'll talk people's ears off about kind of the IVF stuff and my NF. I want people to ask me. I don't want people to stare or anything like that. I want people to just be like, 'Oh, what's that? What's that with your skin,' or, you know…instead of people just making their own judgements about what they think it might be, or just being able to ask. I just tend to talk to people and say, 'If you've got any questions, just ask me, I don't care. Nothing's too embarrassing, just ask away'".

> PARTICIPANT B: "It just becomes in built, it becomes like a reflex that you know you need to do, to get through the situation."

It was sometimes used in a positive way, to educate other people about a condition and increase general awareness:

> PARTICIPANT A: "I think I'm quite open and quite confident for people to have a bad reaction, then I get to educate them and tell them a bit about it".

whereas others actively engaged in a 'weighing up' exercise, taking into account factors including the anticipated longevity of the relationship and the likely reaction of the other person, to decide whether explaining was a worthwhile investment:

> PARTICIPANT R: “Well, when I was younger - this was in the 90s - people would, like, physically recoil in an interview, some people, and some people were really nice. So, if people are nice and make you feel comfortable, then you might, sort of, mention it to them and then they understand and then that's that and you're all, ‘Well, that's that one out the way.’”

> PARTICIPANT B: "there was no (.) there was no great desire to develop a bond with the [young people] where I felt they had to know the ins and outs of my life. [...] Erm…Whereas when I’m in a working environment with colleagues, you’re working with these people day in day out, you want to develop a relationship and a rapport with them. You may not be friends with them but you want to have a rapport with them."

Sometimes the decision to explain was presented not so much as a choice but a necessity - perhaps because of a need to take sick leave or have treatment, or to deal with unwanted questions or assumptions from colleagues:

> PARTICIPANT K: "So in my current workplace, when I first started working there, people asked about the lump on my neck and asked why I had it. I explained what it was. It turns out that they’d had an employee in the past that had a tumour on her neck that moved around and she ended up having paralysis on her face and things like that. My colleagues were comparing her [inaudible] had to stand my ground and say ‘we are not the same this is not the same condition’. [...] ‘Please try to understand that what I have isn’t what

> that lady had. Don't pigeonhole me thinking that I'm going to come in with a paralysed face tomorrow'."

On occasions, some participants had felt forced to explain to deal with the contagion concerns of colleagues regarding their condition:

> PARTICIPANT B: "the person at work who went 'am I going to catch it?' I was just like…I said you're not going to catch it, it's genetic …it's because of my immune system and I just tried to explain it. This person wasn't convinced."

> PARTICIPANT F: "Sometimes with this psoriasis you get 'ooh, what's that?' My hands."
>
> INTERVIEWER: "What – people seeing your skin?"
>
> PARTICIPANT F: "yes"
>
> INTERVIEWER: "At work, that happens?"
>
> PARTICIPANT F: "They've done it at work, yes."
>
> INTERVIEWER: "Mmmm. Do you mind me asking, how do you respond? Do you have a sort of…"
>
> PARTICIPANT F: "I just go 'you can't catch it, it's psoriasis'."

Explaining was not always an easy thing to do for some participants. A couple mentioned having chosen to use pre-completed cards which they could hand to someone instead, explaining a little bit more about their condition. Both participants had found this a helpful strategy on the occasions they had used it.

Theme 2, Sub-theme C: Maintaining the balance between explaining and my own privacy

While many suggested that explaining was usually effective as a way of diffusing potential awkwardness, I also perceived a resentment on some occasions about being put in a position where participants felt they *should* explain:

> PARTICIPANT B: “...you end up managing other people’s emotions on their behalf [...] Because you …you try to put them at ease rather than manage your own emotions, and go ‘Hold on I’m the one that’s got the issue here …’”
>
> INTERVIEWER: “And I’m also having to deal with your reactions…yeah.”
>
> PARTICIPANT B: “Absolutely and you’re managing that…erm incredibly closely.”

> PARTICIPANT K: “I don't say anything. I think it's none of your business. I don't have to talk about it.”

> PARTICIPANT R: “Quite often, if some people have just come out with a flyaway question or comment, you know, ‘Have you been to the dentist?’ or, ‘Have you had a stroke?’ These days, I'm more likely to just say, ‘Did you miss your manners education?’ you know?”
>
> INTERVIEWER: “Yeah”.
>
> PARTICIPANT R: “And just, sort of, pull them up on their bad manners as a deflection or they just get a short, ‘No,’ and a stare. That's pretty much it, really. I'm sure there are ways of coping, but it’s like - you feel like, ‘Oh, why do I have to be the person who teaches this person a lesson?’”

> PARTICIPANT E: “when I’m talking to a customer in the queue and they start looking behind them or when somebody approaches the queue and I’m, like ‘two secs please’, they kind of like do a 360 to try and work out who I’m looking at”
>
> INTERVIEWER: “Mmmm”

> PARTICIPANT E: “in the end, sometimes I lose my patience and just say ‘I might not be looking at you but I am talking to you’. I mean, it’s not really appropriate for me to have that reaction but it’s very frustrating on my part”.

There is a sense here that coping by explaining to others forces participants to sacrifice their own privacy – another consideration to be factored into the decision whether to explain or not.

5.4 THEME 3: ME, VISIBLE DIFFERENCE AND *WORK* – MY HEALTH NEEDS AND MY JOB IN CONFLICT

5.4.1 THEME 3 SUMMARY

This theme relates to the tension between what the participants felt was good for their health, and what they felt was required for their jobs. Participants often felt conflicted between the two or forced to prioritise one over the other.

5.4.2 THEME 3 DETAIL

This conflict breaks down into two contexts, which are presented here as sub-themes:

A: dealing with fit to work and sickness absence procedures

B: meeting the requirements of the role.

Theme 3, Sub-theme A: Dealing with fitness to work and sickness procedures

In terms of 'fitness for work' procedures, Participant B expressed a strong sense of having to overcome extra hurdles to prove himself/herself as fit to work:

> PARTICIPANT B: "so it’s not just it’s not just the visible difference of having scaly skin everywhere [...] it’s also you’ve got hoops that you need to jump through”
>
> INTERVIEWER: “Right”
>
> PARTICIPANT B: “To prove that you’re fit for work."

These hurdles were steps such as passing a referral to occupational health, required disclosure of personal medical details, and consideration of potential risks caused by strong prescribed medication. Hurdles also occurred in the operation of sick leave procedures; several participants perceived unfairness in the operation of sickness absence procedures, with concerns that long-term medical conditions should not always be treated the same as the sort of unconnected short-term absences which everyone has from time to time:

> PARTICIPANT D: "So I basically had these two operations back to back that required a month off work. If I get sick, like the flu for the rest of the year, I'm not going to be paid for that day."

Overcoming the various hurdles encountered was not always felt to be straightforward; one participant noted a lengthy delay to recruitment caused by medical 'checks', and two participants reported feeling that an Occupational Health doctor had misrepresented their condition and discussions to their employer. For example:

> PARTICIPANT F: “There was one report that didn’t reflect what I had said”.
>
> INTERVIEWER: “Right”
>
> PARTICIPANT F: “And…it also mentioned ‘when [name] gets better…these adjustments can be taken away’. I questioned that – I actually rang the company that does the occupational health– but got told only a manager could speak to them. It’s about the report that you sent, ‘when [name] gets better’ – I said I’m not going to get better.”

> INTERVIEWER: “Yeah”.
>
> PARTICIPANT F: “I will deteriorate."

In addition to frustrations with the process of proving fitness, Participant J recollected the hurdle of proving fitness not just as a one-off hurdle but as an express ongoing threat to job security, which indicates perhaps one of the ultimate conflicts between health and work:

> PARTICIPANT J: “I went to my final interview and I was told that, ‘Yes, we’re going to accept you but we want you to go and see the [employer's] doctor before we have any papers signed.’ [...] Then I had to go up to see the [employer's] doctor and he basically said to me, ‘Any problems with this, you will be sacked.’
>
> INTERVIEWER: “On what basis?”
>
> PARTICIPANT J: “Because I’d be medically unable to do the job. [...] And then he said to me, ‘You go away, you've got half an hour probably to think about it, and if you're okay with that, then go and sign your papers’.”

Time off for non-urgent medical treatment and appointments was also often a source of potential conflict for some participants, who felt that they had to choose whether to prioritise their health or their work:

> PARTICIPANT E: "So I have a regular appointment every four weeks that I have to go to. And, er, we have an online day off request booking system so I’m able to book that particular day off. If I got a letter through the post today saying I have a hospital appointment on Wednesday, it sounds quite aggressive of me to say, but I would still turn up for work and say ‘I am having this day off, I have a hospital appointment’. It’s something I’ve learned a lot over the last two years, is that my health comes above work".

> PARTICIPANT D: "I would not have asked my [manager] for a month off work. I just wouldn't have done it. [...] You often are in a team of people

> where you would feel like you were letting them down. But people are really open about just being annoyed with someone being off sick.[...] If it was urgent, then absolutely, of course you would have a month off work but, kind of, having elective surgery, even though it's scheduled by the NHS and obviously you've got no say when it is, I would have waited another year and had it done in the summer. I would have told the NHS, ‘No, I have to do it in August’."

In summary, I perceived tension where health conditions met fitness and sickness policies, which were often felt as disadvantaging the individual in a number of ways.

Theme 3, Sub-theme B: Role requirements

The other area in which I perceived participants to be expressing a conflict between their health and their work life was in terms of the requirements of their role. A couple of participants felt that their condition had been triggered by factors at work (exposure to a virus for one participant with facial palsy, and work-related stress for another). Without attributing the onset of their condition to their job, several other participants also saw an ongoing link between stress and fluctuations or the progression of their condition, including Participant B:

> PARTICIPANT B: "I would say, erm (.) I would say that it took me longer to embed in the organisation because of my psoriasis, because I was worried about it? [...] And of course stress and psoriasis don’t go well together at all. [...] And the more you get worried about your psoriasis it becomes a self-fulfilling prophecy [...] Erm, so it can actually get worse."

Participants noted different approaches to managing these conflicts. Participant G gave an example where he/she felt that he/she had prioritised health over work ambitions to achieve a balance:

> PARTICIPANT G: "Because too much…too much stress affects the palsy, which affects the general health. So your general health is affected. It’s

> compromised. Your immune system is more compromised, so you're more prone to catching things. So obviously, if you're more tired then you're going to get ill more frequently. So it's kind of - get a job that's more tick along and manageable, for my own health and for the hours, so that I can manage the rest of my life, so that actually I can keep surviving. And that felt, kind of, very restricting."

A particular flashpoint between the role demands of employers and the employees' health concerns occurred when they were returning from a period of sick leave; a few participants suggested that, whether deliberately or unintentionally, their employers had prioritised business need over their current health difficulties in determining return to work arrangements, creating an extra hurdle when the participant was feeling vulnerable and unwell:

> PARTICIPANT I: "So, having been off for just over two weeks, at the time, I was the [employer] [role], and somebody had the good idea to put in my diary, literally, a five-hour meeting with various… with [very senior colleagues] and my opposite number reviewing a whole host of, sort of, projects and so on before the summer. And I can remember the, sort of, horror and just feeling, 'I can't do a five-hour meeting'."

> PARTICIPANT H: "Only recently after the surgery when I was due to go back to work and I met with occy health and said, 'Because my face is very swollen at the moment and obviously that impacts on how I feel and therefore able to do the job, I would like to go back to work and be office-based initially, so not have client contact.' They thought that that was absolutely fine. Management used that as an opportunity to get me to work more days, shorter days, but work harder, I guess, than - they basically used it against me."

The very nature of a 'return to work arrangement' is that it occurs fairly early in the individual's recovery period – at which point many participants would not yet know what course their condition would take, and how long it might last. This might sometimes make it hard to know whether the definition or disability is likely to be fulfilled – especially for conditions such as facial palsy where recovery times can be very variable. It is possible that, at this stage, neither employer nor employee are linking the concept of a return to work with the concept of reasonable adjustment, which may partly explain this area of conflict. An approach to adjustment which is linked more to health conditions than the legal definition of disability - discussed further under Theme 4 below – would help to ease this conflict and support employees returning to work. This is addressed further at 5.5.2 below.

5.5 THEME 4: ME, VISIBLE DIFFERENCE AND *SOCIETY* – FEELING THAT I FALL BETWEEN THE CRACKS

5.5.1 THEME 4 SUMMARY

Many participants seemed to feel like their condition made them fall between the cracks, not quite fitting into existing societally created categories or processes. Legally, as well as problems of awareness of the law, participants were often reluctant to identify as disabled, and many viewed disability as an exclusively functional concept. This disability identity mismatch created a dilemma for many participants on whether to disclose a condition during recruitment - with participants divided not just on whether it is in their interests to disclose, but whether they are legally allowed, or legally obliged, to disclose it. Some participants wanted employers to have a more flexible approach to health, rather than a tick box 'disabled or not' approach which exacerbates this dilemma because they don't feel they fit squarely into either box[590].

In health terms, the feeling of falling between the cracks related to both a lack of medical understanding about some conditions and, for some, a need to battle for treatment because their condition is seen as 'cosmetic' or given low priority for care. There was also a common recognition that 'others have it worse' which was sometimes used by participants to explain why they felt like a bit of a grey area medically.

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[590] See 6.2.6 for a discussion of the legal implications of this in the light of the prohibition on pre-employment health questions contained within s.60 of the Act.

Socially, many participants had, at some stage in their lives, felt that visible difference prevented them from fitting in; some felt overlooked, harassed or targeted in the workplace. A feeling of their condition being misunderstood or underestimated by colleagues was also commonly cited. However, there were also many positive stories of inclusion at work; people with good friends and supportive colleagues, many of whom enjoy their job. There was not a pervasive sense of social exclusion but a much more nuanced, and often positive, picture presented.

5.5.2 THEME 4 DETAIL.

This theme breaks down into three sub-themes:

Sub-theme A: Falling between the legal cracks
Sub-theme B: Falling between the medical cracks
Sub-theme C: Falling between the social cracks

Theme 4, Sub-theme A: Falling between the legal cracks

I perceived a very strong sense in the vast majority of interviews that participants do not self-identify as disabled people and thus fall between the cracks in terms of equality rights, which are based on disabled status.

Sometimes the barrier to identifying as disabled was a personal one resulting from a reluctance to be categorised, labelled, or stigmatised:

> PARTICIPANT E: "I do think that I think that disability is a bit of a…I think it's a bit of a stigma word […] So anything that would implicate me as being slightly different as a disability, I don't like that at all. I just think that we are different. I try to avoid the term disability and the definition and things like that. I try to avoid that as much as possible".

> PARTICIPANT A: "Technically, you're disabled and you can get a blue driving pass if you want. No, I don't want to fit into that box. It's that kind

> of judgement on just being disabled that I've got as well, about having to put myself into that box, I think.”

This idea of disability as stigmatised suggests that the way participants position themselves in relation to disability is influenced by wider social discourse; in other words, socially constructed stigma deters people from identifying as disabled, which acts as a barrier to them enforcing their rights. This reluctance to identify as disabled is a theme identified in existing research[591] conducted with people with a variety of other health conditions, so this is not a feature which is unique to visible difference. This reluctance may explain why some participants in this study preferred to refer to their condition as a difference, or a chronic health condition, rather than a disability, and some seemed to feel trapped somewhere in the middle between categories of 'disabled' and 'able-bodied', hence the feeling of falling between the cracks and being a grey area:

> PARTICIPANT B: “I guess, if, if someone said that they were (.) if you could broaden it out more than being disability positive to being health positive, or …erm (.) to encompass more than just disability because chronic illness …erm…can be just as debilitating but maybe not come under the, um, banner of disability.”

Some showed frustration with their belief that disability is treated as a black and white concept, where they felt unable to fit comfortably into either category:

> PARTICIPANT A: “I don’t want to put myself in a box where I'm classified as kind of in that category of disabled, because there's all that stigma attached to it, and all those preconceptions, and all those things that are attached to being disabled. And there's nothing, something like, ‘Oh, I've got this condition but it doesn't affect me’, or someone who maybe, ‘Oh, I've got

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[591] Nick Watson (2002) ‘Well, I know this is going to sound very strange to you, but I don’t see myself as a disabled person: identity and disability’ (2002) 17(5) Disability & Society 509, 524; C Cameron, 'Does anybody like being disabled?', Queen Margaret University 2010) 119-123. For an international perspective on the same point, see also Louis Bertrand, Vincent Caradec and Jean-Sébastien Eideliman, 'Situating disability. The recognition of " disabled workers" in France' (2014) 8 Alter - European Journal of Disability research, Revue européen de recherche sur le handicap 269, 277.

> depression, but I don't consider myself…,' there's no - kind of - I just find it frustrating. It almost feels like it's an equality tick box".

Of particular interest, in this study there were other reasons for not identifying as disabled which would seem to apply specifically to people with a visible difference. Many participants understood disability to be a functional concept - one that relates to what you can't do, not what you look like:

> PARTICIPANT P: "I think it means that you can't do something that you might want to do. [...] I think if my cleft affected my hearing, which it does some people, then I would consider myself to be disabled. If my cleft affected my speech so that people couldn't understand me, then I would consider myself to be disabled. I don't consider having the difference that I have to be a disability."

> PARTICIPANT C: "They do say 'disability', but they don't, kind of, expand on that and say what they mean by that. You automatically think physical disability, don't you? Or mental disability, but you would never think of a visible difference as being a disability."

Interestingly, this understanding of disability in functional terms partly coincided with a common lack of awareness of the severe disfigurement provision (around half of the participants in this study were not aware of this legal provision, which supports the data from Changing Faces set out at paragraph 3.4.1). But lack of awareness does not fully explain the conception of disability in functional terms; some of the participants who *did* know of the severe disfigurement provision still expressed a concept of disability relating exclusively to functional impairment:

> PARTICIPANT K: "But I'm not a disabled person, [...] so it doesn't stop me going out and going to Tesco when you've finished, [...] and cleaning my house, going to work, getting in the car or driving to work, but you see people staring. That's what…then, they might think, 'Oh, look at her,' or..".

> INTERVIEWER: “Yes. No, I understand what you mean. So to you, disability is about…disability is something that stops you doing day-to-day stuff, and therefore, to you, looking different isn't really a disability?”
> PARTICIPANT K: “Yes”

> PARTICIPANT R: “Because it's not really a disability, it's more, like they say, a visible difference. I don't class myself as 'disabled', I don't think- because I am fully able”.
>
> INTERVIEWER: “Okay, so what, to you, then, is disability, and why do you say, ‘I don't class myself as 'disabled’?”
>
> PARTICIPANT R: “I mean, I think a disability would be, obviously, a physical disability like you're a wheelchair user or you need crutches or you need the height of something that you're working at adjusted, if you've got problems, or if you've got vision or hearing”

In addition, some participants felt that the law, and the way it applied to them, was unclear; they felt like a grey area. The word 'severe' was singled out as a particularly uncertain, subjective concept by some participants:

> PARTICIPANT J: “… so what’s severe? Because to anybody who’s ill, it’s quite severe, isn't it? Whether – whether - say you turn your ankle in sport and you’re tender on your leg, it’s severe, whereas if you break your leg, it’s still severe, isn't it?”

> PARTICIPANT D: “I don't know how you quantify that because if you're saying severe disfigurement, that is so subjective based on how you feel as an individual so how can that be part of inequality? [...] To me it doesn't make any sense. Ethnicity and having like an Equality Act around ethnicity is a very objective thing. You can't feel a different race to what you are in terms of experiences. You might do but you're not going to experience discrimination if no one else can see that. You can't feel being in a wheelchair. So to me, that baffles me.”

This suggests a problem of uncertainty; some participants were unsure whether they were entitled to equality rights on the basis of visible difference. The wording of 'disfigurement' was also perceived by one participant as excluding parts of his/her condition beyond the purely aesthetic:

> PARTICIPANT Q: "'Severe disfigurement' just gives you the impression that it's about the way somebody looks and how people are going to judge them or react to them. Actually, it's a bit more than that. It's not just about that. Yes, a lot of it is that feeling, but, actually, there are some physical things going on that are affecting your life and it takes time."

This suggests that the breadth of the participant's complex condition (i.e. one which has functional impacts as well as an aesthetic effect) may be preventing this participant from identifying with the word 'disfigurement' in the law. Although only one participant mooted this idea, over half of the participants mentioned functional complications of their condition in addition to looking different, such as mobility, learning or hearing difficulties, eating or speech difficulties, watering eyes, and others. Understanding the inferences drawn from the wording of 'disfigurement' by people with complex conditions is therefore an area for future research.

For others, changes in their condition over time made it harder to meet the one year duration threshold for legal protection; this was a particular issue for people with facial palsy which can come on suddenly and be severe but, for some, tended to improve somewhat over the course of the first year.

Overall, I perceived a common feeling of being 'stuck in the middle'; a grey area that sits somewhere between having no health condition and being disabled. This seems to have a number of causes – a reluctance to be stigmatised, an understanding of disability as purely functional, and problems with the wording of the severe disfigurement provision.

There are two very practical ways in which this feeling of being in a 'grey area' manifested itself particularly strongly; the dilemma of disclosing a condition during recruitment, and reasonable adjustments.

First, with regard to disclosure of the condition during recruitment, the participants raised a range of concerns and a collective confusion on what the right approach was - in terms of: (i) whether they were allowed to disclose their visible difference as a disability:

> PARTICIPANT J: “I think the reason why I’ve never ticked is, one, I’m unsure of whether I should be ticking it.”
>
> INTERVIEWER: “OK. What might affect whether you should or not?”
>
> PARTICIPANT J: “Because when you fill in an application form, it’s sort of like part of your legally binding contract isn’t it, with them [...]So the information you declare on your information form is part of whether you get your job or not”
>
> INTERVIEWER: “OK”
>
> PARTICIPANT J: “Isn't it, and if you make any false declaration on your application form, then that gives them grounds really, doesn't it, to not give you the job if they think you're lying.”
>
> INTERVIEWER: “Okay, so you haven’t ticked it because you didn't want there to be any suggestion that you’d tried to get some kind of special treatment that you weren’t entitled to, is that what you mean?”
>
> PARTICIPANT J: “Yes, and sometimes if you look at me you think well, really have you got facial palsy?”

> PARTICIPANT K: “I said to one of the managers, and she only interviewed me last time because she said my form wasn't good enough. My examples weren't good enough, not the form, if you see what I mean. It was the content. So I said, ‘Yes, but I declared a disability.’ I said, ‘It's a bit tenuous, isn't it?’ and she sort of nodded”.

> INTERVIEWER: “What's a bit tenuous: the disability?”
>
> PARTICIPANT K: “Me declaring the disability”.
>
> INTERVIEWING: “Right. So she thought that your condition was tenuous to call it a disability?”
>
> PARTICIPANT K: “Well, no, she didn't say that though. She just sort of nodded. It was me that suggested it”.
>
> INTERVIEWER: “So why do you feel it's tenuous, [name]?”
>
> PARTICIPANT K: “I'm not physically disabled, am I?”

(ii) whether they were obliged to disclose it:

> PARTICIPANT J: “for all the jobs that I’ve had, [...], medicals are very important [...] and fitness is very important so it’s always been something that I’ve had to mention [...] and I would always mention it anyway because (.) it’s who I am”.

and (iii) whether it would benefit or hinder them to disclose it:

> PARTICIPANT G: “As soon as you do a health disclosure… I have even tested it. I've put everything down and not got an interview. Then I've put nothing down and have got an interview.”
>
> INTERVIEWER: “The same types of jobs for which you would be equally qualified?”
>
> PARTICIPANT G: “The same types of jobs, yes”.

> INTERVIEWER: “So you think the more you disclose upfront the less your chances?”
>
> PARTICIPANT G: “Yes. Even though that’s meant to go to HR. It’s confidential. I think that it’s looked at and it’s like, ‘Oh, no. You know, you're going to be a liability. You're not going to turn up for work, so we won’t bother with you’."
> […]
>
> PARTICIPANT G: “And at that point I thought, ‘I just keep coming up against barriers.’ So what do you do? Do you just lie? But then you can’t go to work and then go, ‘Oh, well, you know, now I've got this problem or that problem.’ Or even talking to people, colleagues you work with”.
>
> INTERVIEWER: “So you feel it’s awkward not to mention it before and then to mention it once you’ve got the job because it looks …dishonest?”
>
> PARTICIPANT G: “Yes. So I didn’t feel happy doing that”.

> PARTICIPANT A: “I find some people, it kind of raises alarm bells, and it makes me feel concerned about applying for jobs, because I think, ‘Am I going to be (.) judged on the fact that I've ticked that I've got this disability but actually, I don’t view myself disabled in any way whatsoever?’”

Those who indicated that they had disclosed also varied in the stage at which they felt comfortable disclosing it; whether on the initial form, at interview, or after an offer has been made. The dilemma led one participant into feeling the need to disclose their condition when applying for jobs, but refusing a guaranteed interview, because:

> PARTICIPANT H: "I don’t want an interview just based on because I’ve got a disability therefore they have to. I want the interview based on merit, in a sense."

This fits with Theme 1, sub-theme C: *There's more to me that visible difference* which explored the desire to have one's skills recognised – even to the extent of refusing advantages to which I may be entitled.

Second, and perhaps related to the idea of disability as functional (described above), the other practical limitation of this identified legal grey area is that most participants did not perceive that reasonable adjustments were relevant or possible for visible difference. There was a common belief that:

> PARTICIPANT K: "You can't make adjustments for looking different."

This belief also appeared to follow through into their accounts of their work experiences, with few participants reporting having requested or been offered reasonable adjustments in relation to the aesthetic aspect of their condition, rather than any functional complications.

In summary, the legal cracks reveal a difficulty identifying as disabled for many participants, and a corresponding uncertainty on whether, and how, to address their conditions with employers, both during recruitment and at work.

Theme 4, Sub-theme B: Falling between the medical cracks

There was a strong sense in several interviews that participants felt like they fell between the cracks medically, too. Some participants indicated that they had been denied treatment for their visible difference because it was perceived by the NHS to amount to 'cosmetic' treatment, which created a real sense of unfairness for some:

> PARTICIPANT J: "Because mine's a clinical illness, theirs is a clinical illness, yet they're getting their cosmetic treatment whereas I'm asking not even for cosmetic treatment, I'm asking for restorative treatment, but I can't have it".

There was also perceived unfairness in the inconsistency of treatment offered to people with the same condition in different places. Advocating for one's own treatment was something which took up a number of participants' time and energy; something which they felt had to be actively 'managed' to get good health care:

> PARTICIPANT B: “so if you’re able to do the research, speak to your consultant, make suggestions on your own treatment and engage in your own treatment”
>
> INTERVIEWER: “Be very proactive, yeah”
>
> PARTICIPANT B: “I think you’re able to get a better result than if you’re someone who is, like, I’m entirely reliant on an expert, if that makes sense?” [...]
>
> PARTICIPANT B: “And also you don’t want to be that patient, that patient that’s kicking up a fuss. So it’s all about managing relationships both in your everyday life but also with the medical professionals because you’ve got to build an alliance with the medical professionals. Whereas you don’t want to be seen as the adversary going ‘this is the treatment that I want’ and them going ‘well I don’t think that’s what you need…’”

For a couple of participants, this process had gone beyond one of active management and turned into a battle for treatment lasting, in one case, for several years, until the participant decided that "“you know what, I don't have the physical or mentally ability to do this anymore”" (Participant J).

For some participants, there was also a perceived lack of emotional and practical support for their conditions from the health service:

> PARTICIPANT Q: “There's no psychological support for you when you've gone through something really traumatic…[...] that's changed how you feel about yourself and how other people see you, you know. There isn't really that support out there. You feel like, "I got spat out the other end of A&E with a handful of drugs and, sort of, an appointment with the consultant, and that was it." I was like, ‘Oh, my God, is that it?’ and, ‘I'm just supposed to live like that?’”

Although the sample size, being qualitative, is small, the way in which medical care was perceived appeared to vary between conditions; those with cleft lip and palate tended to feel more positive about the medical support they had received than those with other conditions, such as facial palsy. This finding could perhaps also be influenced by the presentation age of differing conditions, though.

Participants sometimes felt that their condition was medically underestimated or misunderstood by their health providers:

> PARTICIPANT G: “Even the GP doesn’t know that. They don’t give a thought to that. So if I went to the GP and said, ‘I need you to sign me off, because I've got this, this and it’s made it worse,’ he would probably go, ‘That’s just ridiculous.’”

> PARTICIPANT J: “…when my GP filled in my application form, they didn't speak to me about filling it in”.
>
> INTERVIEWER: “Right”
>
> PARTICIPANT J: “So they just - it was just all made up from a GP’s point of view”.
>
> INTERVIEWER: “OK”
>
> PARTICIPANT J: “The only thing that they got right on form was my name and my address, my date of birth, my contact telephone number and my NHS number. Everything else was totally wrong”.

For a couple of participants, there was a perceived crossover between NHS policy and the ability to prove your condition and have it taken seriously in other areas of life:

> PARTICIPANT J: “they could say, ‘well are you under a specialist clinic?’ and I have to say ‘well no, because where I live my clinical commissioning group won’t refer me anywhere’”.
>
> INTERVIEWER: “So it goes back to that whole thing, they think you would be if you needed it and therefore you don’t need it?”
>
> PARTICIPANT J: “Yes, ‘so what’s all this about then? Then you must be lying or there must be something more in it.’”

> PARTICIPANT Q: "I think, well, if…from that point of view, if the medical world isn't really supporting us, and like we were saying about feeling like you're just spat out at the end of the hospital and just left to it, and if they're not doing everything when, obviously, they understand it better than anybody, then how on earth does the law and the employers stand any chance of being able to deal with people well when, actually, the medical world hasn't even got it sorted?"

And for some the crossover between health policy and law created confusion and uncertainty about differing tests in different contexts:

> PARTICIPANT J: “…so does it mean that if you have facial palsy and you have long term facial palsy, are you automatically or, we’re talking visible difference so if you have a long term visible difference and you've had it for what the NHS class as long term...what do they call it (.) I think for facial palsy they class anything after nine months as severe. Are they going to class - is that going to run along with the NHS definition?”
>
> INTERVIEWER: “Yes, so have we got different definitions for health and law?”
>
> PARTICIPANT J: “Yes, because from my, sort of, going through the [anonymised] process, the funding application, what the law says and what the NHS apply are very different”.

But running alongside the perceived unfairness of this felt lack of priority in medical care, there was often a conscious factoring in that 'others have it worse'. This was sometimes used by participants as a way of gaining perspective on their own condition, and sometimes to explain why they felt they don't really have the right to complain about their own situation:

> PARTICIPANT D: “I think it's really hard to rank because you look at other people that have what I would call a severe physical difference and then you think, what… ‘I shouldn't really be saying anything’".

> PARTICIPANT Q: “when you get to the point I am now, where I don't feel quite right but nobody else would recognise it, I fall between the gaps somehow."

The perceived cracks are therefore not just about who gets treatment, but whether they feel morally able to ask for better treatment, and how their condition is perceived by others.

Theme 4, Sub-theme C: Falling between the social cracks

Finally, the participants often felt like they fell between the cracks socially; being stared at, disadvantaged, or sometimes expressly targeted because of their appearance. Several participants felt that they had been overlooked in their careers due to visible difference:

> PARTICIPANT J: “I had a [senior colleague] who said to me, “You're a really good [job type], [name], but you've got to get yourself a suntan, got to go on a sunbed and you've got to get rid of that wonky face.”
> [...]
>
> PARTICIPANT J: “...there were squads that I wanted to go on to where people in those squads had an input and said, ‘Oh no, well she doesn't look very nice, does she, so no.’”
>
> INTERVIEWER: “And were you actually given that feedback?”

> PARTICIPANT J: “Not from the bosses but from the [people] on them squads, yes.”

> PARTICIPANT G: “I remember particularly being interviewed by a [job type]. And I can’t remember exactly how it came up, whether he had asked me or he said… Because of course they're trained to see those things. ‘Oh, so how long have you had the palsy?’”
>
> INTERVIEWER: “So he raised it? OK”
>
> PARTICIPANT G: “Hmm. And I said, ‘Oh, a year or two.’ Obviously then you think, ‘Oh, my goodness. Does it look that bad?’ And then, ‘How does that affect you?’ or, ‘How does that affect your health?’ Almost intimating that you're going to take time off. [...]
>
> PARTICIPANT G: “But also it’s, ‘Well, this is a front of house job.’”

> PARTICIPANT E: “there’s absolutely no reason why I wasn’t capable of doing that job, I’m doing sales, I’m doing front of house and things like that – I’m quite a sociable person, I’m quite an outgoing person [...] And…erm, I just think they obviously didn’t want me for my differences. I didn’t fit”

Sometimes participants felt that they had been disadvantaged not just by visible difference but other factors too - particularly age or gender - which suggests an aspect of perceived multiple discrimination, or intersectionality, but one which is hard to unpick with certainty:

> PARTICIPANT G: “I think it’s worse when you look different. So if you’ve got any sort of disability and you look… I would say disability as well. Even if it might be an invisible disability or a seen disability or visible difference. You’ve got that. You’ve got gender. And you’ve got age. Yes, combine that all

> together and you might… And if you are probably over 55, they will just stick your application in the bin.”

And some participants felt that their disadvantage began before they even entered the job market, with bullying or a lack of understanding from schools being cited as limiting both educational achievements and subsequent choices:

> PARTICIPANT J: “I went quite literally from being a straight A student to being like a D and an E student because I just didn't have the information”
>
> INTERVIEWER: “Yes”.
>
> PARTICIPANT J: “…because I missed so much school.”
>
> INTERVIEWER: “And was there no support in terms of, you know, helping you continue to learn while you were off?”
>
> PARTICIPANT J: “No, the school were told I might be contagious so not to come near me.”

> PARTICIPANT R: “And also, my dad had put away money for university, but I barely scraped out of school with some GCSEs because of bullying and not wanting to be at school and low confidence and just not really caring. The thought of, like, moving out at 18 and going to a new city for uni and meeting all these new people at 18 was just beyond me. I couldn't have done it at all. I'd only just got comfortable where I was.”

On occasions, a feeling of disadvantage went further, into a perception of having been specifically targeted because of visible difference:

> PARTICIPANT C: “Colleagues definitely commented, in a derogatory fashion, because in those days, in the '80s, the [public employer] wasn't quite as PC as it is now and people did take the mickey out of you. So, I did have quite a few instances where I could tell people were either talking behind my back or…Subsequently, after I left the [public employer], one of my

> friends said that my pet name in the [workplace], that I didn't even know I had when I was there, was [nickname anonymised] and that would have been, obviously, because of the facial palsy, but nobody ever said it to my face.”

> PARTICIPANT H: “Bizarrely, it was when I was- well, it was actually for a course, [...] (.) and the interviewer- there was a man and a woman and the man kept asking repeatedly, “Well, what will happen if someone doesn’t want to work with you because of your disfigurement?”
> [...]
>
> PARTICIPANT H: “My boss [...] says comments to me inappropriately about my face sometimes.”
>
> INTERVIEWER: “Right. What sort of things?”
>
> PARTICIPANT H: “When I got divorced she said, ‘Oh well, it’s going to be much harder for you obviously to find someone new.’”

The feeling of 'standing out' through being stared at in public carried through, for some participants, to an element of social exclusion at work:

> PARTICIPANT K: “It's hard to put your finger on it. It's makes you wonder about (.) I don't know – being left out of things sometimes not getting (.) if they go out. When they used to go out, I sometimes didn't get asked or things like that. I probably didn’t want to go anyway with the younger ones, but...”

But, in this study, the majority of participants did not feel socially excluded at work. As mentioned under theme 1, for some, the social experience at work was unerringly positive:

> PARTICIPANT P: "I’ve made big huge friends there and I’ve just stayed, really".

and others perhaps portrayed mixed experiences, with one or two uncomfortable recollections balanced by lots of positive memories of supportive colleagues and friends at work. Overall, the interviews do not portray a clear picture of felt social isolation at work.

Certain participants did, however, believe that their condition was often misunderstood or underestimated by others at work:

> PARTICIPANT H: “When your eye waters because that’s quite a common occurrence, you know, constantly hiding my face, they don’t see any of that and they don’t take any of that on board. At all. I find that really upsetting and hurtful because I think, ‘Oh, fuck’s sake. [Laughs]. You know, it’s really hard for me’.”

> PARTICIPANT G: “if I get a cold or flu it’s worse than for probably 10 other people in the room. In as much that I've got weakened throat muscles, so I cough more. My immune system is not as efficient as it should be. I get more – because when you’ve got a cold you’ve got inflammation in your tubes. So it’s worse for me, because it presses on the nerve, so you get more pain. So there’s a whole host of things that are going on. So if somebody else said, ‘Oh, when I have a cold I just keep going.’ Because there’s always bravado in the workplace, you know, of the person that always keeps going when they're not very well. ‘Oh, but why have you needed to then end up having a week off?’ I wouldn’t do that, you see. I've always pushed myself to [inaudible].”
>
> INTERVIEWER: “Because even though it’s not just a cold it would be perceived as, “Oh, she’s had a week off just for a cold?”
>
> PARTICIPANT G: “Yes.”
>
> INTERVIEWER: “So a lack of understanding within colleagues and employers about how different things impact people differently?”
>
> PARTICIPANT G: “Yes.”

Participant O made particular reference to “genetic conditions” being misunderstood, perhaps due to a common lack of awareness about them. Participant B also perceived a “media blackout” about his/her condition – meaning that many people drew comparisons with whatever very limited exposure they had to the condition, whether it was accurate or not:

> PARTICIPANT B: “…there was a guy with psoriasis on television [.] and people often relate it back to – relate it back to that”.
>
> INTERVIEWER: “Oh really”.
>
> PARTICIPANT B: “…Reginald Perrin or something?”

Difficulties expressing emotion – often due to facial palsy or due to speech intonation effects of a cleft palate – put participants at particular risk of being misunderstood, sometimes being perceived (or fearing that they would be perceived) as lacking enthusiasm or unfriendly:

> PARTICIPANT I: “…one person I met […] hadn't got a job promotion at the place they were working. When they asked for feedback oh, that they hadn't seemed to be very enthusiastic about the job. […] But the inability to use normal ways of expressing enthusiasm with one's face […] either because one can't or one doesn't want to smile [inaudible] or whatever, I think are real barriers, actually”.

> PARTICIPANT R: “I know for the interview, I wouldn't have been able to come across as all bubbly and smiley, because you sort of want to hide the smile a bit, but then you come across as, sort of, stern-faced or miserable. Trying to find the medium is not easy”.

> PARTICIPANT N: “it doesn’t just affect your speech, it affects your hearing […] and your tone of your voice. So, you have a bit of a monotone voice. So, I’m very conscious of trying to, and always do, put inflections in.”

> PARTICIPANT J: “…my mum calls me Miss Grumpy because I don’t smile, but when you haven’t got a smile, what are you supposed to do?”

Consistent with a lack of awareness, the vast majority of participants had never seen an employer taking positive action to encourage people with a visible difference to apply for jobs, or including appearance within published equality aims or training initiatives, though many indicated that they would have welcomed this. But several participants did express optimism for the future in terms of society becoming more accepting of people who have a difference.

5.6 THEME 5: ME, VISIBLE DIFFERENCE AND *RIGHTS*: SOLIDARITY VS WARINESS

5.6.1 THEME 5 SUMMARY

In generic terms, rights were seen almost as a necessary exercise of solidarity: something that should be enforced if needed, to stand up for myself or to prevent the same thing from happening to others. However, the participants displayed considerable wariness at the realities of enforcing rights - both in terms of bringing an employment claim to challenge discrimination, and to have reasonable adjustments made if appropriate. There was also a strong sense in some interviews that rights are only positive if handled in a certain way - there is the potential for them to become 'wrongs' if dealt with inappropriately by others. The idea of rights having the potential to make things worse fits within the pattern of general wariness.

5.6.2 THEME 5 DETAIL

Theme 5 divides into 4 sub-themes:

Sub-theme A: Rights as solidarity
Sub-theme B: Wariness about claiming
Sub-theme C: Wariness about reasonable adjustments

Sub-theme D: Wariness about rights becoming wrongs

Theme 5, Sub-theme A: Rights as solidarity

The way in which rights were discussed by some participants was striking - there was a sense in some interviews that employment rights are felt almost as a necessary exercise in solidarity; something which one 'ought' to use if needed. For some participants, this was something that they owed to themselves:

> PARTICIPANT Q: "On the other hand, what puts me off doing it is the stress factor because, of course, it's a bit of a catch-22, and people like my mum are sort of saying, ‘You don't need the stress of it. That's what made you ill in the first place.’ I'm like, ‘Yes, I know, but there's a certain stress if I don't do anything. I'm going to feel like I've kind of let myself down’."

> PARTICIPANT D: "would I then raise an actual claim? Yes, I'd like to think I would. I’d like to think I would."

Or to others:

> PARTICIPANT F: “You need to do something about it because if somebody else came in with a disability or something that needed adjustments and they were being treated like that, it would hopefully stop those behaviours [...] and make things better for other people”.

> PARTICIPANT J: "I think my main hope for pushing as far as I did, it’s not necessarily for me, it’s about the people who are following me".
>
> INTERVIEWER: "Yeah, no, I can understand that".
>
> PARTICIPANT J: "That they get treated better".

> PARTICIPANT C: “It's important, because I think I'd be standing up for other people who've got problems with visible differences. Because I've got more confidence in that area now, I think I would definitely say something”.

> PARTICIPANT Q: "… I've talked to my son a lot about it because he's [age] and he's older. I think it's quite an interesting experience for him to understand what, kind of, happens. I feel like I've got a duty by him. 'You don't just let somebody put you in that position where you end up having to leave. You kind of fight your corner about it.' I feel like I want to show him that I'm, like, prepared to stand up for myself, and it's not right what's happened so I'm going to try and do something about it".

This idea has quite an emotional undertone, as participants felt it was something they should do in a given situation, not something they would relish the prospect of. Yet despite this slightly moral conception of rights as solidarity, the prospect of using and enforcing rights was often met with wariness.

Theme 5, Sub-theme B: Wariness about claiming

With regard to bringing an employment tribunal claim to challenge discrimination, many participants expressed strong reservations and wariness. The perceived prospect of being victimised in some way was a key concern for some:

> PARTICIPANT F: "(.) Because I want to stay in the job". [...] That's why. Erm…"
>
> INTERVIEWER: "You're worried that you'd get victimised"
>
> PARTICIPANT F: "I worry then that you would get victimised, without a doubt".

as were personal factors, such as stress, and a desire to move on with life:

> PARTICIPANT A: "At the time, I wanted to just, 'Fine, whatever.' I wrote a few letters back and never got any".

> PARTICIPANT J:"I don't need additional stress"

> PARTICIPANT G: "Well, there was evidence and no evidence, but you're viewed very suspiciously, and they want you out the way, and you're a troublemaker".

> PARTICIPANT E: "I'm quite happy to be part of a community that races towards change and things like that. [...] I just feel that I don't have the confidence to be the instigator on my own".

A major concern for many participants was proof; how would they be able to evidence suspicions, particularly when they believed that employers tend to hide their real reasons and would never admit that visible difference was underlying their decision:

> PARTICIPANT K: "I know I'm not very good in interviews and that's down to the condition as well. I don't come over very well, but I'm sure the way I look doesn't help. I'm convinced, but I've got no proof".

> PARTICIPANT J: "Yes, and then it comes down to a 'he said she said' doesn't it, and then it's like...[...] If I went to my supervisor and said, 'Such-and-such a person did this and I was offended by that,' they'd say, 'Oh no, they're not the type to do that.'"

> PARTICIPANT R: "Other people, you just know they've made a judgment on you and that's that, but you can never prove anything. That's the only thing, you can never prove to anyone that the reason why they acted in that way or didn't give you the job is because of how you look, because if you ask them, they just say, 'No, we've not…'"

> PARTICIPANT C: "There are certain ways of being able to discriminate without actually overtly discriminating, aren't there?"
>
> INTERVIEWER: "What, so, sort of, hiding what's really going on?"

> PARTICIPANT C: “Yes, exactly. Using a different excuse for not giving them the job but, actually, really, it's because you're black, it's because you're a woman, it's because you're pregnant. They can, sort of, hide what they are really thinking by saying, ‘Well, actually, you didn't answer that question properly,’ and, you know, ‘We found a better candidate,’ but it might not be the case."

One participant highlighted the perceived motivation for the treatment as affecting his/her willingness to claim; if the treatment was perceived to arise through ignorance rather than maliciousness, however upsetting, he/she would not want to claim:

> INTERVIEWER: "Did you bring a claim or think about bringing a claim?"
>
> PARTICIPANT H: "No. No, I just went and got angry and cross."
>
> INTERVIEWER: "Yes. Why was that? Do you think it just didn’t occur to you or were there particular reasons why you wouldn’t have wanted to do it?"
>
> PARTICIPANT H: "Erm. Because I don’t think (.) the intent behind it was malicious. It’s just ignorance, and I have to work with these people".

Once again, this seems to go back to the idea of rights as necessary solidarity - which are engaged to challenge deliberate wrongdoing rather than ignorance or error.

The process of claiming would also motivate some participants not to claim, either because they don't know enough about it, would struggle to know when a ‘tipping point’ of treatment had been reached, due to specific concerns about maintaining their privacy, the prospect of facing up to the colleagues who have treated them poorly, having to listen to negative judgments about their appearance, or the time and effort involved:

> PARTICIPANT G: "you don't want to hear the feedback. You don't want to hear that they're saying to you, 'Well, we don't like the way you look,' or, 'You've got a wonky smile,' or, 'When you smile your eye closes and that frightens our patients,' or something."

> PARTICIPANT B: "So, erm, so yeah so I am aware of it but I suppose I've just never pushed myself down that (.) route because, because the things that psoriasis precludes me from doing are so very intimate and so very personal [...] it's not something I really want to raise as part of my everyday life, if that makes sense."

> PARTICIPANT Q: "I know how much goes into it, how long it can go on for and, kind of, how much work would have to go into it. So I think, 'Do I need that?'"

Some participants were more likely to walk away and reject employers who have behaved badly, feeling that they are better off out of the situation rather than standing up and challenging it:

> PARTICIPANT E: "If people like aren't offering a job based on the visual differences, do I really want to work for that company? Do I really want to work for somebody who's going to judge you based on what they see externally rather than on your capabilities, what you can actually achieve."

> PARTICIPANT J: "For me it was, well, you know what, if that's how you see me and you judge me, then I don't really want to work for people like that."

A few participants displayed considerable loyalty to their employers, indicating that they might not want to claim for fear of causing problems for the employer, or damaging its reputation:

> PARTICIPANT E: "I don't want to feel like I'm causing extra …extra workload and problems and things. I don't want to be responsible for causing a hassle, I suppose".

Interestingly, one participant suggested that claiming on the ground of disfigurement would be harder than claiming due to another protected characteristic:

> PARTICIPANT D: “I think partly that's because when you raise discrimination against a visible difference, you're raising it against an individual and their view of you as someone that looks different to someone else a lot of the time. Whereas it's safer, isn't it, to use like this, what's the word, the wrap around of gender because people talk about that. It's spoken about. It's a real thing”.

This comment seems to suggest that the subjectivity of appearance makes it feel harder as a ground for a claim, rather than more easily ascertainable gender.

Some participants were sceptical about the consequences of bringing a claim, perceiving that it would not "make a difference to my treatment" (Participant O) and that "this Equalities Act is - it’s a piece of paper" (Participant G). A couple of participants had prior experience of either bringing, or helping others to bring, a claim of different sorts. For one, seeing positive outcomes for others had spurred him / her into thinking that he/she might claim in the future if needed:

> PARTICIPANT F: "Probably because of a number of people I’ve represented that have, you know, raised their voice and it’s worked and I’ve seen that it works….I always tell them to but I’m not doing it, that’s wrong”.

For the other, an unsuccessful claim in another area of law had served to make him/her more determined to challenge any future problems, despite being aware of the hurdles he/she might face.

Overall, for a whole variety of reasons, participants in this study on the whole were wary about the idea of bringing a claim. Some of their reasons could be seen to be transferable to other grounds of claim - such as general concerns about evidence and process. Other concerns are more specific to visible difference - such as privacy concerns and the feeling of having one's appearance scrutinised in public, and worries about the subjectivity of the concept of visible difference.

Theme 5, Sub-theme C: Wariness about reasonable adjustments

The wariness theme also extended into the right to have reasonable adjustments made (if appropriate). The participants were divided on whether reasonable adjustments would help them to deal with looking different, but some participants were able to identify some adjustments that might have helped them on occasion. Examples include flexible working to deal with fluctuations in their condition, being able to wear a long-sleeved top instead of a short-sleeved uniform to cover up a skin condition, disapplying make-up requirements under a dress code, being allowed to wear a light-coloured uniform to make flakes of peeling skin less noticeable, having a mentor at work to talk to on difficult days, or being allowed to avoid attending networking conferences. However, most indicated that they had not requested these adjustments and were wary about the concept in general.

Although a majority of participants said they would have welcomed their employer sensitively initiating a discussion to see whether any adjustments would be needed, a few would find this intrusive:

> PARTICIPANT C: "I think I'd find it too much. I think I'd be too sensitive about it and be thinking, ‘Oh, God, is that the first thing you thought about for me, then?’"

And some would also have found it awkward needing to raise it themselves to ask for adjustments:

> PARTICIPANT B: “I think if they were able to, erm, openly say, talk about it, that would mean that I didn’t have to start the conversation [...] erm, which would make it so much easier”.

Some expressed worry that having reasonable adjustments made 'singles me out' as someone who is different, or someone who can't cope:

> PARTICIPANT C: “I think if they'd have offered that adjustment, I'd have thought about it, but then I'd have also thought if I'd have asked them not to video, it looks like I can't ever do that and that might come up again in the actual job role, that I might have to be videoed at some point. So, subconsciously, the people interviewing me will be thinking, ‘Yes, okay, then. Well, you're not going to be any good in this job then, are you?’ So, I probably wouldn't have taken them up on that, I'd have just gritted my teeth and done it anyway, because I wouldn't have wanted to look in any way, shape or form, less able than anyone else”.

and accordingly, some gave examples of ways of avoiding problems themselves rather than asking for adjustments:

> PARTICIPANT K: “What I don't like is they have all these conferences and national conferences you have to go to. [...] We went to one in [place] in the summer, and you feel like people are staring at you there who haven't met you before. [...] I'm trying to book a holiday before they announce it and to try and gauge when it is so I don't have to go”.

> PARTICIPANT E: “I feel as if I’m putting on them and I’m asking too much of them. And then maybe I’ll try and find a way to cope a little better”.

Participants frequently perceived employers as reluctant to make reasonable adjustments, leading to a sense of wariness about how any requests would be received:

> PARTICIPANT E: “I do think that my lazy eye in particular and my hearing loss is something that can deter potential employers. I think that they feel that that is an issue and they don’t want to deal with it.”

Particular types of adjustments were sometimes perceived as harder to get, especially where they relate to duties set out in the job description or which are fundamental to the essence of the role, which were sometimes viewed by participants as non-negotiable:

> INTERVIEWER: "Have you ever considered asking for a specific adjustment in relation to, I don't know, not having to go to things like the thing on Saturday where you're meeting lots of new people during a flare up, or…erm…"
>
> PARTICIPANT F: "I can't because it's part of the job description".

> PARTICIPANT R: "Although I get watery eyes if I'm out in the wind, it's not too bad, but obviously when I applied for [employer], I knew it was going to be outdoors".

> PARTICIPANT B: "I would say when I have to speak in public, that would be something that (.) so often I'll have to address random groups of [job] and trainees and things like that on the systems that they have to use [...] And I would prefer not to do that but, erm, because, primarily because of the fear of judgment [...] because of my skin, but, um, unfortunately it's par for the course. I guess I feel like I've got myself into it, I just have to get through it. [...] But I always, I always thought that after a period of time it would get easier but it just doesn't."
>
> INTERVIEWER: "It doesn't. Is that because you're meeting people for the first time?"
>
> PARTICIPANT B: "Yeah. It's constant new relationships. Um, so, um (.)"
> [...]
>
> INTERVIEWER: "What, but you feel it's too much a fundamental part of this job that you couldn't just take that away and substitute it for something else, because it's…it is the job"
>
> PARTICIPANT B: "No, we'd have to get someone else to do it and my manager – he wouldn't be happy doing it himself, so….[laughs]."

The wariness was increased for some by frustrations with the way that previous requests had been dealt with at work, with participants recounting being asked to do things that they weren't comfortable with, either to avoid the need for an adjustment, or to have it considered:

> PARTICIPANT K: "I asked if we could have the air conditioning off in our room …on sorry…and she wouldn't... She said, 'Oh, why don't you take your clothes off. You're covering your neck up. You're covering your top. You're covering all your skin up.' So…"

It is worth noting, though, that most discussions about frustrations with the reasonable adjustment process took place in the context not of the visible difference aspect of a condition but other physical limitations, such as mobility, vision, or hearing impairments. Most participants said they had not requested or been offered adjustments in relation to their appearance, and therefore few frustrations about process were mentioned in this regard. It is also feasible, though not expressly discussed in interviews, that the uncertainty and difficulties identifying as disabled also contributed to a reluctance to request adjustments.

Theme 5, Sub-theme D: Wariness about 'rights' becoming 'wrongs'

The final sub-theme of wariness relates to the potential for apparently positive initiatives to have a negative effect; for 'rights' to become 'wrongs'. Inclusivity commitments provide a good example here. While most participants wanted employers to run general inclusivity and diversity training, some were wary about the potential for this training to feel too targeted towards them:

> PARTICIPANT R: "...if I was working somewhere and all the staff were called into a meeting and it was basically, 'Oh, today's talk's about people with a visible facial difference,' if I was in the room, I would be squirming and I would probably leave, if it was sprung on me. But then, if it was not a surprise and the boss had told me it was going to happen, then they would say, 'Well, you either need to be included or you don't,' then you'd be like, 'Oh, well, this is just very embarrassing, really.'"

> PARTICIPANT C: "I wouldn't want it done in a, sort of, 'We all know [name]'s got facial palsy and this is how we all should be treating her.' No, I wouldn't want that."

> PARTICIPANT D: "I think it would be very weird to do that, particularly probably in a medium sized organisation there is not that many people that it applies to so what do you mean, everyone go on training? Everyone knows what it's about".

> PARTICIPANT Q: "So that would be a perfect thing: that maybe they could have said, with my permission, 'She's been off for a long time. This is what she's had. She's asked us to share this little video with you and to give you an idea of what it is, and if you've got any questions, here's the Facial Palsy website, just so you're aware. We thought it would be a good opportunity just to remind you that maybe some disabilities you can't see and some things you can see that aren't really a disability'."

Or wary about the potential of positive action messages to single people out and categorise them as different:

> PARTICIPANT B: "... the difficulty is of course that for employers to say that they are, you know, visibility positive, they are almost making a point of difference…which, maybe, I don't know - I personally wouldn't like to be classed as different, I just like to be someone who's got a chronic illness […] so I suppose that's another dichotomy as well about how much you make an issue out of it because if you make an issue of it, it could become upsetting in its own right, I guess…"

Some participants felt quite strongly that 'social skills / confidence' training in the workplace, connected with visible difference, would be patronising and potentially damaging to the person's self-esteem:

> PARTICIPANT H: "it's generally run by someone who has no actual experience and is quite patronising in my experience of things like that in the past".

> PARTICIPANT P: "I don't think a workplace person would have the (.) amount of training or specialism that they might need to know how I might

> feel or cope with things. I think perhaps that it would be better, as it is now, where you have a cleft team at the hospital who has a psychology department and you can go to them and get that support. I think it would be- okay, they could have generic support for anyone with a visual difference, this is what it might be. I would worry that it's someone who has had a tiny bit of training and, actually, it's not really that specialised".

> PARTICIPANT Q: "It almost makes it sound like you're the one that's got the problem and you are the one that's going to have to learn to deal with other people's reactions…"

Similarly, while some participants wanted to feel supported and listened to by their employer, attempts at support were occasionally seen to be hitting the wrong note:

> PARTICIPANT R: "I had one job for quite a while, I think I was about 21. That was when I had just gone on the waiting list for the surgery in [place]
>
> INTERVIEWER: "Right"
>
> PARTICIPANT R: "…and I told my boss at the time. [name], his name was, he was a nice man and he was interested in me as a person. So, when I told him I was waiting for this surgery, but he then kept asking me every month, 'Have you heard yet? Have you heard yet?' It was like, 'No.'"
>
> INTERVIEWER: "A bit intrusive?"
>
> PARTICIPANT R: "It was a little bit intrusive, yes, because if I was waiting for a hysterectomy, he wouldn't have asked me that every month. But I kind of got that he was coming from the right place, even though he was slightly wrong."

This suggests the need for quite a delicate balance in the way that these issues are addressed between employer and visibly different employee. This extends to discussions about reasonable adjustments too; although a majority of participants said that they welcomed an employer initiating a discussion about adjustments, some were conscious that this positive could easily turn into a negative if handled in the wrong way:

> PARTICIPANT B: "it depends on the basis of how they (.) erm, started the conversation really. [...] I wouldn't want them to think – I wouldn't want them to start the conversation as if it was a problem for them, because ultimately I'd be looking for solutions".

> PARTICIPANT Q: "As long as it was done in the right way, I think I'd really appreciate an employer coming to me and, basically, saying, 'I've heard you. Yes, I can't really see, looking at you. I've never met you before. I can't really see a huge amount going on, but you've told me that you've still got some after-effects of this… [...] I just want to make sure that I've heard you properly and understood that there might be some issues, I know what they are and what I might have to do.' So, I wouldn't have any issues, as long as it was done nicely. You know?"

But employers tempted to ignore the topic completely risk making the person feel invisible and unsupported:

> PARTICIPANT H: "So I've always felt that throughout life, and I sometimes think I look in the mirror and I'm like, you know, 'it's clearly a visual disability. Yet why do people'- I don't know. It's something that's always, always bugged me that it's just ignored".
>
> INTERVIEWER: "Would you like then, you would have liked, take school as an example or college. Would you have liked them to have acknowledged it and said, you know, 'There's support if you need it, but entirely up to you'?"
>
> PARTICIPANT H: "Yes, I think so, yes, or just say that, 'We recognise that life might be a bit harder for you.' You know? But, no, it's never been the case".

> PARTICIPANT Q: "...the HR lady was very good in saying, ‘I don't know about this. You're going to have to tell me what you need. Just tell me. Is there anything we can do?’ So very positive from that point of view…"
>
> INTERVIEWER: “Yes"
>
> PARTICIPANT Q: “…but I felt with my boss that she didn't really ask and she didn't really know, so it came across as a bit disinterested. She, kind of, could have done with knowing a bit more and finding out a little bit more, just to be able to have handled it better."

One participant perceived that senior managers within an organisation may be at particular risk of being overlooked for emotional support. This is an interesting observation. It could perhaps be that an ability to cope with a demanding job at work can lead to assumptions that they are more able to cope across the board, or that senior managers are perceived as knowing what’s available and how to access it on their own. This is an area for further research.

The study shows that different people have different preferences on whether the topic of visible difference should be expressly addressed with them by managers at work, though most participants in this study would have appreciated it provided it was done 'in the right way'. The fact that there is not necessarily a preferred 'one size fits all' approach means that managers may sometimes have to use some judgment in deciding whether, and how, to address this topic with visibly different employees. Some suggestions on best practice on this issue are provided in Chapter 6 and Appendix 7.

5.7 CONTRIBUTION OF EMPIRICAL FINDINGS TOWARDS RESEARCH QUESTIONS

The extent to which the present empirical study contributes to answering the Research Questions is summarised below.

The Research Questions

Progress towards Research Question 1: targeting disadvantage	**Research Question 1(a)** was answered at 3.4.1. **Research Question 1(b)** asks whether UK equality law identifies and targets the disadvantage of visible difference. The empirical findings in this study add to the existing analysis in Chapters 3 and 4 in answering this question. The problems outlined by the participants in Theme 4: *Falling between the cracks* suggest that the intended scope of the law here is both unclear and mismatched in several respects in the eyes of those who may need to use it. First, in terms of a perceived mismatch, disability was seen by most participants as a functional concept denoting limits on the person's capability in one or more areas. This prevented some participants from identifying as disabled and conflicted with their determination to prove themselves (see Theme 1, sub-theme C: *There's more to me than visible difference*). The reluctance of many people with health conditions to self-identify as disabled is a common theme in existing literature (see 5.5.2), but there is an added gloss here, in the sense that the perceived functional disadvantage of disability is a particular barrier for some people with a visible difference. Second, the mismatch was increased by the severity threshold; it was apparent in the interviews that people with mild or moderate disfigurements felt disadvantaged, but their self-ratings would suggest they were unlikely to be covered by the law. (Even if their self-ratings do not reflect the ratings which would be made by a Tribunal, it is possible that their self-ratings would deter claims in the first place). Some participants also highlighted a lack of clarity on what 'severe' would mean. This point aligns with that made at sections 3.2.2 and 3.3.3, concerning the lack of a clear linear relationship between objective severity of disfigurement and social / psychological disadvantage.

	Third, the mismatch was intensified by the word 'disfigurement'; one participant assumed that this seemed to focus on aesthetics only and that it would not cover the varied aspects of her condition. This aligns with the argument made at 4.3, which suggested that, linguistically, the word 'disfigurement' may be construed too narrowly to encompass all impairments causing appearance-related disadvantage. Finally, a fourth area of mismatch concerned the one year qualifying period for disability; some participants (particularly those with facial palsy) felt disadvantaged by a sudden and, in some cases, very severe visible difference, but perceived themselves as unable to claim because their condition had improved somewhat over the course of the first year. The legislative mismatch referred to above suggests that the equality right provided by the severe disfigurement provision is hindered practically not only by the narrow criteria of the provision but also by a lack of certainty and difficulties of self-identity which deter people from using it. **Research Question 1(b)** can therefore be answered negatively: UK equality law does not identify and target this disadvantage effectively.

Progress towards research Question 2: intersectionality	**Research Question 2 (a)** asks whether visible difference intersects with the characteristics of gender, race and age to produce crossovers of additional disadvantage. The conflicting evidence on intersections between visible difference and the personal characteristics of age, gender and race was identified in Chapter 3 as inconclusive. The empirical

	study conducted here has broadly affirmed that inconclusiveness. First, no findings were able to be made about race because all of the (self-selecting) participants in this study were White British. With regard to gender, again, 15 of the 17 participants in the dataset were female – thus although some perceived that gender had affected their experiences as someone with a visible difference (see Theme 1, *sub-theme B: A jigsaw of factors affect how I feel*), the lack of a sufficient number of male participants made it hard to reach balanced findings on this point. Even setting to one side the gender balance of the participants, there were mixed views expressed as to whether, and how, gender impacted on the lived experience of visible difference. Interestingly some participants suggested that the context of one's work may affect this – and in particular that visible difference tended to 'matter less' within female dominated settings. It is possible, therefore, that the lack of conclusive evidence about a possible intersection of gender and visible difference actually reflects a much more complex picture. With regard to age, the demographics of the study were a bit more balanced, albeit with only one participant below the age of 30. Here a significant number of participants suggested that the way they felt about having a visible difference had improved as they had aged – this corresponds with the findings of some prior scholarship – see 3.2.2. But this, too, was not straightforward. The participants represented a range of different situations - different ages of presentation, different conditions, different stages of medical treatment, different career stages – all of which could have impacted on their level of personal acceptance, the level of confidence they felt in their job, power relations with colleagues, etc. So, while it is perhaps

	possible to conclude that, for many participants in this study, the passage of time had made them feel *less disadvantaged* by their visible difference, it probably isn't possible to attribute this just to age. Nor is it possible to present this as a straightforward linear trend, because not all participants felt that getting older had eased their experience. The evidence on **Research Question 2(a)**, concerning the extent to which intersections of combined disadvantage are produced, is therefore inconclusive. **Research Question 2(b)** was answered at 3.4.2.4.

Progress towards Research Question 3: reasonable adjustments	Research Question 3(a) was answered at 3.4.3.1. **Research Question 3(b)**, which asks to what extent the duty is applied to people with a visible difference in theory and practice, was only partly addressed by existing research and has been explored in the present empirical study. It was clear that very few participants had asked for, or been offered, adjustments at work to alleviate the disadvantage of looking different (though some had received adjustments for functional difficulties associated with their conditions). There appeared to be a number of reasons for this, which created an overall pattern of wariness showing how the participants positioned themselves relative to reasonable adjustments. To some extent this confirms research on reasonable adjustments for disability generally (see 3.4.3.1). Reasons for this wariness included a belief amongst participants that nothing could be done to adjust for looking different (Theme 4: *Falling between the cracks*), a fear of getting stigmatised as incapable if a request was made (see

3.4.3.1) or a belief that adjustments would be hard to get – particularly those which touched on important role duties (see Theme 5, sub-theme B: *Reasonable adjustments requiring wariness*). There was also concern that some adjustments could end up making things worse; such as social skills training which was patronising or poorly executed, or inclusivity training for colleagues which created resentment or awkwardness (see Theme 5, Sub-theme *Rights can become wrongs*) and 3.4.3.1.

Some participants did indicate that adjustments might have helped them at particular points in their careers. Adjustments could perhaps alleviate the conflict between health needs and work requirements. This was particularly evident as regards fitness and sickness procedures which either created extra hoops for the individual to jump through, or which failed to differentiate adequately between chronic long-term conditions and unrelated short-term illness (see Theme 3 sub-theme*: dealing with fit to work and sickness absence procedures*). Other adjustments included flexible working, mentoring or social skills training, or flexibility about some of the more public aspects of a role or recruitment process, such as video presentations, or photographs. However, it should also be stressed that there was no unanimity on this. The fact that most participants assumed that there were no adjustments which could be made for visible difference also highlights the identity mismatch with disability – adjustments are perhaps perceived as a response to a functional limitation, not to looking different.

Research Question 3(b) is therefore answered as follows: the duty to make reasonable adjustments is rarely being applied in practice to people with a visible difference, and the wariness of some participants in engaging with the duty suggests that perceptions and awareness of the law, and how

	it applies in practice, are acting as a barrier to its effectiveness.

Progress towards Research Question 6: participation and inclusion	**Research Question 6** asks whether the law ensures the participation and inclusion of people who have a visible difference in the workforce and labour market. This has already been partly addressed in Chapter 3, and the partial statistical evidence presented there did not engender optimism about the inclusion of visibly different people in the labour market. The present empirical study did, however, provide further insight into the individual experiences of the participants in this regard. The present empirical study found little evidence of workplace participation (i.e. involving visibly different people in decisions which affect them) because, as noted earlier, for many participants, the aesthetic aspect of their condition had not been formally addressed by employers (such as in the context of a reasonable adjustment discussion – see Theme 4, Sub-theme: *Falling between the legal cracks*). Around half of participants in this study would have actively welcomed the employer initiating that discussion, though. On a more macro level, one type of participation cited by some participants related to charity advisory boards, which were welcomed by those participants as an opportunity to give their views. In terms of social inclusion – i.e. being able to fit in socially within a given workplace – the data was mixed but broadly positive – most participants had either felt socially included throughout (see Theme 1, sub-theme: *There's more to me than visible difference*), or had recounted both positive aspects of inclusion alongside some more negative experiences which they perceived to relate to visible difference. The variability of such reported experiences is also a theme in existing literature – see 3.3.3.

	Again, in relation to wider labour market inclusion, the evidence was mixed – some participants did not feel that their visible difference had affected their recruitment opportunities, but others did, which aligns with the findings of the recruitment studies set out at 3.3.4. It is also worth noting that participants had often avoided roles where they felt appearance would matter (see Theme 2, sub-theme A: *How I cope with visible difference*) – had they not done so, the level of perceived fairness in recruitment opportunities may have altered. This echoes the findings of existing research discussed at 3.3.4. In answer to **Research Question 6**, there is little evidence of measures to secure the participation of people with a visible difference, either at a micro level by individual employers, or a macro level in wider society in relation to policies / initiatives etc. In relation to inclusion, there was mixed evidence on the extent to which this had been achieved within UK workplaces overall, with examples of deliberate exclusion sitting alongside many accounts of positive social inclusion. The evidence in Chapter 3 does, however, suggest low inclusion within the wider job market.

Progress towards Research Questions 4 and 7: recognition and structural change	Questions 4 asks whether the law fosters awareness and respect for visibly different people, and their rights, dignity, capabilities and contributions and combats stereotypes and prejudice relating to visible difference. Question 7 builds on this by addressing the extent to which equality law pursues structural change which accommodates people who are visibly different. As outlined in previous chapters, wider literature suggests that the current law is limited in its potential for effective positive measures, but no evidence was found on this point as it relates to visible difference specifically.

The present empirical study builds on this in a number of respects. First, many participants felt that public awareness of their condition generally was poor – Theme 4 (*Falling between the cracks*) shows that some participants felt that their condition was often misunderstood or underestimated by others. This lack of awareness was felt both at an individual level in interaction with others, and at societal level – with some conditions suffering from a 'media blackout' (Participant B). The perceived lack of awareness is also apparent in the fact that many participants chose – or felt obliged – to explain their condition regularly to others, as identified in Theme 2: *Coping, explaining and privacy*.

Interestingly, a couple of participants felt that there was overlap between their condition being misunderstood and NHS medical policy – with participants who do not qualify for NHS treatment believing that it causes others to doubt the veracity of their condition (see Theme 4, sub-theme B: *Falling between the medical cracks*).

Second, the present empirical study confirmed that awareness of positive action measures amongst the participants was extremely low (a point which confirms research on positive action outside the visible difference context – see 3.4.5.2). Few participants had noted any positive action or inclusivity measures taken in respect of visible difference specifically. One participant worked for an organisation which had signed up to a charity campaign for a commitment to appearance equality (and had a poster of it pinned to the wall), one believed his/her employer was running general training on equality which included a section on appearance, and one other believed he/she may have seen something about appearance equality somewhere. Most participants suggested, however, that seeing positive action about visible difference would attract them to a particular employer or make them feel more comfortable about applying there (with the proviso for

	some that it was felt to be a genuine commitment not a tokenistic tick box exercise – see Theme 5, sub-theme D: *Rights can become wrongs*). So, from this small sample of participants it appears that positive action measures relating to visible difference are not being widely taken and advertised by employers, but there is potential for this to make a difference provided it is done in the right way. As set out at 3.4.5.1, public authorities are under an additional positive duty with respect to equality – but although some public authorities were perceived by participants as being very inclusive to work for, others were certainly not (see Theme 4, sub-theme C: *Falling between the social cracks*). Some participants did express a general feeling of having a bit of extra equality protection a result of working for a public sector employer, though. It is also worth mentioning that some of the more negative public sector experiences recounted took place prior to the introduction of PSED so it is possible that the position within many public authorities may have changed since then. In summary, very little evidence was revealed of employers taking significant positive measures to achieve the aims of Research Question 4 and 7. There is little evidence in this study that the Act's positive action provisions, and the public sector equality duty, are having much effect in practice on the experiences of people with a visible difference. On balance therefore, it can be concluded that the law is not adequately fostering awareness and respect for visibly different people, and their rights, dignity, capabilities and contributions and combatting stereotypes and prejudice relating to visible difference (**Research Question 4**). Nor is

	it pursuing structural change which accommodates people who are visibly different (**Research Question 7**).

Progress towards research Questions 5 and 8: access to justice and remedies	**Research Question 5** asks whether visibly different people have effective access to justice in challenging discrimination and, if not, why not. Chapters 3 and 4 posited several limitations of the law which, it was proposed, may limit its effectiveness. The empirical study in this chapter builds on those foundations. The participants demonstrated considerable wariness about the *process* of enforcing rights, with considerations including privacy, a fear of victimisation, the stress of the process, having to see those who had discriminated again, not knowing how to go about it, difficulty getting reliable legal advice for free, and a lack of confidence, all deterring them from bringing a claim (see Theme 5, sub-theme B: *Being wary of claiming*). These factors are similar to those identified by Hurstfield et al[592] in their study with disabled people. To some extent, these concerns can perhaps be thought of as inevitable consequences of an individual complaints-led approach to rights enforcement, requiring the victims of discrimination to endure the risk and personal burden of litigation to enforce their rights. But the size of this burden is perhaps likely to be greater for those whose condition affects them emotionally and psychologically – and Theme 1, sub-theme A: *Feeling self conscious, low in confidence and worrying about being judged* emphasises the intense self-consciousness, lack of confidence and worry about being judged felt by many participants with a visible difference. This suggests that the anticipated public scrutiny of the court process is perhaps likely to represent an even greater barrier for many people with a visible difference

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[592] Hurstfield and others (n437) 13.

	than some other types of disability, and this could contribute to the very low number of reported claims under the severe disfigurement provision. One deterrent factor which was particularly prominent in the participant accounts in this study was a concern about how to prove discrimination. Often participants perceived that employers disguise their real reasons, making it impossible to 'prove' discriminatory motivation. While this consideration is not unique to cases involving visible difference (in fact it was also cited in research by Hurstfield et al[593] see paragraph 3.4.6) it does reflect perhaps an overly simplified view of the law, which actually only obliges the Claimant to show a prima facie case of discrimination, with the burden then shifting to the employer to explain the treatment. A prima facie case does not necessarily require documentary proof specifying visible difference as the reason for a particular action. This is a point on which awareness could perhaps be improved generally to prevent it from deterring claims unnecessarily. **Research Question 5** can therefore be answered as follows: visibly different people do not have effective access to justice in challenging discrimination. **Research Question 8** has been answered at 3.4.6.

5.8 CHAPTER 5 SUMMARY

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[593] Ibid.

The analysis in Chapters 3,4 and 5 combined has produced answers to all of the eight research Questions identified in Chapter 1. Research Questions 1,3,4,5, 7 and 8 have all been answered in the negative, identifying ways in which UK law is failing to achieve the standards provided by the framework of substantive equality and CRPD principles which was set out in Chapter 1. Research Questions 2 and 6 are less conclusive, with mixed evidence (both positive and negative) making it hard to draw firm conclusions. Overall, though, the balance of evidence points to the conclusion that, at present, UK law is not providing effective equality for people with a visible difference in the workplace in a number of respects.

In the next chapter, I will consider possible changes which could be made to solve the problems identified to date. This includes possible changes to the law, with consideration of some international examples used by way of comparison, but also how best practice could be adapted by employers to overcome some of the barriers to equality identified.

6. LAW REFORM

6.1 CHAPTER INTRODUCTION

The preceding chapters have identified a number of problems with the law and the way it is being applied to people with a visible difference. In simplified terms, these problems are as follows:

Research Question	Identified problem
1:Targeting disadvantage	The scope of the severe disfigurement provision fails to identify and target the breadth of the scope of disadvantage suffered by those with a visible difference. In particular: • There is a mismatch between the narrow scope of 'severe disfigurement' and the disadvantage suffered by those with moderate disfigurements or conditions which impair appearance without being easily categorised as a typical 'disfigurement' (see 4.5 and 4.3). • There exists a rigid legal dichotomy between conditions which impair function and those which impair aesthetics. This hinders those with complex conditions which may have some effects in both categories (see 4.6). • The law fails to recognise the relative nature of some disfigurements, which require the personal characteristics of the person concerned to be taken into account in

	determining the extent to which the impairment disfigures her personally. Connected with this, there is uncertainty over the concept of impairment as it relates to conditions impacting appearance rather than function. (See 4.3).
2: Intersectionality	The legal challenge represented by intersectional discrimination, which is not expressly provided for in the Act (see 3.4.2.4) and which appears likely to create additional layers of disadvantage for many of those with a visible difference.
3:Reasonable adjustments	There is confusion and wariness over the concept of applying reasonable adjustments to people with disfigurements (see 4.7.2, 5.5.2 and 5.6.2)
4: Recognition	There are problems with the way that the law, disability status and equality rights are perceived by those affected: • Awareness and understanding of some conditions among colleagues and managers (and society in general) is low, sometimes leading to people with a visible difference feeling that their condition is misunderstood (see 5.5.2). Sometimes employees feel personally compromised by having to explain their condition to deal with others' reactions (see 5.3.2). • A reluctance to be labelled as 'disabled', or a perception of disability as purely functional, preventing many of those who may need to use the law from doing so (see 5.5.2).

	- A dilemma about whether to disclose a disfiguring condition during recruitment, and uncertainty whether this is required, permitted, or beneficial (see 5.5.2).
5: Access to justice	A wariness of claiming under the Act to challenge discrimination (see 5.6.2).
6: Participation and inclusion	There is little evidence of structured participation in relation to visible difference; the topic has remained well-hidden at national legal / policy level, and within individual workplaces the topic is often ignored. Evidence about employment and pay rates suggests poor inclusion, although the evidence on social inclusion within particular workplaces is mixed. (See 3.4.4 and 5.5.2).
7: Structural change	The measures in the Act designed to achieve structural change (such as the Public Sector Equality Duty) are limited both in number and scope (see 3.4.5.1). In additional, primarily reactive non-discrimination duties do not engage early enough to prevent visible difference from deterring participation in the labour market.
8: Remedies	The usual remedies under the Act are retrospective and individual so fail to encourage

	wider change or increased participation going forward (see 3.4.6).

Of these, the problems relating to research Question 2 (Intersectionality) and 8 (Remedies) are wider problems which affect not just disfigurement, or even disability, but also other protected characteristics under the Act. These two issues have been widely debated in existing literature and therefore are not addressed further in this Chapter. The problems relating to research Question 7 (structural change) have also been widely debated elsewhere and are therefore addressed only briefly here with a focus on visible difference specifically.

For the remaining identified problems, there are multiple possible approaches which could be adopted, which I present below as four tiers. The tiers represent different degrees of legislative change – from discrete amendments within the law's existing structure (Tier 1), to a different structure within the protected characteristic of disability (Tier 2), to the creation of a new protected characteristic (Tier 3), to steps mitigating the current heavy reliance on individual enforcement (Tier 4).

6.2 FIRST TIER: DISCRETE AMENDMENTS TO THE ACT'S SEVERE DISFIGUREMENT PROVISION AND RELATED GUIDANCE

At the most discrete level of law reform, a few changes could be made to the Act's existing provisions, and related guidance, to help solve some of the problems identified above.

6.2.1 SEVERITY THRESHOLD

First, the severity threshold[594] could be changed to substantiality to bring it into line with the threshold for functional impairment provided by s.6[595]. Removing the severity threshold would make it easier to understand and apply the provision, because 'substantial' is a lower threshold to meet then 'severe' and there is already considerable case law to aid its interpretation.

6.2.2 'CONSISTS OF…'

Second, the wording of 'an impairment which *consists of* a [substantial] disfigurement*'* could be changed to 'an impairment which *consists of or includes* a [substantial] disfigurement'. This would allow both functional and aesthetic effects to be combined in determining whether someone is disabled, in contrast to the approach adopted in *Cosgrove* (discussed at 4.6).

6.2.3 PROGRESSIVELY DISFIGURING CONDITIONS

Third, the progressive condition provision [596] could be amended to include progressively disfiguring conditions (see 4.5.2).

6.2.4 DISFIGURING EFFECTS AND DISFIGUREMENT AS A RELATIVE CONCEPT

Fourth, the Guidance on the definition of disability could also be amended to widen the scope of 'disfigurement'. As outlined at 4.3, key extensions would encompass conditions which have a disfiguring effect – such as facial movement impairments and other processual impairments – and those which depend on the relative nature of the personal characteristics of the Claimant, such as facial hair, baldness or height.

6.2.5 INTERNATIONAL COMPARISONS

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[594] Equality Act 2010, Schedule 1, s.3.
[595] Equality Act 2010, s.6.
[596] Equality Act 2010, Schedule 1, s.8.

I found very little international evidence dealing with any of these definitional issues specifically, despite the Americans with Disabilities Act adopting the term 'cosmetic disfigurement'[597] – which is not limited by any severity threshold. In the US, much of the available case law on this provision concerns scars and birthmarks (which fall easily within the scope of the term 'disfigurement'), but an additional line of authority shows the courts recognising visible dental problems (particularly significant numbers of missing teeth) as a cosmetic disfigurement within this provision[598]. This arguably represents a tentative extension of the concept[599] as established under domestic case law. I also noted some US caselaw relating to alopecia[600], where the plaintiff sought to argue that, by virtue of her hair loss, her employer 'regarded her' as disabled (the 'regarded as' prong of the ADA is explained further at 6.3.1 below). Although the claim did not succeed on the facts (because it was not proven that the employer regarded her alopecia as substantially limiting one or more major life activities[601]), the issue of alopecia as an impairment (presumably under the category of a cosmetic disfigurement) appears to have been implicitly accepted in the judgment.

It will be remembered from Chapter 4 that the criteria of 'impairment' is also problematic in implementing a relative approach to disfigurement, where a distinction between appearance and impairment needs to be drawn based on the personal characteristics of the person concerned. In order to allow this relativity to be addressed, the concept of impairment needs to be better at differentiating difficult cases which fall close to the border. US federal law

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[597] Regulations to Implement the Equal Employment Provisions of the Americans with Disabilities Act, as amended, 29 CFR 1630.2(h).

[598] See, for example, *Hodsgon v Mt Mansfield Co* No.91-346 (Vt.Nov. 6 1992); *Johnson v American Chamber of Commerce Publishers Inc* 108 F.3d 818 (7th Cir 1997); *Talanda v KFC National Management Co* 140 F.3d 1090 (7th Cir 1998).

[599] In these cases, consistent with the British and European case law on obesity and other potentially 'self-induced' conditions, the cause of the missing teeth is irrelevant.

[600] See e.g. *Janice Otero Barreto v Doctors' Center Hospital, Inc* [2016] (District Court, Puerto Rico), Case 3:14-cv-01457-SEC.

[601] This finding is surprising because, after the ADA was amended in 2008, a claim under the 'regarded as' prong no longer needed to show a substantial limitation of life activity. The court appears to have applied the old law rather than the post-2008 law, and the reason for this is unclear.

provides a useful comparator in this regard. The Interpretive Guidance to the Americans with Disabilities Act 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 and are not the result of a physiological disorder’[602]. Although this guidance doesn’t go as far as to link expressly the ‘normal range’ to the personal characteristics of the person concerned, it could perhaps be argued that this is implicit. It does at least provide a mechanism to distinguish general appearance traits from impairments (see 4.3), and does so by reference to what is ‘outside the norm’ (which echoes the discussion of substantive equality at 1.3.1). Provided that this list of exclusions was not engaged, Tribunals would be free to adopt a more relaxed approach to the concept of impairment, which is more in line with the body of case law surrounding functional impairment set out at 4.3.

6.2.6 BEST PRACTICE MODELS

An additional model of best practice concerning reasonable adjustment for visible difference would also be a discrete change. After extensive searches, I found a few organisations who had attempted to create their own, but these were poorly advertised and left room for improvement. A number of participants in the study at Chapter 5 also identified a lack of useful available information. By way of example, further guidance could usefully cover the following issues:

1. suggestions of possible reasonable adjustments which some people with a visible difference may find helpful (especially given that many participants in the study didn’t think that adjustments could be made for visible difference). Appendix 7 provides a list of possible adjustments subject to context.

2. Clearer advice on who may be covered by the provision, both in terms of types and degrees of disfigurement. A possible checklist of factors is

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[602] Title 29 CFR Appendix to Part 1630, *Interpretive Guidance of Title 1 of the Americans with Disabilities Act*, para 1630.2(h)

attached at Appendix 6. One participant during the study in Chapter 5 indicated that partial photographs of disfigurements deemed to meet the relevant threshold should be included in guidance. This clarity is particularly important given the identified socio-legal theme 4: *Falling between the cracks*, where participants felt confused by different approaches in medicine and law, and uncertain whether they were covered.

3. Adopting flexible recruitment and promotion procedures, such as allowing candidates the ability to opt out of a video interview, for example, or to opt to have a telephone interview first. Making these small changes available to all candidates may ensure that those with a visible difference do not feel too conspicuous in requesting this, and may benefit other groups of people too, such as those with anxiety, or those for whom English is a second language.

4. Including appearance within equality policies and within general inclusivity training programmes. The outcome of one French study includes suggested useful training materials to encourage debate about general appearance stereotypes and discrimination[603]. While more individualised information programmes may sometimes be helpful (for example to inform colleagues of someone's return to work after acquiring a facial disfigurement), it is vital that the individual is in control of any such decisions via a process of consultation.

5. Enabling (but not requiring) job applicants to make a *health* mention <u>if they choose to</u>, without labelling it as a *disability*. This recommendation is difficult because, under the Act, employers are not allowed to ask pre-employment health questions[604], save where one of a number of limited exceptions apply. The most common exception is to establish whether the applicant can carry out a duty intrinsic to the job applied for[605]. While the

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[603] Isabelle Barth and Anne-Lorraine Wagner, 'Physical Appearance as Invisible Discrimination' (2017) 4 International Perspectives on Equality, Diversity and inclusion 127, 143.

[604] Equality Act 2010, s60.

[605] Ibid, s60(6)(b). French law also provides that employees do not have to disclose health conditions to their employers and often have the right to lie about it if asked Sophie Fantoni-Quinton and Anne-Marie Laflamme, 'Medical selection upon hiring and the applicant's right to lie about his health status: A comparative study of French and Quebec Law' (2017) 11

pre-employment health questions rule is designed to protect applicants from discrimination, it arguably makes it harder for people with conditions which are inevitably visible during an interview, because it increases the potential for employers to jump covertly to conclusions based on assumptions and stereotypes rather than information. While the Act's provision does not prevent the applicant from raising the health topic herself to explain that it does not impact her ability to carry out the role, some of the participants in my empirical study expressed difficulty raising this topic in person (and indeed some used pre-completed cards to ease this process). The employer's response to a voluntary oral disclosure during interview may in any event feel rather stilted as they would be prevented from seeking clarification once the applicant raised it.

How should this contradiction be addressed? Perhaps the best option, as one participant suggested, is for application forms to include a space where applicants can choose to make a brief health mention if they want to. This would need to be accompanied by a very clear note explaining that the applicant is not obliged to disclose any health information at this stage, and how the information will be treated if it is disclosed – statutory guidance could provide appropriate wording. This would better reflect the concerns of those with visible conditions for whom the ban on pre-employment health questions may be a double-edged sword.

6.2.7 FIRST TIER SUMMARY

These discrete changes together have the potential to mitigate many of the legal inconsistencies and limitations noted earlier. But what they lack is the potential to increase awareness, either among the general public or people who are visibly different, and the willingness of those with a visible difference to identify as disabled. These discrete changes may perhaps make it slightly easier for individuals to understand whether they are covered by these rights – the severity threshold, in particular, was identified as a hurdle in this regard (see 5.6.2) – but they don't remove the numerous reasons why participants are wary of enforcing

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Alter - European Journal of Disability research, Revue européen de recherche sur le handicap 85, 88.

their rights in the Employment Tribunals, as set out in theme 5, sub-theme B: *wariness about claiming* in Chapter 5. Nor do they deal with the wider social barriers which can deter some of those affected before the Act's discrimination provisions engage, including lowered expectations, reduced educational attainment, and a lack of confidence.

6.3 SECOND TIER: STRUCTURED LEGAL CHANGES WITHIN THE PROTECTED CHARACTERISTIC OF DISABILITY.

A different answer is to bring the Act's disability definition into line with the approach taken in the CRPD and the social model. A definition which focused at least partly on external barriers could include people who are visibly different without the friction caused by trying to bolt on a separate disfigurement provision.

The potential of a social model disability concept is not unique to visible difference; people with other types of impairments could also benefit from a legislative approach which recognised society's role in creating disability. A social model focus creates a natural progression towards wider, preventative changes because it shifts the attention to society – perhaps via more robust positive action and related measures – and away from the individual's medical limitations. But a social model definition is certainly not a new idea. Many commentators have lamented the Act's medical model approach, yet it remains entrenched, and reaffirmed relatively recently in the Act[606]. Thus while an ideological shift in the Act's understanding of disability would undoubtedly have considerable promise (subject to its drafting managing to provide sufficient clarity as discussed at 1.2.2), this suggestion is perhaps also unlikely to be realised in the near future. I will therefore move on to consider some other ways in which social model principles could be partly realised in the Act, without a wholesale shift in the Act's ideology.

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[606] The reluctance to embrace a social model definition can also be found at EU level; a proposed 2008 framework directive on equality failed to include a legally binding definition of disability linked to social model principles despite calls for it to do so – see Lisa Waddington, 'Future prospects for EU equality law: lessons to be learnt from the proposed equal treatment directive' (2011) 36 European Law Review 163

U.S.A.

The Americans with Disabilities Act (which was significantly amended in 2008 to expand its scope) offers an interesting hybrid approach to the medical / social model distinction. It provides a three-pronged approach to defining disability (labelled A, B and C below):

“SEC. 12102. [SECTION 3]

As used in this chapter:

(**1**) Disability. - The term "disability" means, with respect to an individual-

A) a physical or mental impairment that substantially limits one or more major life activities of such individual;

(B) a record of such an impairment; or

(C) being regarded as having such an impairment (as described in paragraph (3)).

For purposes of paragraph (1)(C):

A) An individual meets the requirement of "being regarded as having such an impairment" if the individual establishes that he or she has been subjected to an action prohibited under this chapter because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.

(B) Paragraph (1)(C) shall not apply to impairments that are transitory and minor. A transitory impairment is an impairment with an actual or expected duration of 6 months or less.”

‘Prong 1’ (labelled A above) provides a (mostly) functional test. The list of major life activities’[607] mainly comprises a number of functional tasks such as breathing, sitting, hearing and seeing, but it also lists ‘working’ as a major life activity, which could in principle include both social and

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[607] Americans with Disabilities Act of 1990, as amended, s12102(2).

functional limitations. But case law on ‘working’ as a major life activity under the ADA shows such a restrictive approach that it is recommended only as the major life activity of last resort[608]. It is not enough that the plaintiff is limited by the disfigurement in respect of one job, she must be limited in respect of the relevant class of jobs[609]. So, in *Talanda v KFC International Management Company*[610], a fast-food restaurant worker who was moved to a behind-the-scenes role in the restaurant in order that her missing teeth did not put off customers was not substantially limited because there were other roles within the fast-food industry where missing teeth did not limit her ability to work. Although this case was decided before the 2008 amendments, the amended Act retains this ‘class of jobs’ requirement, despite regulations providing that it should be applied “in a more straightforward and simple manner” than before the 2008 amendments[611].

The amended ADA provides an alternative method for satisfying the major life activity test: a plaintiff can prove that her impairment affects a major bodily function, such as the digestive, circulatory or other bodily functions[612]. Depending on the nature of the visible difference, it may be possible to argue that a major bodily function is impacted – perhaps skin function and healing for acne or psoriasis, for example - but no case law was found on this point. In summary, Prong 1 under the ADA is not easy to satisfy for people with a visible difference and no functional impairment[613], and a greater number of cases are found under Prong 3.

While ‘prong 1’ provides a functional test (i.e. the impairment must substantially limit one or more major life activities), prong 3 does not. Prior to 2008, under a prong 3 claim, the plaintiff would have to show that an

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[608] EEOC, Interpretive Guidance on the Americans with Disabilities Act (2011) §1630.2(j).

[609] Ibid.

[610] See *Talanda v KFC International Management Company* 140 F.3d 1090 (7th Circ. 1998).

[611] EEOC (n608) §1630.2(j).

[612] Americans with Disabilities Act of 1990, as amended, §12102(2)(B).

[613] Note also that an employee who succeeds in proving herself substantially limited in the major life activity of working faces a dilemma: if found to be too limited to perform the role satisfactorily with reasonable adjustments, the employer may have a defence to discrimination under §12113.

(actual or perceived) impairment was *perceived* as substantially limiting a major life activity. This created difficulties for many plaintiffs with a visible difference. Although some managed to pass this test (including a chambermaid banned from attending work and ultimately dismissed because she could not afford to wear dentures to hide her missing teeth[614]), others struggled to demonstrate a perception of a substantially limited major life activity[615].But this is now much easier. To bring a claim under the 'regarded as' prong since the 2008 amendments, it is not even necessary to show that the perpetrator *perceived* that the impairment (actual or perceived) substantially limited a major life activity; a plaintiff may now succeed in a claim under prong 3 by proving simply that (1) he has (or is regarded as having) a physical or mental impairment and (2) that he was discriminated against by the employer as a result.

While perceptive discrimination is not, of course, unique to the United States, the US version is significantly wider than the version provided by Act, because of the absence of a need to prove that the scope of the perpetrator's perception matched the legal definition of disability (see 4.7.1). The focus of the US provision is therefore on the discriminatory treatment, not the technicalities of what the perpetrator assumed. By focusing on social barriers rather than the reality of any physical limitations, it supports a social model focus.

However, despite being hailed by many as a huge step forward in rights protection, the amended 'regarded as' provision does not appear to have had a drastic impact. EEOC data between 1997 and 2018 shows no significant increase in the number of merit factor resolutions[616] within this period

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[614] *Hodgson v Mt Mansfield Co* 61 USLW 2337, 625 A2D 1122 (1993). This case was decided under Vermont's Fair Employment Practices Act which contained a similar disability definition to the ADA prior to the 2008 amendments. See further Sharlene McEvoy, 'Employment Discrimination Based on Appearance', (1994) Labor Law Journal (September) 592.

[615] *Johnson v Dunhill Temporary Systems Inc*. 11 Nat'l Disability L. Rep. (BNA) 78, at 320 (ND Ill Oct,24, 1997); *Van Sickle v Automatic Data Processing Inc*. 952 F.Supp.1213, 1223 (ED Mich.1997); *Schwertfager v City of Boynton Beach* 42 F. Supp. 2D 1347 (SD Fla 1999);

[616] Merit factor resolutions include successful claims and mediated settlements.

relating to disfigurement[617], despite the drastic changes to the 'regarded as' prong in 2008, which made it much easier for plaintiffs to succeed in this claim. The reason for this lack of impact (to disability claims generally) is unclear; Christine Jolls argues that the breadth of the provision could be deterring employers from hiring people with impairments in the first place due to the costs of making adjustments for disabled people[618]. Alternatively, Ruth Colker argues that the widened definition of disability won't lead to meaningful change, because the low wages earned by many disabled people in the US mean that most lawyers are reluctant to represent them on a contingency basis, and so they have very limited access to advice[619]. It is also possible that the ease of this new law is not yet properly understood.

It is, however, worth noting a couple of limitations to this expanded definition of disability under the ADA. First, a perceived disability does not trigger the duty of reasonable accommodation. So, someone with a visible difference, whose condition did not substantially limit one or more major life activities under Prong 1 (perhaps someone with a 'pure' disfigurement but who was nonetheless discriminated against because of her (actual or perceived) impairment), would not qualify for adjustments at work. Second, transitory impairments lasting less than 6 months are excluded from protection – although this limit is still more favourable to claimants than the one year limit under the Equality Act, it may still prevent people with sudden, but relatively short-lived, visible differences (e.g. Bell's palsy) from qualifying under it.

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[617] EEOC, 'ADA change data by impairment / bases – merit factor resolutions (charged filed with EEOC)' (2018) <https://www.eeoc.gov/eeoc/statistics/enforcement/ada-merit.cfm> accessed 20 September 2019.

[618] Christine Jolls, interview cited in Marie Mercat-Bruns, *Discrimination at Work: Comparing European, French, and American Law* (University of California Press 2016) 205.

[619] Ruth Colker, interview cited in ibid 201.

Assessing the relevance of the US approach to the Act, it is submitted that, although undoubtedly helpful for people with other types of impairment, widening the ambit of perceptive discrimination (following the US model) would be unlikely to make a significant difference to people with a visible difference in the UK. As explained at 4.7.1, given that severe disfigurement is 'deemed' to be a disability by the Act, it seems likely that the technicalities of perception are in fact already minimal for people using this provision. And a technical amendment to the rules on perceptive discrimination is probably unlikely to change the more fundamental problems revealed in Chapter 5, including a lack of awareness and the conception of disability as functional. The difficulty making reasonable adjustments to cases of perceived disability also indicates that this is not a complete answer to disfigurement discrimination.

France

Turning to France, the meaning of 'disability' appears equally focused on individual function, rather than societal hindrance:

> "toute personne dont les possibilités d'obtenir ou de conserver un emploi sont effectivement réduites par suite de l'altération d'une ou plusieurs fonctions physique, sensorielle, mentale ou psychique"[620].
>
> (Translation: "any person whose chances of obtaining or keeping a job are effectively reduced following the alteration of one or more physical, sensorial, mental, or psychological functions".)

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[620] Code du Travail art L5213-1.

But this is less relevant, because French law protects not just on the basis of a medical conception of disability, but also 'état de santé'[621] (health condition - which can be used for more transitory impairments) and 'apparence physique[622]' (physical appearance). In other words, someone treated poorly at work because of a disfigurement may be able to allege discrimination under more than one head. An example where this happened is a 2011 case recommendation[623] by the Defenseur des Droits (the French investigative and mediation body), where the victim, a butcher with a disfigurement resulting from an operation to remove a tumour on his head, was found to have been discriminated against under all three grounds. So, although the definition of disability in the French labour code is not fully social model-complaint, the impact of this to people with a visible difference or more minor (non-disabling) health conditions is less crucial. The French law on physical appearance is discussed further at 6.4.3 below

6.3.2 AMENDING THE S.6 DEFINITION OF DISABILITY

An alternative amendment to the concept of disability in the Act is to retain the existing functional definition of s.6 but incorporate an additional limb to cover impairments causing appearance-related disadvantage. A basic framework could perhaps be as follows:

> (1) A person (P) has a disability if P has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on:
>
> > (a) P's ability to carry out normal day-to-day activities; or
> >
> > (b) P's appearance.

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[621] Code du Travail, art 1132-1.

[622] Ibid.

[623] Défenseur des Droits MLD/2015-3-4 (le 4 Décembre 2015) < https://juridique.defenseurdesdroits.fr/doc_num.php?explnum_id=14024> accessed 18 August 2019.

> (2) The effects under sub-paragraph (1) (a) and sub-paragraph (1) (b) may be considered either separately or cumulatively in determining whether section 1 is satisfied.

'Impairment' could be defined as suggested in Tier 1, as excluding specified appearance characteristics (such as height or facial hair) which are within the normal range for the relevant person. Although not a fully 'social model' definition, the inclusion of impairments adversely affecting appearance does partially incorporate the concept as it applies to visible difference. This has some advantages:

1. Consistent with the approach taken under s.6, the proposed wording measures the impact of the impairment on the claimant's own appearance. Although it does involve reference to an external standard (i.e. a normal range), in this instance it relates only to assessing the relevant physical characteristic (such as height or eye colour), not to making judgments of overall appearance or attractiveness, with the added intrusiveness this entails.

2. Allowing functional and appearance effects to be combined seems to avoid the problem created by the *Cosgrove*[624] case, enabling people with complex conditions to combine the different types of effects in meeting the disability threshold.

3. The proposed definition also helps to realign disfigurement with the wider concept of appearance-related disadvantage, in that it doesn't focus exclusively on disfigurements at the expense of other disfiguring impairments, such as alopecia.

4. Remembering the analysis at 4.3, the reference to '*P*'s appearance' allows personal contextuality to be taken into account in determining whether the severe disfigurement threshold is met.

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[624] (n466).

5. Crucially, this definition may also increase awareness among employers and those affected. It was noted in Chapter 5 that those affected commonly seemed to associate disability purely with functional limitations, and some made reference to the current language of s.6 in this regard, which suggests that the law is partly responsible for this perception. Changing the law in this way may encourage wider awareness and the willingness of those with a visible difference to identify as disabled.

So how would this definition remedy the problems identified? Some existing case outcomes may well be unaffected. The decision in *Campbell*[625] relating to male pattern baldness, for example, would seem likely to fall foul of an impairment exclusion relating to hair loss within the normal range for a man in his sixties, likely prompting no change to the finding of no impairment. Other cases, however, could lead to a different outcome. The height of 4'8" in *Hussain* seems more likely to fall outside the normal height range for an adult male, so a finding of impairment could well follow. (Whether the Tribunal found that the Claimant's height amounted to a *severe* disfigurement or disability is, of course a separate matter). In both of these cases, the result could be different if the claimant's personal characteristics were altered in a relevant way.

The proposed definition might also impact on a minority of cases relating to obesity; given the prevalence of mild to moderate obesity, a finding of impairment (i.e. weight outside of the normal range) may be limited to cases of morbid obesity. A claimant would still need to fulfil the remaining aspects of the definition of disability, but a return to the spirit of the *Ring* definition could achieve this by reference to social, rather than physical, limitations resulting from morbid obesity. Conditions like synkinesis and other facial movement impairments would perhaps also be more likely to be included by the proposed definition, due to the increased breadth (or at least perceived breadth) which it provides.

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[625] (n496)

6.3.3 SECOND TIER SUMMARY

The potential to amend the definition of disability to include both substantial functional and aesthetic effects offers considerable promise. It offers the best method of dealing with complex conditions, avoiding the 'either/or' approach currently taken by the law. It has the potential to increase awareness and to begin challenging attitudes towards disability as a functional only concept. It reduces anticipated concerns about floodgates which would be likely to accompany a general protected characteristic of appearance, yet makes it easier for people with a visible difference to meet the threshold. Its main disadvantage is that it still faces the challenge of breaking down the barriers which discourage people from self-identifying as disabled, and being prepared to enforce their rights accordingly. Some wider societal measures and positive duties, discussed at level 4 below, may assist in this regard.

6.4 THIRD TIER: A NEW PROTECTED CHARACTERISTIC

An alternative approach is to reconceptualise the link between disfigurement and disability so that the rights of visibly different people are recognised independent of disability. Two possibilities will be considered: the creation of a separate protected characteristic of disfigurement [626] and the prohibition of general appearance discrimination, which already exists in France, Belgium[627] and some local laws (to varying degrees) in the US[628].

6.4.1 DISFIGUREMENT AS A PROTECTED CHARACTERISTIC

In addition to its awareness-raising potential, the partial separation of disfigurement into its own protected characteristic could provide an opportunity to resolve the uneasy relationship between the 'social model' disfigurement concept

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[626] Changing Faces, (n275) 303. This document proposes a separate characteristic of *facial* disfigurement.

[627] Belgium prohibits discrimination due to physical or genetic characteristics. See Emanuelle Bribosia and Isabelle Rorive, *Country report: Belgium* (European network of legal experts in gender equality and non-discrimination, European Commission 2018) 38.

[628] Deborah Rhodes, *The Beauty Bias* (Oxford University Press 2010), 126.

and the ‘medical model’ disability provisions, which lies at the root of much of the legislative friction identified earlier. The reference to ‘partial’ separation reflects the fact that the inclusive concept of disability in the CRPD would still encompass disfigurement, enabling the two concepts to retain a degree of unity over the disabling barriers they encounter.

However, separation would also bring difficulty. First, the law needs to ensure sufficient permeability to provide for ‘complex’ disfiguring conditions involving both visible difference and functional impairment. Given the failure of the Act to achieve this combination under the single characteristic of disability, it may prove even harder across characteristics.

Second, the definition of disfigurement is likely to lead to problems similar to those already encountered, including a lack of clarity of scope. This would again necessitate additional guidance to prevent the concept being interpreted narrowly, to the exclusion of people with wider disfiguring conditions, such as alopecia. Even with additional guidance, though, the linguistic constraints of the word ‘disfigurement’ are such that grey areas and illogical exclusions are likely to remain - obesity is an obvious example.

The wording of ‘disfigurement’ could perhaps also be thought of as a deterrent in its own right – many charities for people with relevant conditions prefer not to use this terminology. The study outlined in Chapter 5 did not support the idea that ‘disfigurement’ is a difficult word for those affected, but this was not a matter which I specifically directed the participants to during interviews. This is an area for future research.

6.4.2 APPEARANCE AS A PROTECTED CHARACTERISTIC

Remembering the discussion about the theoretical scope of equality law at 1.3.1, a protected characteristic of appearance is perhaps the broadest, most ‘symmetrical’ method of granting equality rights to people with a visible difference. This may be both its strongest and weakest feature.

On the one hand, appearance is a spectrum which applies to everyone. There are no threshold tests of severity, or even disfigurement, to meet in order to qualify for protection, which may benefit those who struggle to pass the current threshold. On the other hand, while bringing the implicit bias of 'beauty is good'[629] into the public consciousness may benefit people who are visibly different to some degree, aligning disfigurement with the debate about how to determine nuances of appearance[630] may result in a diluted recognition of the reality of living with visible difference. As one commentator opined:

> 'while early cases may involve plaintiffs with severe facial disfigurement, the concept of "mindless incrementalism" so familiar to employment law will likely soon take over … those seeking to take advantage of a cause of action for appearance discrimination are soon likely to expand beyond the severely disfigured to the merely homely or unkempt'.'[631]

Returning to the discussion of equality theory at 1.3.1, recognising wider disadvantage has appeal, but perhaps not if it means treating all disadvantage (including any resulting from general appearance imperfections within the normal range) as equivalent. Replacing the 'severe disfigurement' provision, flawed as it is, with a general prohibition on appearance discrimination could in some respects dilute the relevant rights by spreading them thinly across a much wider class incorporating almost everyone. To provide a concrete example, should the law's priority be to enable positive action in favour of the vast numbers of us with big noses and bushy eyebrows, or more restrictively, in favour of those living with a disfiguring condition?

A prohibition against appearance discrimination could, of course, be expressly limited to immutable traits. Even so, some commentators argue that hiring good-looking staff is a valid commercial consideration[632] and morally no different from

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[629] Dion, Berscheid and Walster (n242) 285.

[630] Heather R. James, 'If you are attractive and you know it, please apply: appearance based discrimination and employers' discretion' (2008) 42 Valparaiso University Law Review 629, 660.

[631] James J. McDonald, Jr., 'Civil rights for the aesthetically-challenged.(physical appearance discrimination)' (2003) 29 Employee Relations Law Journal 118, 127.

[632] Robert J Barro, 'So you want to hire the beautiful. Well why not?' *Business Week* (USA

hiring based on intelligence, which is outside of the individual's control[633] in the same way as immutable appearance characteristics like hair colour and the size of one's ears. Others have questioned the practicality of a law which requires employers to be 'blind to almost everything which is normally salient in everyday social life…In what sense does a person without an appearance remain a person?[634]'. Robert Post argues that imposing requirements of appearance blindness in this way encourages employers to think of their staff not as people but "merely as means for accomplishing the managerial purposes of an employer's business"[635], thus dehumanising the workforce.

Introducing a separate protected characteristic of appearance instead of the severe disfigurement provision would also remove people with a visible difference from the reasonable adjustments duty which, although apparently not applied much in practice in this context, has potential, as argued at 4.7.2.

Appearance discrimination protection is not common internationally. As noted above, it is not a listed ground within the relevant EU Directive, nor the CRPD, nor the International Labour Organisation's convention on employment discrimination[636] (which has been ratified by the UK). The position in France and some states of the US are discussed below.

6.4.3 INTERNATIONAL COMPARISONS

France

As noted above, the Code du Travail in France was amended in 2001 to include some new protected characteristics. This added physical appearance to the existing categories of health condition and disability.

<https://scholar.harvard.edu/files/barro/files/98_0316_hire_bw.pdf> accessed 1 March 2018; Samuel V. Bruton, 'Looks-Based Hiring and Wrongful Discrimination' (2015) 120 Business and Society Review 607.

[633] Barro, ibid.

[634] Robert Post, *Prejudicial Appearances: the logic of American antidiscrimination law* (Duke University Press 2001)

[635] Ibid.

[636] Discrimination (Employment and Occupation) Convention 1958 (n43).

The concept of physical appearance in the legislation is broad. One decision by the Défenseur des Droits noted that:

> "Elle récouvre un périmètre particulièrement large puisqu'on peut y inclure les caractéristiques inaltérables d'une personne - telles que la couleur de peau, les traits du visage, les stigmates ou la taille - et les caractéristiques manipulables par une personne : piercing, vêtements, coiffure…"[637]
>
> (Translation: 'physical appearance' covers a particularly large area because one can include in it immutable characteristics such as skin colour, facial features, scars or size – and characteristics chosen by a person: piercings, clothes, hairstyle…".

Originally enacted to combat discrimination based on skin colour, complaints sometimes link with other protected grounds, covering issues such as facial hair connected with religious beliefs, or physical appearance while changing sex.

The right not to be discriminated against is not inalienable, thus indirectly discriminatory restrictions may be justified by the nature of the task and proportionate to the aim pursued, and directly discriminatory differences in treatment may be justified by an occupational need which is both legitimate and proportionate (similar to a genuine occupational requirement under the Act).

Much of the case law about this provision focuses on either weight or chosen traits (particularly clothing – including a memorable dispute about wearing Bermuda shorts to work[638]). There is a difficult balance between the employer's desire to create a particular brand and the employee's right not to be discriminated against on the basis of physical appearance. In relation to occupational requirements, the Défenseur des Droits ("DfD") guidance[639] gives the example of an image requirement for fashion models which could

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[637] Le Défenseur des Droits, 'Decision-cadre MLD 2016-058' (12 Fevrier 2016) <https://juridique.defenseurdesdroits.fr/doc_num.php?explnum_id=14278> accessed 10 July 2019.

[638] Cour de Cassation, Chambre Sociale, (28 May 2003) 02-40273.

[639] Le Defenseur des Droits, 'Le Physique de L'Emploi' (2016), 3.

be justified – whereas Abercrombie and Fitch's aesthetic recruitment criteria for sales staff in its French stores was not, despite labelling them as store 'models'[640].

Outside of professions like modelling, though, it is hard to conceive how discrimination against someone on the basis of a disfigurement could be justified under French law, but no case law was found on this point. As one Défenseur des Droits recommendation commented:

> "Concernant les postes de nature commerciale, ou les métiers de services nécessitant une part d'interaction directe avec la clientèle, le recruteur pourra attacher de l'importance au caractère soigné de la présentation des candidats, sans pour autant tenir compte de leurs caractéristiques corporelles non manipulables"[641].
>
> (Translation: 'regarding commercial jobs, or professions involving direct interaction with clients, the recruiter is able to take into account the importance of a well-groomed appearance among the candidates, without, however, taking into account immutable bodily characteristics'.

Despite the above, a significant body of research in France suggests that discrimination against people with disabilities, health conditions, and impaired appearances is still a problem. By way of example, a 2016 investigation by the DfD[642] found that 40% of male respondents felt it would be acceptable to refuse to hire a physically unattractive candidate in some situations, and 7% felt it would be acceptable to do so in every situation. 8% felt that they had suffered discrimination during recruitment due to their physical appearance. A recent survey of those people affected by potentially disfiguring conditions also supports this perception that the law is not

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[640] Le Defenseur des Droits, 'Abercrombie and Fitch: Grace au Defenseur, la société annonce la fin de recrutements discriminatoires' (Defenseur des Droits, 2015) <https://www.defenseurdesdroits.fr/fr/a-la-une/2015/05/abercrombie-and-fitch-grace-au-defenseur-la-societe-annonce-la-fin-de-recrutements> accessed 10 July 2019.

[641] Le Defenseur des Droits (n637) 11.

[642] Défenseur des Droits, 9ème édition du Baromètre des droits et de l'OIT sur la perception des discriminations sur l'emploi (Fevrier 2016) https://www.defenseurdesdroits.fr/sites/default/files/atoms/files/etudes_et_resultats_barometre_ap_vf-v4.pdf accessed 19 September 2019.

succeeding in preventing negative treatment in France[643], with 70% of participants with psoriasis reporting that they had been teased about their appearance at work, and 31% reporting that they had lost their job because of it. Yet the number of claims based on physical appearance discrimination in France remains extremely low[644]. It has been suggested by some that this may, ironically, be because appearance discrimination is so prevalent that it is implicitly legitimised:

> "..its omnipresence makes it something that is rarely called into question and leads to very few complaints. In effect, we may presume that everyone has assimilated and legitimised it because it just seems so natural"[645].

This suggests that the ongoing tension between legal provision and legal enforcement remains a problem in France as well as in Britain, despite its wider-ranging provisions.

U.S.A.

In the US, a few local appearance discrimination laws sit alongside equality law applicable to people with disfigurements in the Americans with Disabilities Act, as summarised in the table below:

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[643] Association France Psoriasis, 'Enquête inédite sue l'impact do Pso sur la vie professionelle (9 October 2017) https://francepsoriasis.org/actualites/enquete-inedite-sur-limpact-du-pso-dans-la-vie-professionnelle/accessed 19 September 2019.

[644] Barth and Wagner (n603) 137.

[645] Ibid 145.

Jurisdiction	What is prohibited?	Notable points
Local ordinance of Santa Cruz[646]	Discrimination on the basis of **height, weight and physical characteristic**. Physical characteristics are defined as 'a bodily condition or bodily characteristics of any person which is from birth, accident or disease, or from any natural physical development, or any other event outside the control of that person including individual physical mannerisms'. Reasonable business purpose exemption.	Immutable characteristics only. 'Physical mannerisms' could arguably include facial movement impairments, though no case law on this point found. Enforced primarily through mediation not litigation.
Local ordinance of Urbana[647]	Discrimination by way of **personal appearance or any other discrimination based upon categorizing or classifying a person rather than evaluating a person's unique qualifications relevant to an opportunity…'** Personal appearance defined as 'outward appearance'.	Deborah Rhodes notes that inadequate remedies under this provision create little incentive to file complaints[648].
San Francisco[649]	**Height and weight discrimination**. (Includes	This provision could perhaps include conditions

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[646] Santa Cruz, Cal., Municipal Code §9.83.020 (12) and §9.83.030.

[647] Urbana, Ill., Municipal Code §12-37 (amended version enacted 19 November 2018 (Supp. No 42).

[648] Rhodes (n628) 127.

[649] San Francisco, Cal., Administrative Code §12A.1 (amended version enacted 1 July 2019).

	not just numerical measurement of body weight but also an individual's unique physical composition of weight through body size, shape, and proportions.	such as lipoedema, which cause one part of the body to swell, but most forms of disfiguring condition would not be covered.
District of Columbia local human rights act[650]	Discrimination on grounds of **personal appearance.** Exceptions are available for requirements like cleanliness and uniforms, when uniformly applied for a reasonable business purpose. Business necessity justification available.	Some reported complaints related to disfigurement e.g. skin lesions and discolouration resulting from HIV status[651], but most did not. Many of the others could have been brought under other heads of discrimination.
Maryland Counties: Prince George's County[652], Howard County[653], and Harford County[654].	All three counties ban discrimination on **personal appearance.** The detail of each law differs, though. Uniforms and cleanliness allowed.	Rhodes notes that most claims brought included other protected characteristics too[655]. While Howard County includes 'physical characteristics' in its definition of personal appearance, both Prince George's County and Harford County limit the definitions to 'hair style, beards, or manner of dress', seemingly

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[650] District of Columbia Code §2-1401.01 (amended version enacted 11 April 2019).

[651] Natural Motion by Sandra Inc v Estate of Richard Andrew Hamilton (Intervenor) No. 95-AA-1465 (9 Jan 1997).

[652] Prince George's County, MD, Code §2-186 (14) and 2-185.

[653] Howard County, MD, Code §12.200 and 12.201 (xy).

[654] Harford County, MD, Code §95-3 and 95-5.

[655] Rhodes (n628) 130.

		excluding immutable characteristics of appearance.
Madison[656]	Discrimination based on **physical appearance.** Excludes cleanliness, uniforms and prescribed attire.	Rhodes notes that the majority of claims brought were unsuccessful and combined with other grounds[657].
Michigan Civil Rights Act[658]	Includes **height and weight**	Rhodes notes low success rates of claims brought[659].
Massachusetts	Proposed a bill in 2017 to present discrimination on basis of **height and weight[660].**	Not yet passed into law.
One aspect which unites all of these varying local provisions is a surprisingly low level of enforcement – the Santa Cruz provision, for example, has had no claims brought under it in its entire history[661], and the highest number of claims identified in Rhodes' study was an average of 9 per year in Madison[662]. In many cases, success rates were also low[663] – although statistics were not available in all cases and unpublished settlements could distort this data. But enforcement is only part of the issue and, again, the potential of such laws to raise the public consciousness and change behaviours may remain.[664]		

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[656] Madison, Wisconsin, Code of Ordinances §39.03 (1) (amended 29 June 2019).

[657] Rhodes (n628) 131.

[658] Elliott-Larsen Civil Rights Act, Michigan, No 453 of 1976 §372202(1).

[659] Rhodes (n628) 133.

[660] Bill H.952, Massachusetts, (2017-2018). See <https://malegislature.gov/Bills/190/H952> accessed 18 August 2019.

[661] Email from Santa Cruz Human Resources Department (n150).

[662] Rhodes (n628) 130.

[663] Ibid, 131.

[664] Ibid, 140.

Concerns about 'floodgates opening' do not, therefore, appear to have been well-founded based on the French and US evidence above. Nor do the relevant provisions reflect a preponderance of case law concerning disfigurement; on the contrary, the majority of claims relate to matters such as style of dress and weight. Given empirical data suggesting that appearance discrimination remains a problem in both France and the US, one could infer that barriers to visible difference equality often remain even when the law provides protection on the basis of appearance.

6.4.4 THIRD TIER SUMMARY

Although a protected characteristic of disfigurement seems initially appealing due to its awareness-raising potential, I do not believe that creating a more entrenched barrier between the aesthetic and functional effects of different impairments would benefit many of those who might want to use it. I do not regard this as an optimum method of reform.

A protected characteristic of appearance offers greater promise, albeit that comparative international analysis has revealed very low enforcement rates (though the deterrent effect of such laws is harder to measure). Again, it entrenches a barrier between the functional and the aesthetic which may prove difficult for those with complex conditions. Whilst I would view the creation of a protected characteristic of appearance (at least insofar as it relates to immutable physical characteristics) as a positive step forward in rights protection, I do not regard it as an answer to the problem of disfigurement discrimination. It could, however, make a worthy partner to a strengthened protected characteristic of disability which included visible difference.

6.5 FOURTH TIER: ADDRESSING THE BARRIERS OF THE INDIVIDUAL ENFORCEMENT MODEL

The empirical study in Chapter 5 underlined a problem already identified in a considerable body of scholarship; an individual enforcement model puts the onus on the victims of discrimination, many of whom are reluctant or unable to bring a legal challenge.

An alternative method of reform – perhaps in conjunction with one of the other approaches put forward above – is to shift this burden, partially or wholly, away from the victim. There are numerous different degrees of approach which can be taken in this regard.

Chartermark schemes similar to the Athena SWAN charter on gender equality[665] in higher education offer some promise. Although voluntary, the Athena SWAN charter is in some cases being externally reinforced through criteria for research grants, showing that a 'carrot and stick' approach can work in motivating compliance. Similar example schemes exist in both the US[666] and France, such as the French government-run equality label designed to recognise businesses leading the way in equality between the sexes[667]. A scheme based on appearance has potential.

In addition, individual enforcement mechanisms could be 'tweaked' to make them more accessible to individuals – with less risk and formality attached to them. One commentator, for example, notes the investigative, mediation-based approach of the DfD in France, compared with the "adversarial procedure with cross-examination at its heart" found in the British employment tribunal system[668]. Despite mediation existing in the UK as an option, its use is not as widespread as litigation.

The mantle of enforcement can also be widened to other bodies. In France, for example, Trade Unions tend to have a wider role than in Britain and trade union

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[665] Equality Challenge Unit (n426).

[666] For a discussion of US affirmative action, see Uduak Archibong and Phyllis W. Sharps, 'A Comparative Analysis of Affirmative Action in the United Kingdom and United States' (2013) 3 Journal of Psychological Issues in Organizational Culture 28

[667] Label d'égalité, https://www.egalite-femmes-hommes.gouv.fr/dossiers/egalite-professionnelle/legalite-un-objectif-partage/le-label-egalite/ accessed 14 June 2019.

[668] Corby, William and Richard (n146) 48.

membership is not a prerequisite for helping an employee as it tends to be in the UK[669].

The French DfD, which mediates most discrimination disputes, also has investigative powers, which are used to assess individual complaints of discrimination. The same goes for the EEOC in the US[670]. Although neither body attracts universal acclaim for their approach in this regard, they do at least conduct more individual investigations than the EHRC, which is often criticised by some for being weak in substance, underused[671] and focusing on broad sector-wide issues rather than individual cases. Under UK law, an individual wanting to investigate perceived discrimination by her employer is likely in practice to need to issue a claim before receiving documents to clarify what happened. The removal of the pre-claim questionnaire process (discussed at 3.4.6) compounded this problem.

Even more significant perhaps, France (in common with a number of other European countries) has a quota system in place which requires businesses with 20 staff or more to ensure that at least 6% are disabled people[672]. Quotas are not perfect and have often been criticised for creating a stigma around disability[673], and for encouraging procedural compliance (for example, motivating employers to pressure existing employees to declare possible disabilities in order that they can be taken into account for the quota[674]). Quotas are also not always adhered to – many businesses prefer to pay a fine instead[675]. On the other hand, not only is the rate of employment of disabled people higher in France than in Britain, but the levy

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[669] Ibid 50.

[670] Figures since 2009 show that the EEOC has received on average 42 charges of disfigurement discrimination each year. Of these, 12 per year on average reached what is termed 'merit factor resolutions' (i.e. a resolution favourable for the individual), after investigation by the EEOC. No figures were found disclosing the number of EEOC investigations overall. See https://www.eeoc.gov/eeoc/statistics/enforcement/ada-merit.cfm. For an example EEOC charge pursuant to an investigation concerning disfigurement discrimination, see *EEOC vs. R.P.H. Management, Inc., d/b/a McDonald's*, Civil Action No. 03-RRA-502-J.

[671] Corby, William and Richard (n146) 47.

[672] Code du Travail, Art L323-1.

[673] Lisa Waddington, 'Reassessing the employment of people with disabilities in Europe: from quotas to anti- discrimination laws' (1996) 18 Comparative Labor Law Journal 62, 71.

[674] Alain Klarsfeld, Eddy Ng and Ahu Tatli, 'Social regulation and diversity management: A comparative study of France, Canada and the UK' (2012) 18 European Journal of Industrial Relations 309, 315.

[675] Ibid.

coming from businesses who don't meet their quota is protected to be used for initiatives to support the employment of disabled people[676].

Although Britain has no quota system in place, it does have the Public Sector Equality duty. Despite criticisms (see 3.4.5.1), a further option would be to revamp this duty to give it more 'teeth' perhaps by removing the 'due regard' limit, extending its reach to the private sector, and resurrecting the equality scheme and consultation aspects of the specific equality duty to ensure participation of disabled people in decision-making processes.

The way the law views discrimination could also be reconsidered. At present, the reason for the less favourable treatment (whether conscious or unconscious) must be determined in a claim for direct discrimination[677] or victimisation, so the Tribunal must be satisfied that disability was the reason why the action took place. David Oppenheimer argues instead for a negligence-based approach to discrimination, where employers are under a duty to take reasonable care to avoid discrimination, thus mitigating the hurdles of proving that treatment was 'because of' a particular characteristic and requiring active engagement to avoid unconscious bias:

> "As an employer, you are supposed to pay attention to things like race and gender in order to avoid discriminating. So, when you get a batch of résumés, if you hire the good-looking white guy, you should say before you make that commitment, Why am I picking the good-looking white guy? Should I be concerned that every time I get to hire somebody I pick the good-looking white guy? Should I have looked a little more carefully at the résumés of the black man or black woman?"[678]

Although this perhaps sits uncomfortably with the approach taken in EU law to discrimination, Britain's imminent departure from the EU may ultimately open the door to rethinking these concepts.

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[676] Corby, William and Richard (n146) 51.

[677] *Nagarajan v London Regional Transport and others* [1999] IRLR 572 (HL).

[678] Mercat-Bruns (n618) 79.

Empowering and helping employers to self-regulate to bring about deeper changes in attitudes within their own sphere presents another opportunity. Bob Hepple argues that “society is not structured hierarchically with law at the top. One should not expect law to change behaviour by simple ‘command and control’”. Instead, drawing on the work of Braithwaite, he suggests a three-tier structure of regulation: 1) self-regulation by the organisation, 2) regulation by interest groups (perhaps employees or service users) and 3) enforcement by an external body such as the EHRC. Braithwaite terms this the ‘regulatory pyramid’[679]. The regulatory pyramid does not abolish the possibility of individual complaint, but removes some of the burden from it; individual enforcement actions could also be supported by external investigations and action. Greater engagement and self-regulation by employers should encourage more dialogue, which might help to create communities of best practice.

While many of these proposals offer considerable merit in changing attitudes towards disabled people in the workplace generally, the extent to which they would make a significant difference to people with a visible difference is a moot point. There is undoubtedly a risk that, without more impairment-specific intervention, measures taken to improve ‘disability equality’ generally would focus on well-known types of impairments – such as mobility and sensory impairments, to the exclusion of people with other types of impairment, including visible difference. This risk could perhaps be reduced with the aid of very detailed guidance and the ongoing involvement of relevant interest groups.

6.5.1 FOURTH TIER SUMMARY

Measures need to be taken to encourage attitudinal change, while at the same time reducing the burden of individual enforcement on the victims of disfigurement discrimination. Various legal routes could be taken to achieve this as discussed

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[679] John Braithwaite, 'Rewards and Regulation' (2002) 29 Journal of Law and Society 12, 30.

above, but it is also worth remembering that the impetus for change is not exclusively a matter for discrimination law. Awareness campaigns and better media engagement with positive, non-sensationalised images of visible difference are a starting point[680]. While numerous countries, including France[681], are banning invisibly retouched images of models to make them look thinner or bigger (which links with concerns that these images create unrealistic body image), I found no evidence of countries legislating to encourage positive images of visible difference. Increasing awareness of legal rights and making them more accessible via free legal advice mechanisms are also important. The issue is perhaps best tackled as a societal problem, with the law just one part of the armoury.

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[680] Diana Garrisi, Laima Janciute and Jacob Johanssen, *Appearance, Discrimination and the Media* (University of Westminster 2018) 21.

[681] David Chazan, 'Photoshopped images to come with a warning under new French law' (2017) The Telegraph <https://www.telegraph.co.uk/news/2017/09/30/photoshopped-images-come-warning-new-french-law/> accessed 9 July 2019.

7. CONCLUSION

When I proposed the topic of this thesis, I was sure of two things about it: first, that there were few reported cases under it, and second, that surveys of people with a visible difference commonly reported high levels of perceived discrimination and stigmatisation. This suggested a disconnect of some kind.

Understanding this disconnect necessitated the following steps. First, the creation of an evaluative framework assimilating broad principles of substantive equality with the detailed provisions of the CRPD. Second, a literature review to identify the key themes in the fields of sociology, psychology and law relating to visible difference. Third, the implementation of a detailed socio-legal methodology, combining doctrinal and comparative legal research with empirical methods.

Although the literature review, doctrinal analysis and empirical study are presented here in different chapters, the findings from each show that they are inextricably linked. By way of example:

- In relation to RQ1 (targeting disadvantage), the literature review provided a picture of the lived experience of visible difference. One theme which stood out from this literature was the lack of a linear relationship between clinical severity and psychosocial experience. This theme then clearly mapped onto the doctrinal analysis (enabling a critique of the 'severity' threshold under the Act) and onto the empirical study, which highlighted a lack of certainty about what 'severe' disfigurement actually means. This contributed to the conclusion that the law does not effectively identify and target the scope of visible difference disadvantage.

- With regard to RQ4 (recognition) and 7 (structural change), the literature review showed significant criticism of the lack of depth and effectiveness of positive measures in the law, and this was reinforced by the empirical study, where participants felt their conditions and concerns were often misunderstood both socially and medically – and awareness of positive action and equality rights was low.

- Under RQ5 (access to justice), the literature review suggested several reasons for a relatively low number of discrimination claims by disabled people generally, including a reluctance to identify as disabled, and concerns about the procedure of claiming. Both of these themes were also apparent in the doctrinal and empirical work here, although with an added nuance: in my empirical study, quite a number of participants viewed disability as an exclusively functional concept, suggesting an extra identity hurdle for people whose impairments do not impair function.

7.1 THESIS LIMITATIONS

The methodological choices made in reaching these findings provided significant advantages. I do not believe, for example, that the depth of data set out in Chapter 5 would have been as clearly evidenced by an online survey. Nor that the same level of understanding would have been accessible using a single-channel research design, rather than a combination of doctrinal and empirical methods. However, I must also acknowledge four limitations of the research design adopted.

First, as set out at 2.3.1.5, having used a small qualitative sample, this research cannot claim to represent the views of a wider community. There is therefore an urgent need for an open consultation process to provide breadth, as well as depth, to the partial understanding gained through this thesis.

Second, as the self-selecting sample here was not diverse in terms of race or gender identity, it lacks an understanding of how these intersections may impact, and require a different legal approach. Young people were also underrepresented (see Appendix 3). The difficulty experienced in recruiting participants through non-charitable mediums may also bias the sample (see 2.3.3).

Third, another difficulty with the sample was that the range of conditions identified by the participants did not cover the full range of potentially disfiguring conditions. For example, while seven participants had facial palsy, none had a burns injury. The reasons for this are unclear but it could simply reflect the way in which different charities advertised the research, and who happened to see it at the right time. However, this relatively narrow range of conditions missed an opportunity to understand better any variations in experiences between different conditions.

Fourth, difficulties recruiting employer participants missed an opportunity to triangulate the empirical data which could have provided a useful extra perspective (see 2.3.2).

7.2 AVENUES FOR FURTHER RESEARCH

Three main avenues for future research are proposed, all of which arose during this project but were not able to be fully explored due to practical constraints (such as wordcount and access to additional participants) or the need to keep to scope:

- Employer-focused research testing models of best practice (such as those suggested at 6.2.6, potentially extending to an evaluation of a trial charter mark appearance equality scheme);

- Research focused on whether and how law could be used to improve positive awareness of visible difference in the media and creative arts. Could the public sector equality duty hold potential (for example by bringing decisions about broadcast content within its scope)?

- At 6.2.6, it was suggested that the ban on pre-employment health questions may disadvantage some people with a visible difference. To what extent can this finding be generalised to the wider visible difference and disability community? Is the ban meeting its aims or encouraging covert assumptions?

7.3 WHERE DO WE GO FROM HERE?

Overall, the eight Research Questions posed in Chapter 1 have been answered and together demonstrate that the law in the UK does not succeed in providing effective workplace equality for people with a visible difference. The evidence suggests in particular that, in relation to people with a visible difference: i) the scope of the severe disfigurement provision in the Act does not match the group of people disadvantaged (RQ1) ii) the duty to make reasonable adjustments is not working effectively (RQ3) iii) the law is failing to tackle stereotypes, promote positive attitudes and achieve structural change (RQ4 and 7) iv) access to justice is hindered by issues of process and perception (RQ5) and v) available remedies do not encourage meaningful change (RQ8). In addition, the evidence on participation and inclusion (RQ6) and the intersectionality aspect of visible difference (RQ2) is inconclusive.

It is worth stressing that this finding does not, however, paint a wholly negative picture of the working lives of all people with a visible difference; both existing literature and the empirical study in Chapter 5 found significant variations in the experiences of those affected, with some positive experiences as well as negative recollections of discrimination. Rather, the finding suggests that, when negative experiences do happen (which still seems to be a common occurrence for many), the above disconnect makes the law an ineffective tool for challenging it and preventing it from recurring.

As set out in Chapter 6, a range of steps could be taken to address the identified problems. Presenting 'tiers' of options in that chapter enabled me to analyse more than one route to reform, but from those tiers an amended definition of disability (see 6.3.2) combined with a softening of the individual complaints-led model (see 6.5) and some more detailed guidance (see 6.2 and Appendix 6 and 7) offers particular promise.

This recommendation is perhaps coloured not just by legal analysis, but also a little pragmatism, because the changes to the legal system which this reform would involve are moderate rather than radical and could be adopted without ripping up the current legal framework entirely. But, more importantly, changing the definition of disability as suggested, to include 'impairments which have a substantial adverse effect on that person's appearance', could generate significant publicity and awareness too. It was notable that the functional concept of disability mentioned by some of the participants in Chapter 5 had clearly been influenced by the legal definition. Changing the legal definition may therefore help to change the perception of disability as a purely functional concept, and to revise self-identities accordingly. It also appears to provide a reasonable compromise in terms of its scope – increasing its breadth by removing the higher 'severity' threshold, without expanding so far that the core disadvantage of visible difference becomes lost within the relative disadvantage of normal imperfections of appearance.

Ideally, this definitional change would be accompanied, as outlined above, by a softening of the individual complaints model, both to lessen the burden on individuals, and to encourage more proactive engagement with equality matters by employers in the form of positive objectives. I was struck, during the empirical study discussed in Chapter 5, by the fact that various small, non-legal changes would have made a big difference to some participants at different times of their lives. One example is the opportunity (not obligation) during recruitment to make a health/appearance mention without labelling it as a disability. A legal system which seeks to motivate employers to be inclusive, as well as to penalise them when they get it wrong, makes it more likely that small matters of good practice like this will develop through dialogue.

Choosing a path for reform is not straightforward. Underlying the various options for change outlined above, there are issues of self and group identity, in particular as regards the relationship between visible difference and disability. Low levels of reported disfigurement discrimination claims mean that the application of the existing legislation has not regularly received judicial scrutiny and, perhaps as a consequence, little public debate has taken place. In line with the obligation of participation and inclusion contained within the CRPD, consultation would therefore prove a fruitful next step both in raising awareness and shaping changes to the law. This would also mitigate the limitations discussed above, with the potential to reach a wider audience than the deliberately small qualitative sample in this research.

In conclusion, in this thesis I have shown that the law as it stands is not providing effective workplace equality for people with a visible difference in the UK, but some relatively discrete changes have the potential to improve its effectiveness considerably. I hope that this thesis, and the journal articles and conference paper written as part of it, will contribute to a wider debate on this issue.

TABLE OF CASES

European case law

C-236/09 *Association Belge des Consommateurs Test-Achats ASBL and Others v Conseil Ministres* [2011] ECR-I 773.

C-395/15 *Daouidi v Bootes Plus SL* [2017] 2 CMLR 21.

C-354/13 *FOA v Kommuneres Landsforening (Kaltoft)* [2015] 2 CMLR 19.

C-131/12 *Google Spain SL and Google Inc v Agencia Española de Protección de Datos (AEPD) and Mario Costeja González* [2014] 3 CMLR 50.

C-335/11 and C-337/11 *HK Danmark, acting on behalf of Ring v Dansk almennyttigt Boligselskab and HK Danmark, acting on behalf of Lone Skouboe Werge v Dansk Arbejdsgiverforening, acting on behalf of Pro Display A/S (Ring and Skouboe Werge)* [2013] 3 CMLR 21.

C-270/16 *Ruiz Conejero v Ferroser Servicios Auxiliares and Ministerio Fiscal* [2018] 2 CMLR 27.

ECtHR case law

I.B. v Greece App no. 552/10 (ECtHR 3 October 2013).

Kiyutin v Russia (2013) 53 EHRR 26.

UN Case decisions

CRPD Committee 02.10.2014, Communication No. 5/2011, *Marie-Louise Jungelin v Sweden*, CRPD/C/12/D/5/2011.

U.S. case law

EEOC vs. R.P.H. Management, Inc., d/b/a McDonald's, Civil Action No. 03-RRA-502-J.

Hodgson v Mount Mansfield Co 61 USLW 2337, 625 A2D 1122 (1993).

Janice Otero Barreto v Doctors' Center Hospital Inc, 3:14-cv-01457-SEC (District Court, P.R. 1996).

Johnson v Dunhill Temporary Systems Inc. 11 Nat'l Disability L. Rep. (BNA) 78, at 320 (ND III Oct,24, 1997)

Natural Motion by Sandra Inc v Estate of Richard Andrew Hamilton (Intervenor) No. 95-AA-1465 (9 Jan 1997).

Schwertfager v City of Boynton Beach 42 F. Supp. 2D 1347 (SD Fla 1999)

Superior Min. Co. v. Industrial Commission (1923) 309 Ill. 339, 141 N.E. 165

Talanda v KFC National Management Co 140 F.3d 1090 (7th Cir 1998).

Van Sickle v Automatic Data Processing Inc. 952 F.Supp.1213, 1223 (ED Mich.1997)

French case law

Cass. Soc. 28 May 2003 No. 02-40273.

Décision du Défenseur des Droits MLD/2015-3-4 (le 4 Décembre 2015).

Décision du Défenseur des Droits MLD 2016-058 (le 12 Fevrier 2016).

Domestic case law

Blyth v Historic Scotland [2001] S/4000514/00.

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

Chief Constable of Norfolk v Coffey [2019] EWCA Civ 1061, [2019] IRLR 805.

Cosgrove v Northern Ireland Ambulance Service [2006] NICA 44, [2007] IRLR 397.

English v Thomas Sanderson Blinds Ltd [2008] EWCA Civ 1421, [2009] I.C.R. 543.

Goodwin v Patent Office EAT/57/98 [1999] IRLR 4.

Griffiths v Lancashire County Council [2009] (unreported, ET).

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

Hewage v Grampian Health Board [2012] UKSC 37, [2012] 4 All ER 447.

Hussain v Sky In-Home Services Ltd ET/2300908/16, [2016] 9 WLUK 178.

Hutchison (3G) Limited v Edwards [2014] UKEAT/0467/13/DM, [2014] Eq.LR 525.

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

J -v- DLA Piper LLP [2009] UKEAT/0263/09/RN, [2010] ICR 1052.

Kamlesh Bahl v Law Society [2004] EWCA Civ 1070, [2004] IRLR 799.

McNicol v Balfour Beatty [2002] EWCA Civ 1074, [2002] IRLR 711.

Ministry of Defence v De Bique [2009] UKEAT/0048/09/MAA, [2010] IRLR 471.

Nagarajan v London Regional Transport and others [2000] 1 AC 501, [1999] IRLR 572 (HL).

Paterson v The Commissioner of the Police of the Metropolis [2007] UKEAT 0635/06, [2007] ICR 1522.

Pepper v Hart [1993] AC 593.

R –v- Secretary of State for Employment, ex p Begbie, [2000] 1 WLR 1115.

Riam Dean v Abercrombie and Fitch [2008] ET2203221/2008.

Rugamer v Sony Music Entertainment UK Limited [2001] UKEAT1385_99_2707, [2001] IRLR 644.

Smith v HM Prison Service (Unreported), August 10, 2004.

Taylor v Ladbrokes Betting and Gaming Limited [2017] UKEAT/0353/15/DA, [2016] 12 WLUK 445.

Vatcher v Kelly Services (UK) Ltd [1999] UKEAT 595_99_0510.

Whyte v First Capital East Limited [2005] UKEAT/0686/04/DM, [2005] 3WLUK 720.

TABLE OF LEGISLATION AND RELATED DOCUMENTS

Domestic statutes

Equality Act 2010

Human Rights Act 1998

Domestic statutory instruments

Equality Act 2010 (Disability) Regulations 2010

Equality Act 2010 (Specific Duties) Regulations 2011

Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012

Equality Act (Statutory Duties) (Wales) Regulations 2011

French legislation

Code du Travail (version consolidé au 1 Septembre 2019).

US statutes and bills

Americans with Disabilities Act of 1990 (as amended)

Bill H.952, Massachusetts (190th, 2017-2018)

US state / city codes

Chicago Municipal Code 1881

City of Madison, Wisconsin, Code of Ordinances (version amended: 29 June 2019).

Code of Ordinances of Howard County, MD (amended version: 6 June 2019).

County Code of Harford County, MD (amended version: 19 June 2019).

District of Columbia Code (amended version:11 April 2019).

Elliott-Larsen Civil Rights Act, Michigan, No 453 of 1976.

Prince George's County Code of Ordinances, MD (amended version: 15 August 2019).

San Francisco, California, Administrative Code (amended version: 2 September 2019).

Santa Cruz, Cal., Municipal Code (amended version: 11 June 2019).

Urbana, Ill., Municipal Code of ordinances (amended version:31 July 2019, Supp. No 43).

Conventions and related decisions and documents

Discrimination (Employment and Occupation) Convention 1958 (adopted 25 June 1958) ILO C-111.

UN Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the initial report of the United Kingdom of Great Britain and Northern Ireland' (2017) CRPD/C/GBR/CO1.

UN Committee on the Rights of Persons with Disabilities, 'General Comment No. 3 on Article 6' (2016) CRPD/C/GC/3.

UN Committee on the Rights of Persons with Disabilities, 'General comment No. 6 on equality and non-discrimination' (2018) CRPD/C/GC/6.

UN Committee on the Rights of Persons with Disabilities, 'Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under Article 5 of the Optional Protocol to the Convention' (2016) CRPD/C/15/R.2/Rev.1

UN Committee on the Rights of Persons with Disabilities, ‘Views adopted by the Committee at its twelfth session’ (15 September – 3 October 2014) Communication No 5/2011.

UN Convention on the Rights of Persons with Disabilities adopted 24 January 2007, A/RES/61/106.

UNGA ‘Universal Declaration of Human Rights’ (10 December 1948) Res 217 A(III) Doc A/810.

United Kingdom Government, ‘Response To The Report By The United Nations Committee On The Rights Of Persons With Disabilities Under Article 6 Of The Optional Protocol To The Convention' (2017) 3 CRPD/C/17.R.3.

United Nations, ‘The Convention on the Rights of Persons with Disabilities Training Guide’ (2014) HR/P/PT/19.

UN Optional Protocol to the Convention on the Rights of Persons with Disabilities (2007) A/RES/61/106).

BIBLIOGRAPHY

Books

Arnadottir OM, *Equality and Non-Discrimination Under the European Convention on Human Rights*, vol 74 (International Studies in Human Rights, Martinus Nijhoff Publishers 2003)

Bell M, *Racism and Equality in the European Union* (Oxford University Press 2008)

Berger PL, *The social construction of reality: a treatise in the sociology of knowledge* (Harmondsworth: Penguin 1967)

Beuf AH, *Beauty Is the Beast: Appearance-Impaired Children in America* (Philadelphia: University of Pennsylvania Press 2016)

Bhattacherjee A, *Social Science Research: Principles, Methods and Practices* (Scholar Commons 2012)

Braithwaite J, *Restorative justice & responsive regulation (Studies in crime and public policy*, New York: Oxford University Press 2002)

Braun V and Clarke V, *Successful qualitative research: a practical guide for beginners* (London: SAGE 2013)

Burr V, *Social constructionism* (Third edition. edn, London; New York:Routledge 2015)

Charmaz K, *Constructing Grounded Theory* (SAGE Publications Ltd 2014)

Crotty M, *The Foundations of Social research* (Sage Publications Ltd 1998)

Denscombe M, *The Good research Guide For small-scale social research projects* (5th edn, Open University Press 2014)

Etcoff N, *Survival of the Prettiest* (1st edn, Anchor Books 2000)

Fredman S, *Discrimination Law* (2nd edn, Oxford University Press 2011)

Goffman I, *Notes on the management of spoiled identity* (Penguin 1990)

Hamermesh DS, *Beauty Pays* (Princeton University Press 2011)

Hepple BA, *Equality: a new framework. Report of the independent review of the enforcement of UK anti-discrimination legislation* (Hart e-books, Oxford; Portland, Or.: Hart Pub. 2000)

Kanter AS, *The Development of Disability Rights under International Law* (Routledge 2015)

Lawson A, *Disability and equality law in Britain: the role of reasonable adjustment* (Hart Publishing 2008)

Lincoln YS, *Naturalistic inquiry* (Newbury Park: Sage 1985)

Mercat-Bruns M, *Discrimination at Work: Comparing European, French, and American Law* (University of California Press 2016)

Mertens DM, *Research and evaluation in education and psychology: integrating diversity with quantitative, qualitative, and mixed methods* (Fourth edition. edn, Thousand Oaks, CA: SAGE Publications, Inc. 2015)

Oliver M, *Understanding disability* (2nd edn, Palgrave Macmillan 2009)

Oliver M, Sapey B and Thomas P, *Social Work with Disabled People* (Macmillan 2012)

Partridge J, *Changing faces: the challenge of facial disfigurement* (Penguin Books 1990)

Post R, *Prejudicial Appearances: the logic of American antidiscrimination law* (Duke University Press 2001)

Rhodes D, *The Beauty Bias* (Oxford University Press 2010)

Schweik SM, *The Ugly Laws: Disability in Public* (New York University Press 2009)

Shakespeare T, *Disability rights and wrongs revis*ited (Second edn, New York: Routledge 2014)

Shaw D, *Facial Shift* (Lightning Source UK Ltd, 2016)

Solanke I, *Discrimination as Stigma* (1st edn, Hart Publishing 2017)

Zweigert K and Kotz H, *Introduction to comparative law* (3rd rev. edn, Oxford : Clarendon Press 1998)

Book chapters

Amundson R, 'Biological Normality and the ADA' in Pickering Francis L and

Silvers A (eds), *Americans with Disabilities* (Americans with Disabilities, Routledge 2000)

Arnadottir OM, 'A Future of Multidimensional Disadvantage Equality?' in Arnadottir OM and Quinn G (eds), *The UN Convention on the Rights of Persons with Disabilities* (The UN Convention on the Rights of Persons with Disabilities, Martinus Nijhoff Publishers 2009)

Barnes C, 'Understanding the social model of disability: past, present and future' in Watson N and others (eds), *Routledge Handbook of disability studies* (Routledge Handbook of disability studies, London; New York: Routledge 2012)

Braun V and Clarke V, 'Thematic Analysis' in Cooper H (ed) *APA Handbook of Research Methods in Psychology* (The American Psychological Association 2012)

Bull R, 'The General Public's Reactions to Facial Disfigurement' in Graham JA and Kligman AM (eds), *The Psychology of Cosmetic Treatments* (The Psychology of Cosmetic Treatments, Praeger 1985)

Clements L and Read J, 'The dog that didn't bark: the issue of access to rights under the European Convention on Human Rights by disabled people' in Lawson A and Gooding C (eds), *Disability rights in Europe: from theory to practice* (Hart 2005)

Crossley M, 'Impairment and Embodiment' in Pickering Francis L and Silvers A (eds), *Americans with Disabilities* (Routledge 2000)

Fasciglione M, 'Article 27 of the CRPD and the Right of Inclusive Employment of People with Autism' in Della Fina V and Cera R (eds), *Protecting the Rights of People with Autism in the Fields of Education and Employment* (Springer 2015)

Finkelstein V, 'The commonality of disability' in Finkelstein V and others (eds), *Disabling Barriers, Enabling Environments* (1st edn, Sage Publications Ltd, 1993)

Gallagher S, 'Hermeneutics and education' in Denzin NK and Lincoln YS (eds*), The landscape of qualitative research* (3rd edn, SAGE 2008)

Harcourt D and Rumsey N, 'Using novel methods in appearance research' in Rumsey N (ed) *The Oxford handbook of the Psychology of Appearance* (Oxford University Press 2012)

Kimber C, ‘Equality or Self-determination’ in Gearty, Conor and Tomkins (eds), *Understanding human rights* (London: Mansell Publishing 1996)

Lacy K, 'Katherine Lacy's account' in Lansdown R and others (eds), *Visibly Different: Coping with disfigurement* (Butterworth Heinemann 1997)

Moss TP and Rosser B, 'Adult Psychosocial Adjustment to visible differences: physical and psychological predictors of variation' in Rumsey N and Harcourt N (eds), *The Oxford handbook of the Psychology of Appearance* (Oxford University Press 2012)

Naqvi H and Krysia S, 'Culture and Ethnicity' in Rumsey N and Harcourt D (eds), *The Oxford Handbook of the Psychology of Appearance* (Oxford University Press 2012)

Nishikura M, 'Three employment-related difficulties: understanding the experiences of people with visible differences' in Matsui et al (eds), *Creating a Society for all: disability and economy* (The Disability Press 2011)

O’Gorman K and MacIntosh R, 'Mapping Research Methods' in 2nd (ed) *Research Methods for Business and Management* (Goodfellow Publishers Ltd 2015)

Priestley M, 'We’re all Europeans now! The social model of disability and European social policy' in Barnes C and Mercer G (eds), *The Social Model of Disability: Europe and the Majority World* (The Disability Press 2005)

Robinson E, 'Psychological research on visible differences in adults' in Lansdown R and others (eds), *Visibly Different* (Butterworth-Heinemann 1997)

Rumsey N and Harcourt D, 'Where do we go from here?' in Rumsey N and Harcourt D (eds), *The Oxford Handbook of the Psychology of Appearance* (Oxford University Press 2012)

Schwandt T, 'Three Epistemological Stances for Qualitative Inquiry' in Lincoln YS and Denzin NK (eds), *The Landscape of Qualitative Research* (3rd edn, SAGE 2008)

Shakespeare T and Watson N, 'The social model of disability: An outdated ideology?' in Barnartt S and Altman B (eds), *Exploring Theories and Expanding Methodologies: Where we are and where we need to go to*, vol 2 (Emerald Group Publishing Limited 2001)

Stone E, Stone D and Dipboye R, 'Stigmas in organizations: race, handicaps and physical unattractiveness' in Kelley K (ed) *Organizational Psychology* (North-Holland 1992)

Wasserman D, 'Stigma without impairment' in Pickering Francis L and Silvers A (eds), *Americans with Disabilities* (Routledge 2000)

Articles

Anastasiou D and Kauffman JM, 'The Social Model of Disability: Dichotomy between Impairment and Disability' (2013) 38 Journal of Medicine and Philosophy 441

Andrews T, 'What is Social Constructionism?' (2012) 11(1) GTR 39.

Anonymous, 'Facial Discrimination: Extending Handicap Law to Employment Discrimination on the Basis of Physical Appearance' (1987) 100 Harvard Law Review 2035

Archibong U and Sharps PW, 'A Comparative Analysis of Affirmative Action in the United Kingdom and United States' (2013) 3 Journal of Psychological Issues in Organizational Culture 28

Ayala F and others, 'The impact of psoriasis on work-related problems: a multicenter cross-sectional survey' (2014) 28 Journal of the European Academy of Dermatology and Venereology 1623

Balser D, 'Predictors of Workplace Accommodations for Employees with Mobility-Related Disabilities' (2007) 39 Administration and Society 656

Barmes L, 'Equality law and experimentation: the positive action challenge' (2009) 68 CLJ 623

Barnard C and Hepple B, 'Substantive Equality' (2000) 59 Cam Law J 562

Barro RJ, 'So you want to hire the beautiful. Well why not?' Business Week (USA, 16 March 1998)

Barth I and Wagner A-L, 'Physical Appearance as Invisible Discrimination' (2017) 4 International Perspectives on Equality, Diversity and inclusion 127

Baumberg B, Jones M and Wass V, 'Disability prevalence and disability- related employment gaps in the UK 1998–2012: Different trends in different surveys?' (2015) 141 Social Science & Medicine 72

Beckett AE and Buckner L, 'Promoting Positive Attitudes towards Disabled People: Definition of, Rationale and Prospects for Anti-Disablist Education' (2012) 33 British Journal of Sociology of Education 873

Bell D and Heitmueller A, 'The Disability Discrimination Act in the UK: Helping or hindering employment among the disabled?' (2009) 28 Journal of Health Economics 465

Bell M, 'Mental Health at Work and the Duty to Make Reasonable Adjustments' (2015) 44 Industrial Law Journal 194

Berghs M, Atkin K and Graham H, 'Implications for public health research of models and theories of disability: a scoping study and evidence synthesis' (2016) 4

Bertrand L, Caradec V and Eideliman J-S, 'Situating disability. The recognition of "disabled workers" in France' (2014) 8 European Journal of Disability research 269

Braithwaite J, ‘Rewards and Regulation’ (2002) 29 Journal of Law and Society 12

Braun V and Clarke V, 'Using thematic analysis in psychology' (2006) 3 Qualitative Research in Psychology 77

Braun V and Clarke V, 'Teaching thematic analysis' (2013) 26 The Psychologist 120

Broderick A, Muir E and Waddington L, 'A reflection on substantive equality jurisprudence' (2015) 15 International Journal of Discrimination and the Law 101

Bruton SV, 'Looks-Based Hiring and Wrongful Discrimination' (2015) 120 Business and Society Review 607

Bruyère SM, Erickson WA and Vanlooy S, 'Comparative Study of Workplace Policy and Practices Contributing to Disability Nondiscrimination' (2004) 49 Rehabilitation Psychology 28

Buck DW and Herbst KL, 'Lipedema: A relatively common disease with extremely common misconceptions' (2016) Plastic Reconstructive Surgery Global Open 1043

Budds K, Locke A and Burr V, '“Risky Business”: Constructing the “choice” to “delay” motherhood in the British press' (2013) 13 Feminist Media Studies 132

Bull R and Stevens J, 'The effects of facial disfigurement on helping behaviour' (1981) 8 Italian Journal of Psychology 25

Cahners S, 'Young women with breast burns: a self-help "group by mail"' (1992) 13 Journal of Burn Care and Rehabilitation 44

Carlsson IK, Dahlin LB, and Rosberg HE, ‘Congenital thumb abnormalities and the consequences for daily life patients’ long-term experience after corrective surgery: A qualitative study’ (2018) 40(1) Disability and Rehabilitation 69

Carroll P and Shute R, 'School peer victimization of young people with craniofacial conditions: A comparative study' (2005) 10 Psychology, Health & Medicine 291

Cho S, Crenshaw KW and McCall L, 'Toward a Field of Intersectionality Studies: Theory, Applications, and Praxis' (2013) 38 Signs 785

Clarke JA, 'Against immutability (of characteristics in employment discrimination law)' (2015) 125 Yale Law Journal 2

Clarke V and Braun V, 'Thematic analysis' (2017) 12 The Journal of Positive Psychology 297

Clarke V and Braun V, 'Using thematic analysis in counselling and psychotherapy research: A critical reflection' (2018) 18 Counselling and Psychotherapy Research 107

Clarke V and Smith M, '“Not Hiding, Not Shouting, Just Me”: Gay Men Negotiate Their Visual Identities' (2014) 62 Journal of Homosexuality 1

Cline T and others, 'Educational Research Volume 40 Number 1 Spring 1998 The effects of brief exposure and of classroom teaching on attitudes children express towards facial disfigurement in peers' (1998) 40 Educational Research 55

Corby S, William L and Richard S, 'Combatting disability discrimination: A comparison of France and Great Britain' (2019) 25 European Journal of Industrial Relations 41

Cranwell W and Sinclair R, 'Male Androgenetic Alopecia' (2016) Endotext < https://www.ncbi.nlm.nih.gov/books/NBK278957/> accessed 10 September 2019.

Crasnow R and Butlin SF, 'Disabled Compared to Whom? An analysis of the Current Jurisprudence on the Appropriate Comparator under the UK Equality Act's Reasonable Adjustments Duty' (2015) 15 Equal Rights Review.

Davies C and others, 'Bridging the gap' (2016) 16 International Journal of Discrimination and the Law 83

Davis F, 'Deviance Disavowal: The Management of Strained Interaction by the Visibly Handicapped' (1961) 9 Social Problems 120

De Beco G, 'Is obesity a disability? The definition of disability by the Court of Justice of the European Union and its consequences for the application of EU anti-discrimination law' (2016) 22 Columbia Journal of European Law 381

Degener T, 'Disability in a Human Rights Context' (2016) 5 Laws 35

Dell L and Prior J, 'Evaluating a Schools' Service for Children with a Facial Disfigurement: The Views of Teaching and Support Staff' (2005) 20 Support for Learning 35

Devine PG and others, 'Long- term reduction in implicit race bias: A prejudice habit-breaking intervention' (2012) 48 Journal of Experimental Social Psychology 1267

Dion K, Berscheid E and Walster E, 'What is beautiful is good' (1972) 24 Journal of Personality and Social Psychology 285

Egan K, Harcourt D and Rumsey N, 'A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference' (2011) 16 Journal of health psychology 739

Eiserman W, 'Unique Outcomes and Positive Contributions Associated with Facial Difference: Expanding Research and Practice' (2001) 38 The Cleft Palate-Craniofacial Journal 236

Fantoni-Quinton S and Laflamme A-M, 'Medical selection upon hiring and the applicant's right to lie about his health status: A comparative study of French and Quebec Law' (2017) 11 European Journal of Disability research 85

Foster D, 'Legal obligation or personal lottery?' (2007) 21 Work, Employment & Society 67

Foster D and Fosh P, 'Negotiating 'Difference': Representing Disabled Employees in the British Workplace' (2010) 48 British Journal of Industrial Relations 560

Foster D and Scott P, 'Nobody's responsibility: the precarious position of disabled employees in the UK workplace' (2015) 46 Industrial Relations Journal 328

Foster D and Wass V, 'Disability in the Labour Market: An Exploration of Concepts of the Ideal Worker and Organisational Fit that Disadvantage Employees with Impairments' (2013) 47 Sociology 705

Fraser Butlin S, 'The UN Convention on the Rights of Persons with Disabilities: Does the Equality Act 2010 Measure up to UK International Commitments?' (2011) 40 Industrial Law Journal 428

Fredman S, 'Double Trouble: Multiple Discrimination and EU law' (2005) European Discrimination Law Review 13

Fredman S, 'The Public Sector Equality Duty' (2011) 40 Industrial Law Journal 405

Fredman S, 'Emerging from the Shadows: Substantive Equality and Article 14 of the European Convention on Human Rights' (2016) 16 Human Rights Law Review 273

Fredman S, 'Substantive equality revisited' (2016) 14 International Journal Of Constitutional Law 712

Fredman S, 'Substantive equality revisited: A rejoinder to Catharine MacKinnon' (2016) 14 International Journal Of Constitutional Law 747

Gardiner MD 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

Ginsburg I and Link B, 'Psychosocial consequences of rejection and stigma in patients with psoriasis' (1993) 32 International Journal of Dermatology 587

Goisis A, Sacker A and Kelly Y, 'Why are poorer children at higher risk of obesity and overweight? A UK cohort study' (2016) 26 The European Journal of Public Health 7

Goldschmidt JE, 'New Perspectives on Equality: Towards Transformative Justice through the Disability Convention?' (2017) 35 Nordic Journal of Human Rights 1

Gouvier WD and others, 'Employment Discrimination Against Handicapped Job Candidates: An Analog Study of the Effects of Neurological Causation, Visibility of Handicap, and Public Contact' (1991) 36 Rehabilitation Psychology 121

Harcourt D and Frith H, 'Women's Experiences of an Altered Appearance during Chemotherapy' (2008) 13 Journal of Health Psychology 597

Harlan SL and Robert PM, 'The Social Construction of Disability in Organizations. Why Employers Resist Reasonable Accommodation' (1998) 25 Work and Occupations: An International Sociological Journal 397

Hartnett H and others, 'Employment Accommodations for People with Disabilities: Does Gender Really Matter?' (2014) 34(3) Disability Studies Quarterly

Hartung F and others, ‘Behavioural and neural responses to facial disfigurements’ (2018) PsyArXiv 1

Harwood R, '‘The dying of the light’: the impact of the spending cuts, and cuts to employment law protections, on disability adjustments in British local authorities' (2014) Disability & Society 1

Harwood R, 'Can International Human Rights Law Help Restore Access to Justice for Disabled Workers?' (2016) 5 Laws 17

Harwood R, 'What Has Limited the Impact of UK Disability Equality Law on Social Justice?' (2016) 5 Laws 42

Hepple B, 'The New Single Equality Act in Britain' (2010) 5 The Equal Rights Review 11

Hepple B, 'Enforcing Equality Law: Two Steps Forward and Two Steps Backwards for Reflexive Regulation' (2011) 40 Industrial Law Journal 315

Hoffman S, 'The importance of immutability in employment discrimination law' (2011) 52 William and Mary Law Review 1483

Hoque K and Noon M, 'Equal Opportunities Policy and Practice in Britain' (2004) 18 Work, Employment and Society 481

Hosoda M, Stone-Romero EF and Coats G, 'The effects of physical attractiveness on job-related outcomes: a metal-analysis of experimental studies' (2003) 56 Personnel Psychology 431

Houston V and Bull R, 'Do people avoid sitting next to someone who is facially disfigured?' (1994) 24 European Journal of Social Psychology 279

Hughes J and others, 'South Asian Community Views about individuals with a Disfigurement' (2009) 6 Diversity and Equality in Health Care 241

Hutchinson T, 'The Doctrinal Method: Incorporating Interdisciplinary Methods in Reforming the Law' (2015) 3 Erasmus Law Review 130

James HR, 'If you are attractive and you know it, please apply: appearance based discrimination and employers' discretion' (2008) 42 Valparaiso University Law Review 629

Jamrozik A and others, 'More Than Skin Deep: Judgments of Individuals With Facial Disfigurement' (2019) 13 Psychology of Aesthetics, Creativity, and the Arts 117

Jones BA, Buchanan H and Harcourt D, 'The experiences of older adults living with an appearance altering burn injury: an exploratory qualitative study' (2017) 22 Journal of Health Psychology 364

Jones G and Stone D, 'Perceived discomfort associated with working with persons with varying disabilities' (1995) 81 Perceptual and Motor Skills 911

Jowett S and Ryan T, 'Skin disease and handicap: An analysis of the impact of skin conditions' (1985) 20 Social Science & Medicine 425

Kent G and Keohane S, 'Social anxiety and disfigurement: The moderating effects of fear of negative evaluation and past experience' (2001) 40 British Journal of Clinical Psychology 23

Klarsfeld A, Ng E and Tatli A, 'Social regulation and diversity management: A comparative study of France, Canada and the UK' (2012) 18 European Journal of Industrial Relations 309

Kleck RE and Strenta A, 'Perceptions of the impact of negatively valued physical characteristics on social interaction' (1980) 39 Journal of Personality and Social Psychology 861

Knudson-Cooper MS, 'Adjustment to visible stigma: The case of the severely burned child' (1981) 15 Social Science and Medicine Part B Medical Anthropology 31

Lane JA and Ingleby R, 'Indirect Discrimination, Justification and Proportionality: Are UK Claimants at a Disadvantage? (European Union)' (2018) 47 Industrial Law Journal 531

Langer EJ and others, 'Stigma, staring, and discomfort: A novel- stimulus hypothesis' (1976) 12 Journal of Experimental Social Psychology 451

Langlois JH and others, 'Maxims or Myths of Beauty? A Meta-Analytic and Theoretical Review' (2000) 126 Psychological Bulletin 390

Lawrence J and others, 'Visible vs hidden scars and their relation to body esteem' (2004) 25 Journal of Burn Care and Rehabilitation 25

Lawson A, The United Nations convention on the rights of persons with disabilities: new era or false dawn? (2007) 34 Syracuse Journal of International Law and Commerce 563

Lawson A, 'Disability and Employment in the Equality Act 2010: Opportunities Seized, Lost and Generated' (2011) 40 Industrial Law Journal 359

Lengnick-Hall ML, Gaunt PM and Kulkarni M, 'Overlooked and underutilized: People with disabilities are an untapped human resource' (2008) 47 Human Resource Management 255

Lucy W, ‘Abstraction and the Rule of Law’ (2009) 29(3) OJLS 481

Macgregor FC, 'Social and Psychological Implications of Dentofacial Disfigurement' (1970) 40 The Angle Orthodontist 231

Macgregor FC, 'Facial disfigurement: Problems and management of social interaction and implications for mental health' (1990) 14 Official Journal of the International Society of Plastic Surgery 249

Mack H and Paylor I, 'Employment Experiences of Those Living With and Being Treated For Hepatitis C: Seeking Reasonable Adjustments and the Role of Disability Legislation' (2016) 15 Social Policy and Society 555

MacKinnon CA, 'Substantive equality revisited: A reply to Sandra Fredman' (2016) 14 International Journal Of Constitutional Law 739

Malleson K, ‘Equality Law and the Protected Characteristics’ (2018) 81(4) MLR 598

Manfredi S, Vickers L and Clayton-Hathway K, 'The Public Sector Equality Duty: Enforcing Equality Rights Through Second-Generation Regulation' (2018) 47 Industrial Law Journal 365

Markus H, 'Self- schemata and processing information about the self' (1977) 35 Journal of Personality and Social Psychology 63

Masnari O and others, 'Self- and parent- perceived stigmatisation in children and adolescents with congenital or acquired facial differences' (2012) 65 Journal of Plastic, Reconstructive & Aesthetic Surgery 1664

McCrudden C, 'Rethinking positive action' (1986) 15 Industrial Law Journal 219

McCrudden C, 'The new concept of equality' (2003) 4 ERA forum scripta iuris europaei 9

McCrudden C, 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19 European Journal of International Law 655

McDonald JJ, Jr., 'Civil rights for the aesthetically- challenged (physical appearance discrimination)' (2003) 29 Employee Relations Law Journal 118

McEnhill L and Byrne V, ''Beat the cheat’: portrayals of disability benefit claimants in print media' (2014) 22 Journal of Poverty and Social Justice 99

McEvoy S, ‘Employment Discrimination Based on Appearance’, (1994) Labor Law Journal (September) 592

McGrouther DA, 'Facial Disfigurement: The Last Bastion of Discrimination' (1997) 314 BMJ: British Medical Journal 991

McLachlan C and Garcia R, 'Philosophy in practice? Doctoral struggles with ontology and subjectivity in qualitative interviewing' (2015) 195

McTigue P, 'From Navas to Kaltoft' (2015) 15 International Journal of Discrimination and the Law 241

Meyerson MD, 'Resiliency and Success in Adults with Moebius Syndrome' (2001) 38 The Cleft Palate-Craniofacial Journal 231

Moon G, 'Multiple Discrimination - Problems confounded or solutions found?' (2006) 3 Justice Journal 86

Nevala N and others, 'Workplace Accommodation Among Persons with Disabilities: A Systematic Review of Its Effectiveness and Barriers or Facilitators' (2015) 25 Journal of Occupational Rehabilitation 432

Newell R and Marks I, 'Phobic nature of social difficulty in facially disfigured people' (2000) 176 The British journal of psychiatry: the journal of mental science 177

Nguyen NT and others, 'Barriers and facilitators to work reintegration and burn survivors’ perspectives on educating work colleagues' (2016) 42 Burns 1477

Noon M, 'The shackled runner: time to rethink positive discrimination?' (2010) 24 Work, Employment & Society 728

Nordstrom C, Huffaker B and Williams K, 'When physical disabilities are not liabilities: the role of applicant and interviewer characteristics on employment interview outcomes' (1998) 28 Journal of Applied Social Psychology 283

Novak DW and Lerner MJ, 'Rejection as a consequence of perceived similarity' (1968) 9 Journal of Personality and Social Psychology 147

O'Cinneide C and others, 'Defining the limits of discrimination law in the United Kingdom' (2015) 15 International Journal of Discrimination and the Law 80

Pieper M and Haji Mohammadi J, 'Ableism and Racism - Barriers in the Labour Market' (2014) 3 Canadian Journal of Disability Studies 65.

Porter JR and Beuf AH, 'Response of older people to impaired appearance: The effect of age on disturbance by Vitiligo' (1988) 2 Journal of Aging Studies 167

Puhl RM and Heuer CA, 'Obesity stigma: important considerations for public health.' (2010) 100 The American Journal of Public Health 1019

Rankin M and Borah G, 'Perceived Functional Impact of Abnormal Facial Appearance' (2002) 111 Plastic & Reconstructive Surgery 2140

Ringel W, 'Non-discrimination, Accommodation, and Intersectionality under the CRPD: New Trends and Challenges for the UN Human Rights System' (2017) 20 Max Planck Yearbook of United Nations Law Online 98

Robinson E, Rumsey N and Partridge J, 'An evaluation of the impact of social interaction skills training for facially disfigured people' (1996) 49 British Journal of Plastic Surgery 281

Rumsey N, Bull R and Gahagan D, 'The Effect of Facial Disfigurement on the Proxemic Behaviour of the General Public' (1982) 12 Journal of Applied Social Psychology 137

Rumsey N, Bull R and Gahagan D, 'A preliminary study of the potential for social skills for improving the quality of social interaction for the facially disfigured' (1986) 1 Social Behaviour 143

Rumsey N and others, 'Altered body image: appearance-related concerns of people with visible disfigurement' (2004) 48 Journal of Advanced Nursing 443

Rumsey N and Harcourt D, 'Body image and disfigurement: issues and interventions' (2004) 1 Body Image 83

Sarwer DB, Bartlett SP and Whitaker LA, 'Adult Psychological Functioning of Individuals Born with Craniofacial Anomalies' (1999) 103 Plastic and reconstructive surgery 412

Saunders H, 'The invisible law of visible difference: disfigurement in the workplace' (2018) Industrial law journal

Schiek D, 'Intersectionality and the notion of disability in EU discrimination law' (2016) 53 Common Market Law Review 35

Sharratt N D and others, ‘Understandings and experiences of visible difference and romantic relationships: A qualitative exploration’ (2018) 27 Body Image 32

Sherlaw W and Hudebine H, 'The United Nations Convention on the rights of persons with disabilities: Opportunities and tensions within the social inclusion and participation of persons with disabilities' (2015) 9 European Journal of Disability research 9

Smith B, 'Intersectional Discrimination and Substantive Equality: A comparative and Theoretical Perspective' (2016) 16 The Equal Rights Review 73

Stevenage SV and McKay Y, 'Model applicants: The effect of facial appearance on recruitment decisions' (1999) 90 British Journal of Psychology 221

Steyn J, 'Pepper v Hart; A Re-examination' (2001) 21 Oxford Journal of Legal Studies 59

Stone A and Wright T, 'When your face doesn't fit: employment discrimination against people with facial disfigurements' (2013) 43 Journal of Applied Social Psychology 515

Svegar D, 'What does facial symmetry reveal about health and personality?' (2016) 47 Polish Psychological Bulletin 356

Tartaglia A and others, 'Workplace discrimination and disfigurement: the national EEOC ADA research project' (2005) 25 Work (Reading, Mass) 57

Taylor GW and Ussher JM, 'Making Sense of S& M: A Discourse Analytic Account' (2001) 4 Sexualities 293

Thompson A and Kent G, 'Adjusting to disfigurement: processes involved in dealing with being visibly different' (2001) 21 Clinical Psychology Review 663

Uccellari P, 'Multiple Discrimination: How Law can Reflect reality' (2008) 1 The Equal Rights Review 24

Van Den Elzen MEP and others, 'Adults with congenital or acquired facial disfigurement: Impact of appearance on social functioning' (2012) 40 Journal of Cranio-Maxillofacial Surgery 777

Van Hoecke M, ‘Methodology of Comparative Legal Research’ (2015) *Law and Method* 1

Versnel SL and others, 'Satisfaction with facial appearance and its determinants in adults with severe congenital facial disfigurement: A case-referent study' (2010) 63 Journal of Plastic, Reconstructive & Aesthetic Surgery 1642

Vornholt K and others, 'Disability and employment – overview and highlights' (2018) 27 European Journal of Work and Organizational Psychology 40

Waddington L, 'Reassessing the employment of people with disabilities in Europe: from quotas to anti- discrimination laws' (1996) 18 Comparative Labor Law Journal 62

Waddington L, 'Future prospects for EU equality law: lessons to be learnt from the proposed equal treatment directive' (2011) 36 European Law Review 163

Waddington L, 'Saying All the Right Things and Still Getting it Wrong' (2015) 22 Maastricht Journal of European and Comparative Law 576

Wendell S, 'Toward a Feminist Theory of Disability' (1989) 4 Hypatia 104

Westen P, 'The empty idea of equality' (1982) 95 Harvard Law Review 537

William LC, 'The implementation of equality legislation: the case of disabled graduates and reasonable adjustments' (2016) 47 Industrial Relations Journal 341

Williams-Whitt K and Taras D, 'Disability and the Performance Paradox: Can Social Capital Bridge the Divide?' (2010) 48 British Journal of Industrial Relations 534

Young D and Quibell R, 'Why Rights are Never Enough: Rights, intellectual disability and understanding' (2000) 15 Disability and Society 747

Official publications and reports

Abrams D, Swift H and Mahmood L, *Prejudice and unlawful behaviour: Exploring levers for change* (Equality and Human Rights Commission 2017)

All Party Parliamentary Group on Skin, ‘The Psychological and Social impact of skin diseases on people’s lives’ (London 2013)

Baker C, ‘House of Commons Briefing Paper No 3336’ (20 March 2018)

Bribosia E and Rorive I, *Country report: Belgium* (European network of legal experts in gender equality and non-discrimination), European Commission 2018)

Byrnes A and others, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities* (UN-DESA, OHCHR and IPU 2007)

De Vos M, *Beyond Formal Equality* (European Commission 2007)

EHRC, *Employment statutory Code of Practice* (The Stationery office Limited 2011)

EHRC, *Hidden in Plain Sight: Inquiry into Disability-related harassment* (ECHR 2011)

EHRC, *Religion or belief: a guide to the law* (EHRC 2016)

Ferri D and Lawson A, *Reasonable accommodation for disabled people in employment* (European network of legal experts in gender equality and non-discrimination for the European Commission, 2016)

Fredman S, *Intersectional discrimination in EU gender equality and non-discrimination law* (European network of legal experts in gender equality and non-discrimination for the European Commission, 2016)

HL Deb, 1995, vol 564

House of Commons Standing Committee E debate, 7 February 1995,
per David Hanson.

House of Lords and House of Commons Joint Committee on Human Rights, *Implementation Of The Right Of Disabled People To Independent Living* (Report 23 of 2010-12, 2012)

House of Lords Select Committee, *The Equality Act 2010: the impact on disabled people* (Paper 117, 2016)

Hudson M, *Research paper: the experience of discrimination on multiple grounds* (ACAS Research Papers, ACAS 2012)

Hurstfield J and others, 'Monitoring the Disability Discrimination Act (DDA) 1995: Phase 3' (Disability Rights Commission, Department for Work and Pensions and the Equality Commission (Northern Ireland) 2004)

IFF Research on behalf of Department for Business Innovation and Skills, 'Payment of Tribunal Awards' (Department for Business Innovation and Skills 2013)

Judicial College, *Guidelines for the Assessment of General Damages in Personal Injury Cases* (13th Edition, Oxford University Press, 2015)

Judicial College, *Guidelines for the assessment of General Damages in Personal Injury Cases* (14th Edition, Oxford University Press 2017)

Le Defenseur des Droits, 'Le Physique de L'Emploi' (Fevrier 2016)

Longhi S, *The disability pay gap* (EHRC Research reports, 2017)

Meager N and others, 'Awareness, knowledge and exercise of individual employment rights' (Employment Relations Research Series, DTI 2002)

Office for Disability Issues, *Equality Act 2010: Guidance on matters to be taken into account in determining questions relating to the definition of disability* (HM Government 2011)

Pierce M, 'Minority Ethnic People with Disabilities in Ireland' (The Equality Authority, 2003)

UK Government, *Government response to the House of Lords Select Committee on the Equality Act 2010 and Disability* (Publications Office 2016)

Other print sources

Broderick A, 'The Long and Winding Road to Equality and Inclusion for Persons with Disabilities' (PhD thesis, Maastricht 2015)

Bruce A, 'Which Entitlements and for Whom? The Convention on the Rights of Persons with Disabilities and its Ideological Antecedents' (PhD thesis, Lund University 2014)

Cameron C, 'Does anybody like being disabled?' (PhD thesis, Queen Margaret University 2010)

Centre for Social Justice, 'Rethinking disability at work' (Centre for Social Justice 2017)

Changing Faces, 'Evidence (EQD0131) to the House of Lords Select Committee on the Equality Act 2010 and Disability' (House of Lords Stationery Office 2015).

Changing Faces, 'Disfigurement in the UK' (Changing Faces 2017)

Garrisi D, Janciute L and Johanssen J, *Appearance, Discrimination and the Media* (University of Westminster, CAMRI Policy Brief 3, 2018)

Geffen R, 'The Equality Act 2010 and the Social Model of Disability' (LLM thesis, Leeds University 2013)

Law Centres Network, 'Equality Act 2010 and Disability Committee, House of Lords: Evidence from the Law Centres Network' (2015)

Moss TP, 'Individual differences in psychological adjustment to perceived abnormalities of appearance' (PhD thesis, Plymouth University 1997)

O'Cinneide C, 'Taking equal opportunities seriously: the extension of positive duties to promote equality' (Equality and Diversity Forum, 2004).

Wardle C and Boyce T, ‘Media Coverage and Audience Reception of Disfigurement on Television’ (Cardiff University / The Healing Foundation 2009)

Internet / audiovisual sources

ACAS, ‘Asking and responding to questions of discrimination in the workplace’ (undated) <https://www.acas.org.uk/media/3920/Asking-and-responding-to-questions-of-discrimination-in-the-workplace/pdf> accessed 20 October 2019.

Advance HE, 'Athena SWAN charter' (Advance HE, undated) <https://www.ecu.ac.uk/equality-charters/athena-swan/> accessed 5 July 2019

Alopecia UK (undated), <https://www.alopecia.org.uk/Pages/FAQs/Category/types-of-alopecia > accessed 30 January 2019)

Anonymous, ‘Hair loss reversed in alopecia areata sufferers’, *BBC* <https://www.bbc.co.uk/news/health-28834058> accessed 30 January 2019

Association France Psoriasis, ‘Enquête inédite sue l’impact do Pso sur la vie professionelle (9 October 2017) https://francepsoriasis.org/actualites/enquete-inedite-sur-limpact-du-pso-dans-la-vie-professionnelle/accessed 19 September 2019.

BBC News, ‘TUC calls for ban on ‘class discrimination’ at work’ (*BBC News*, 9 September 2019) <https://www.bbc.co.uk/news/business-49625848 accessed 11 September 2019.

Bedell G, 'Girl, Interrupted' The Guardian (London 5 May 2002) Culture <https://www.theguardian.com/theobserver/2002/may/05/features.review27> accessed 15 August 2019

Blacks legal dictionary online, <https://thelawdictionary.org> accessed 29 April 2019

Borwick G, 'Disfigurement: Looking beyond face value' (Personnel Today, 2010) <http://www.personneltoday.com/hr/disfigurement-looking-beyond-face-value/> accessed 4 July 2019

Business Disability Forum, 'Factsheet for employers on disfigurement' (Rhondda Cynon Taf Council, Undated) <https://rct.learningpool.com/pluginfile.php/711/mod_folder/content/0/Saesneg%20%20English/Factsheet%20on%20Disfigurement%2012_13.pdf?forcedownload=1> accessed 4 July 2019

Center GaRDI, 'Wrinkly skin syndrome' (2016) <https://rarediseases.info.nih.gov/diseases/273/wrinkly-skin-syndrome> accessed 1 February 2019

Changing Faces, ‘Achieving face equality in the workplace’ (undated) www.changingfaces.org.uk/education/work accessed 10 October 2019.

Chazan D, 'Photoshopped images to come with a warning under new French law' The Telegraph <https://www.telegraph.co.uk/news/2017/09/30/photoshopped-images-come-warning-new-french-law/> accessed 9 July 2019

Cigna, 'Assessing the Fit to Work service rollout' (Cigna Corporation, 2015) <https://www.cigna.co.uk/downloads/2015/Fit%20for%20Work%20research%20article.pdf> accessed 4 July 2019

City of Santa Cruz Human Resources Department to Hannah Saunders, 'Email: physical characteristics discrimination' (13 June 2019)

COG Research on behalf of Changing Faces, 'Public Attitudes to Disfigurement in 2017' (Changing Faces, 2017) <https://www.changingfaces.org.uk/wp-content/uploads/2017/05/IAT2017.pdf> accessed 3 July 2019

Crow L, 'Renewing the Social Model of Disability' <http://www.roaring-girl.com/work/renewing-the-social-model-of-disability/> accessed 25 June 2019

Défenseur des Droits, 9ème édition du Baromètre des droits et de l'OIT sur la perception des discriminations sur l'emploi (Fevrier 2016) https://www.defenseurdesdroits.fr/sites/default/files/atoms/files/etudes_et_resultats_barometre_ap_vf-v4.pdf accessed 19 September 2019.

EEOC, 'ADA charge data by impairment / bases – merit factor resolutions (charged filed with EEOC)' (2018) <https://www.eeoc.gov/eeoc/statistics/enforcement/ada-merit.cfm> accessed 20 September 2019

EHRC, 'Employing People: Workplace Adjustments' (updated 14 May 2019) https://www.equalityhumanrights.com/en/multipage-guide/examples-reasonable-adjustments-practice accessed 13 September 2019.

EHRC, 'UN Convention on the Rights of Persons with Disabilities' (2018) <https://www.equalityhumanrights.com/en/our-human-rights-work/monitoring-and-promoting-un-treaties/un-convention-rights-persons-disabilities> accessed 25 June 2019.

Faragher J, 'Tribunal claims up 90% since fees abolished' (Personnel Today, 8 March 2018) < https://www.personneltoday.com/hr/employment-tribunal-claims-autumn-2017-up-since-fees-abolished/ accessed 13 September 2019.

Gergen K, Social Construction (2010) < https://www.youtube.com/watch?v=-AsKFFX9Ib0> accessed 10 September 2019.

Investors in People website https://www.investorsinpeople.com accessed 10 October 2019.

ITV News, 'Ex-CBeebies presenter: 'Parents criticised my decision not to wear prosthetic arm', (2017) <https://www.itv.com/news/2017-05-04/ex-cbeebies-presenter-cerrie-burnell-parents-rang-up-complaining-about-my-arm/>accessed 31 January 2019.

Label d'egalite, https://www.egalite-femmes-hommes.gouv.fr/dossiers/egalite-professionnelle/legalite-un-objectif-partage/le-label-egalite/ accessed 14 June 2019.

Labour Party, 'Nothing About You, Without You: A Manifesto With And For Disabled People' (2017) < https://labour.org.uk/manifesto/a-more-equal-society/#fifth> accessed 4 July 2018.

Le Défenseur des Droits, 'Abercrombie and Fitch: Grace au Défenseur, la société annonce la fin de recrutements discriminatoires' (Defenseur des Droits, 2015) <https://www.defenseurdesdroits.fr/fr/a-la-une/2015/05/abercrombie-and-fitch-grace-au-defenseur-la-societe-annonce-la-fin-de-recrutements> accessed 10 July 2019

Minelle B, 'Morbid obesity in Britain to double within twenty years', (2018), *Sky* <https://news.sky.com/story/morbid-obesity-in-britain-to-double-within-20-years-11385734> accessed 30 January 2019

Ministry of Justice , 'Tribunal statistics' (UK government, 2018) <https://www.gov.uk/government/collections/tribunals-statistics> accessed 6 July 2019

Oxford Dictionaries online, <https://en.oxforddictionaries.com/definition/disfigurement> accessed 29 April 2019.

Restricted Growth Association, (undated), <https://rgauk.org/about-restricted-growth> accessed 29 April 2019

Spalding H, Changing Faces (BBC Radio 4, 18 April 2018)

US Equal Employment Opportunity Commission, 'Confidentiality' (EEOC, undated) <https://www.eeoc.gov//employees/confidentiality.cfm> accessed 8 July 2019

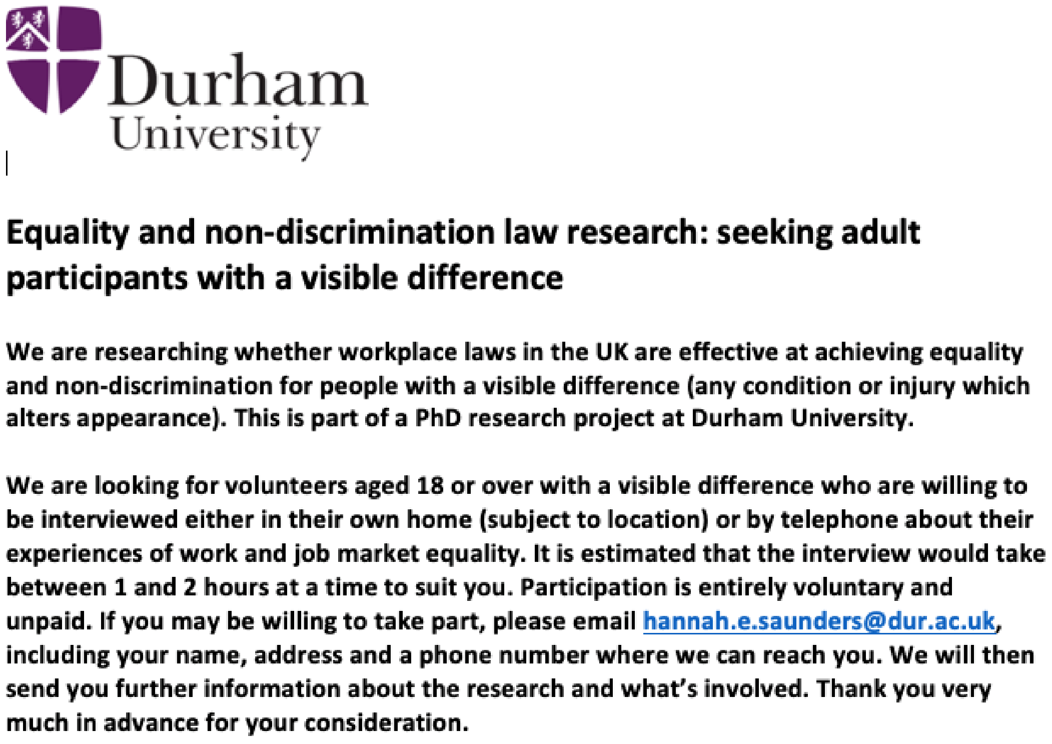
Wagner A, Can Britain "ignore Europe on human rights?" (*UK human rights blog*, 23 October 2011) < https://ukhumanrightsblog.com/2011/10/23/can-britain-ignore-europe-on-human-rights>accessed 10 September 2019.

Waterfield B and Huggler J, "I don't feel my weight is a big problem,' says Dane in EU obesity ruling' The Telegraph (24 May 2019) <https://www.telegraph.co.uk/lifestyle/wellbeing/diet/11302442/I-dont-feel-my-weight-is-a-big-problem-says-Dane-in-EU-obesity-ruling.html> accessed 24 May 2019

World Health Organisation, 'A practical manual for using the International Classification of Functioning, Disability and Health (draft)', https://www.who.int/classifications/drafticfpracticalmanual2.pdf?ua=1 accessed 29 April 2019

World Health Organisation, 'Weight bias and obesity stigma: considerations for the WHO European region' (undated, Copenhagen), <http://www.euro.who.int/__data/assets/pdf_file/0017/351026/WeightBias.pdf> accessed 24 May 2019.

APPENDIX 1 (PARTICIPANT ADVERT AND BLOG)

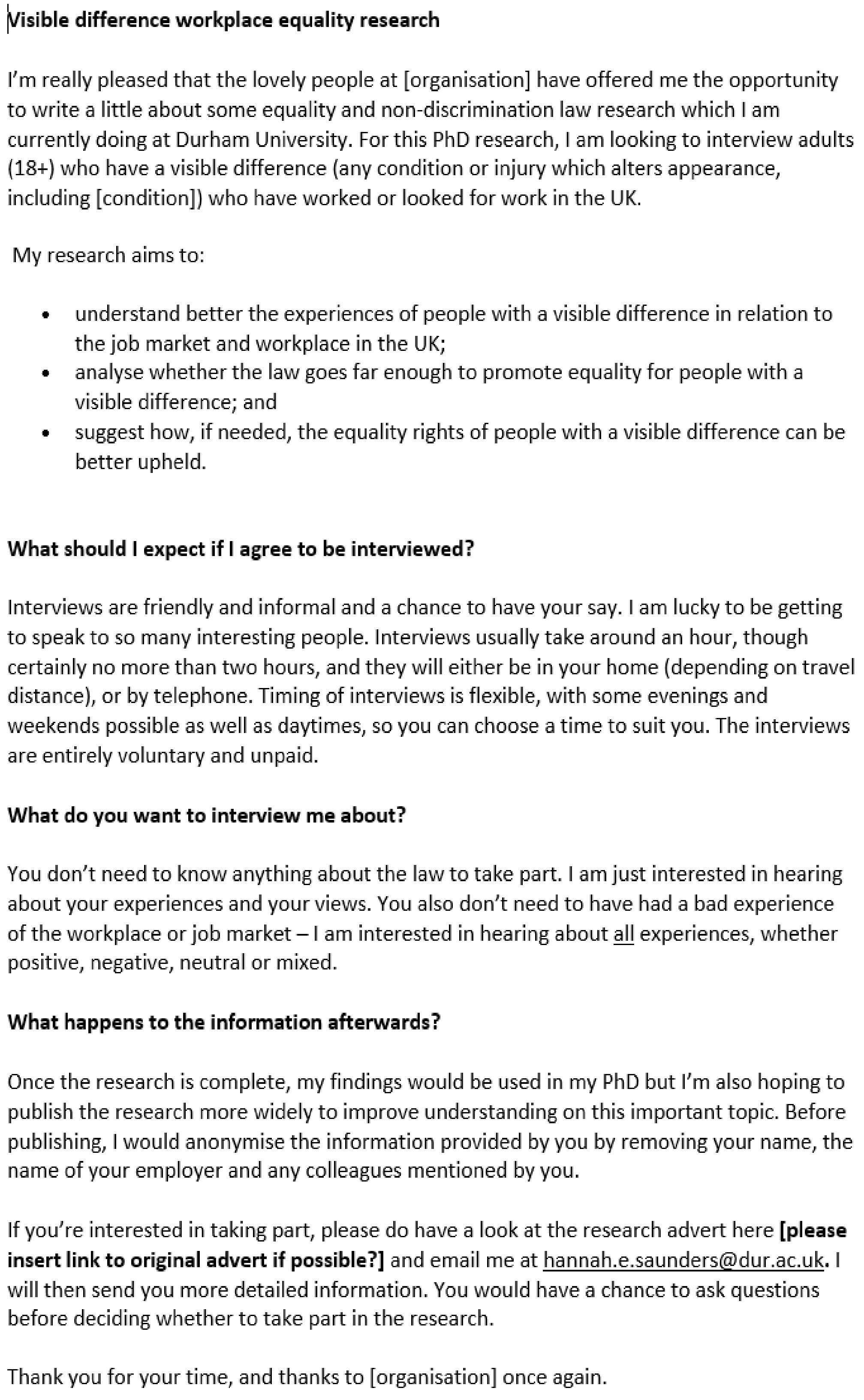


Durham
University

Equality and non-discrimination law research: seeking adult participants with a visible difference

We are researching whether workplace laws in the UK are effective at achieving equality and non-discrimination for people with a visible difference (any condition or injury which alters appearance). This is part of a PhD research project at Durham University.

We are looking for volunteers aged 18 or over with a visible difference who are willing to be interviewed either in their own home (subject to location) or by telephone about their experiences of work and job market equality. It is estimated that the interview would take between 1 and 2 hours at a time to suit you. Participation is entirely voluntary and unpaid. If you may be willing to take part, please email hannah.e.saunders@dur.ac.uk, including your name, address and a phone number where we can reach you. We will then send you further information about the research and what's involved. Thank you very much in advance for your consideration.



Visible difference workplace equality research

I'm really pleased that the lovely people at [organisation] have offered me the opportunity to write a little about some equality and non-discrimination law research which I am currently doing at Durham University. For this PhD research, I am looking to interview adults (18+) who have a visible difference (any condition or injury which alters appearance, including [condition]) who have worked or looked for work in the UK.

My research aims to:

- understand better the experiences of people with a visible difference in relation to the job market and workplace in the UK;
- analyse whether the law goes far enough to promote equality for people with a visible difference; and
- suggest how, if needed, the equality rights of people with a visible difference can be better upheld.

What should I expect if I agree to be interviewed?

Interviews are friendly and informal and a chance to have your say. I am lucky to be getting to speak to so many interesting people. Interviews usually take around an hour, though certainly no more than two hours, and they will either be in your home (depending on travel distance), or by telephone. Timing of interviews is flexible, with some evenings and weekends possible as well as daytimes, so you can choose a time to suit you. The interviews are entirely voluntary and unpaid.

What do you want to interview me about?

You don't need to know anything about the law to take part. I am just interested in hearing about your experiences and your views. You also don't need to have had a bad experience of the workplace or job market – I am interested in hearing about all experiences, whether positive, negative, neutral or mixed.

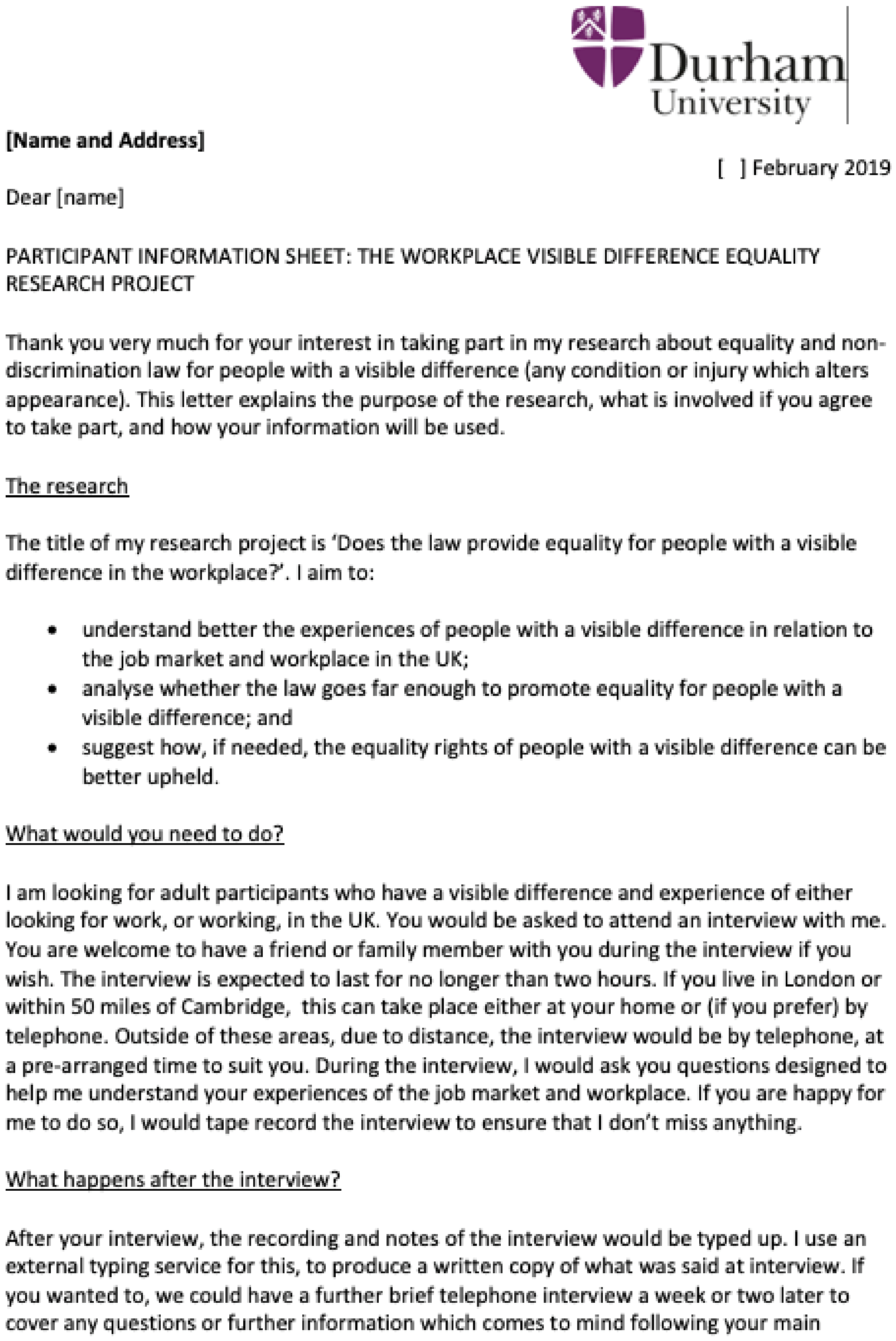
What happens to the information afterwards?

Once the research is complete, my findings would be used in my PhD but I'm also hoping to publish the research more widely to improve understanding on this important topic. Before publishing, I would anonymise the information provided by you by removing your name, the name of your employer and any colleagues mentioned by you.

If you're interested in taking part, please do have a look at the research advert here **[please insert link to original advert if possible?]** and email me at hannah.e.saunders@dur.ac.uk**.** I will then send you more detailed information. You would have a chance to ask questions before deciding whether to take part in the research.

Thank you for your time, and thanks to [organisation] once again.

APPENDIX 2 (INFORMATION LETTER AND CONSENT)



Durham
University

[Name and Address]

[ ] February 2019

Dear [name]

PARTICIPANT INFORMATION SHEET: THE WORKPLACE VISIBLE DIFFERENCE EQUALITY RESEARCH PROJECT

Thank you very much for your interest in taking part in my research about equality and non-discrimination law for people with a visible difference (any condition or injury which alters appearance). This letter explains the purpose of the research, what is involved if you agree to take part, and how your information will be used.

The research

The title of my research project is 'Does the law provide equality for people with a visible difference in the workplace?'. I aim to:

- understand better the experiences of people with a visible difference in relation to the job market and workplace in the UK;
- analyse whether the law goes far enough to promote equality for people with a visible difference; and
- suggest how, if needed, the equality rights of people with a visible difference can be better upheld.

What would you need to do?

I am looking for adult participants who have a visible difference and experience of either looking for work, or working, in the UK. You would be asked to attend an interview with me. You are welcome to have a friend or family member with you during the interview if you wish. The interview is expected to last for no longer than two hours. If you live in London or within 50 miles of Cambridge, this can take place either at your home or (if you prefer) by telephone. Outside of these areas, due to distance, the interview would be by telephone, at a pre-arranged time to suit you. During the interview, I would ask you questions designed to help me understand your experiences of the job market and workplace. If you are happy for me to do so, I would tape record the interview to ensure that I don't miss anything.

What happens after the interview?

After your interview, the recording and notes of the interview would be typed up. I use an external typing service for this, to produce a written copy of what was said at interview. If you wanted to, we could have a further brief telephone interview a week or two later to cover any questions or further information which comes to mind following your main interview. You can decide whether this follow-up conversation would be helpful at a later date.

What will the information be used for?

I expect that the final research will be detailed as part of my PhD thesis (which will be made publicly available), and may also be published elsewhere (e.g. in academic journals, lectures etc).

Reassuring you about anonymity

The final published research may include some anonymous quotes from you and other participants as well as explanations of key themes emerging from the interviews. Before publishing, I would first anonymise the information provided by you, by removing your name and the names of any employers / colleagues mentioned by you. The external typing service which I will use to type up the recordings of the interviews will also sign a non-disclosure agreement.

I believe that the topic of this research is both important and necessary. If you agree to participate, I will send you a summary of my research findings at the end of the project. Please note that I am not able to provide legal advice to you. I will, however, offer you a list of contact details of relevant organisations, including some who may be able to provide free advice to you on any legal / equality matters should you need it. I will also provide contact details of support organisations.

I hope that this is clear and enclose a consent form. I will telephone you on the number you provided next week in case you have any questions about the research. After that, if you are willing to take part in the research, please complete the consent form and return it to me as soon as possible, either by scanning it in and emailing it to hannah.e.saunders@dur.ac.uk or enclosing it in the stamped envelope provided.

I do appreciate the time you have taken in responding, and look forward to speaking with you soon.

Yours sincerely

Hannah Saunders
Durham University, PhD researcher in Law.

CONSENT FORM

The workplace visible difference equality research project

	Please cross out as necessary
Have you read the Participant Information Sheet?	YES / NO
Have you had an opportunity to ask questions and to discuss the study?	YES / NO
Have you received satisfactory answers to all of your questions?	YES / NO
Have you received enough information about the study and the Intended uses of, and access arrangements to, any data which you supply ?	YES / NO
Were you given enough time to consider whether you want to participate?	YES/NO
Do you understand that your name will not be identified or identifiable in any reports that result from the research? But that the information provided by you may be used, and quoted, for the purposes of this PhD research and for publication of research findings?	YES/NO

Who have you spoken to? Dr/Mr/Mrs/Ms/Prof..

Do you consent to your interview(s) being recorded and transcribed? Do you also understand that, after completion of the research project, the recordings will be deleted but the transcripts will be retained for 6 years in accordance with the University's data protection policy?	YES/NO
Do you consent to participate in the study?	YES/NO
Do you understand that you are free to withdraw from the study: * at any time and * without having to give a reason for withdrawing and * without any adverse result of any kind?	YES / NO

Signed .... **Date** ....

(NAME IN BLOCK LETTERS) ....

Signature of witness .... **Date** ....

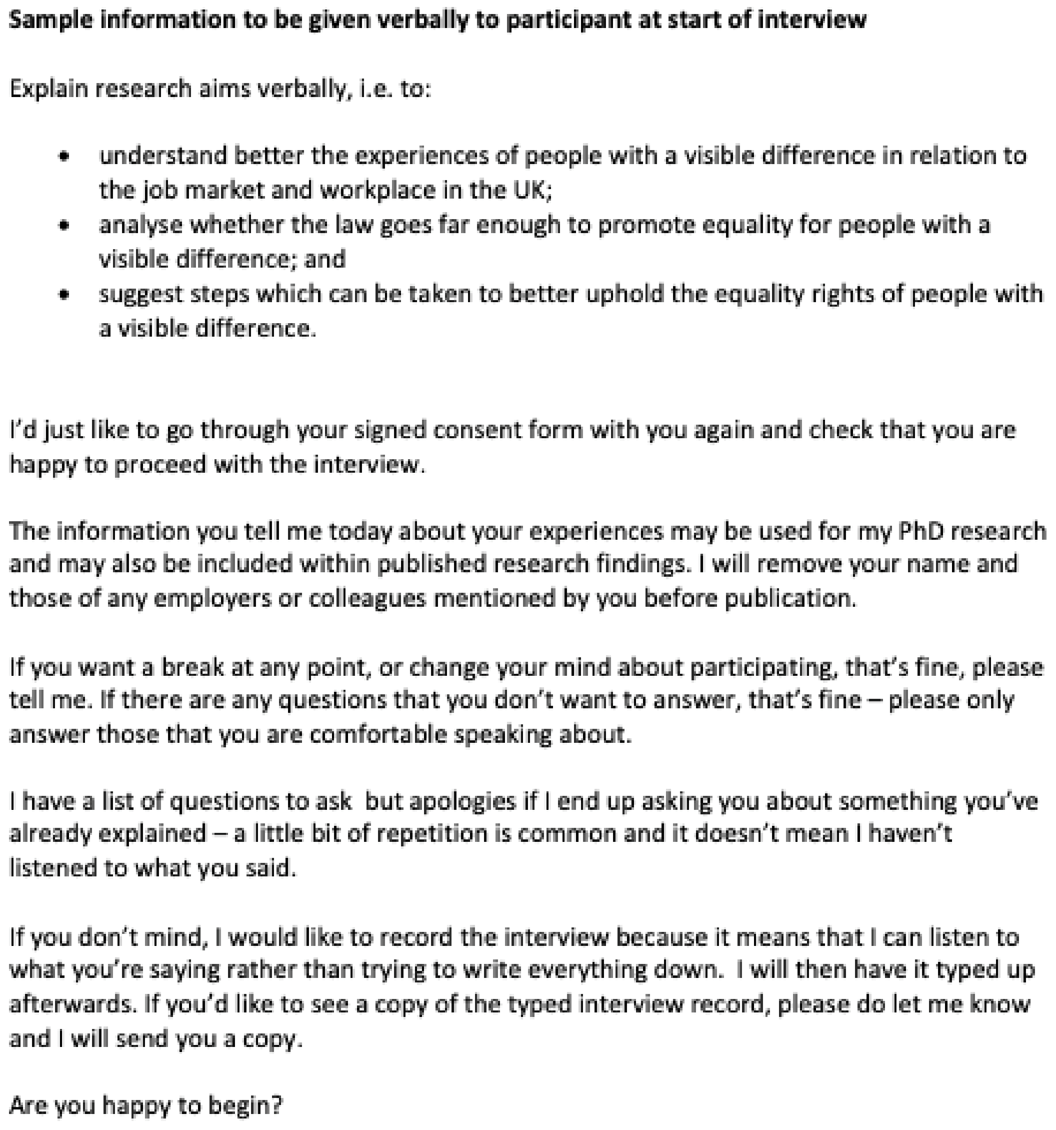
(NAME IN BLOCK LETTERS) ....

APPENDIX 3 (PARTICIPANTS SCHEDULE)

The table below summarises key (anonymised) information relating to participants in this study at the date of interview.

Interview method	**Work situation**	**Age band**	**Gender identity**	**Race / ethnic origin**
Face to face: 5 Telephone: 12	Employed:10 Self-employed: 2 Retired: 2 Unemployed/not working: 3	0-30: 1 30-40: 3 40-50: 3 50-60: 6 60-70: 3 70+: 1	Female:15 Male:2 Non-binary:0	White British: 17

APPENDIX 4 (INTERVIEW QUESTION TEMPLATE)



Sample information to be given verbally to participant at start of interview

Explain research aims verbally, i.e. to:

- understand better the experiences of people with a visible difference in relation to the job market and workplace in the UK;
- analyse whether the law goes far enough to promote equality for people with a visible difference; and
- suggest steps which can be taken to better uphold the equality rights of people with a visible difference.

I'd just like to go through your signed consent form with you again and check that you are happy to proceed with the interview.

The information you tell me today about your experiences may be used for my PhD research and may also be included within published research findings. I will remove your name and those of any employers or colleagues mentioned by you before publication.

If you want a break at any point, or change your mind about participating, that's fine, please tell me. If there are any questions that you don't want to answer, that's fine – please only answer those that you are comfortable speaking about.

I have a list of questions to ask but apologies if I end up asking you about something you've already explained – a little bit of repetition is common and it doesn't mean I haven't listened to what you said.

If you don't mind, I would like to record the interview because it means that I can listen to what you're saying rather than trying to write everything down. I will then have it typed up afterwards. If you'd like to see a copy of the typed interview record, please do let me know and I will send you a copy.

Are you happy to begin?

Background information

1. Interviewee code (not name):
2. Where saw research study advertised:
3. Age:
4. Ethnic origin: (using categories from 2011 census).
5. Gender:
6. Interviewee's own description of visible difference:
7. Interviewee's own rating of appearance of disfigurement: mild / moderate / severe
8. Age at which visible difference became apparent:
9. Current work situation: Employed? Industry? Nature of role? How long worked there?
10. Prior work history (numbers and types of job and length of time held):

Experiences once in work

15. Are your employer and colleagues aware of your visible difference?
16. Do you enjoy work? Why?
17. Do you feel fairly treated and included at work? Why?
    a. [Prompt if necessary] e.g. hostility / treated less favourably than colleagues?
18. Once employed, do you feel that having a visible difference has impacted in any way on your career progression (such as the type of work you do, or the seniority of your role?)
19. Have you adopted any techniques / strategies to deal with visible difference at work? Have they been effective?
20. Do you think your experiences at work have been affected by any other factors, including your gender / age / ethnic origin?

Reasonable adjustments

21. Are you aware that someone with a severe disfigurement is classed as a disabled person for the purpose of non-discrimination law? (If not, if you had known this, would this have changed the way you would have dealt with any work situations?)

22. Disabled people (including people with severe disfigurements) are sometimes entitled to have reasonable adjustments made to their roles and work arrangements to make up for specific disadvantages caused by their disability. Have you ever requested, or been offered, a reasonable adjustment at work? Please describe the process and what happened. (If it was refused, why? If granted, did it help? Did you use the adjustment?)

23. If you haven't requested reasonable adjustments, why is this?

24. When you first start a new job, would you like your employer to discuss visible difference and possible adjustments with you privately? Or would you rather decide whether to raise it with them?

25. Can you think of any reasonable adjustments relating to your visible difference which would have helped you at any point during your career?

26. [Which, if any, of the following adjustments do you feel would benefit you at work now or would have benefited you in previous employment: **[prompts if needed]**

    - Training or mentoring to help you manage the reactions of other people to visible difference
    - Training for colleagues about visible difference
    - Flexible work patterns for reasons connected with visible difference
    - Changes to your role duties (what changes?)
    - Changes to policies (e.g. relating to sickness procedures or dress codes).]

Access to justice

27. [You mentioned earlier that you believe that you have been discriminated against on ground of visible difference at work or when applying for work]. Did you bring a claim? Why?

28. If you felt you had been discriminated against at work now on ground of visible difference, would you consider bringing a claim now? If not, why not?

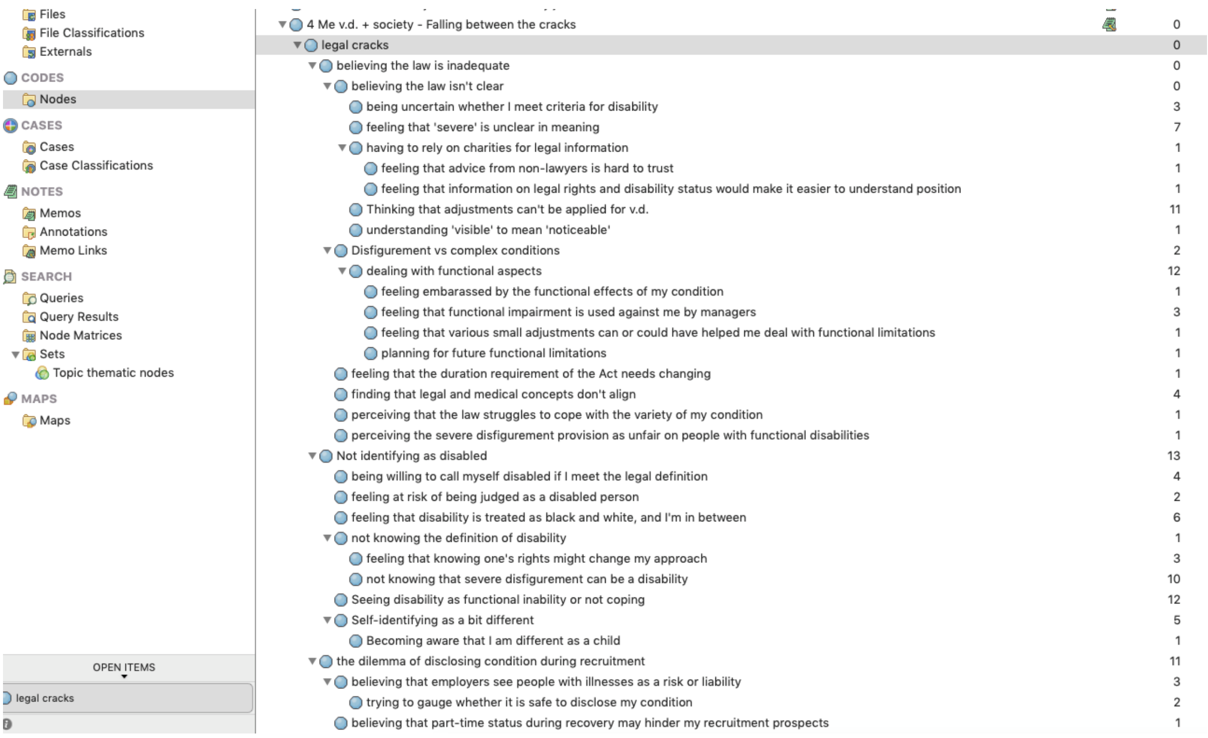
29. Is there anything else relating to your experiences of visible difference at work which you would like to mention?

Post-interview information

1. Thank the participant for their help.
2. Explain process now – transcript to be typed up. Once other interviews have been conducted, the information from all participants will be analysed and look for common themes. I will also look at how the information fits with information from other research studies, and with what the law says. It's possible that may want to clarify one or two things – would you mind me contacting you again at that stage if so?
3. Offer list of help organizations which offer counselling and /or legal support.
4. Offer to keep informed of findings of research.
5. Provide my contact details for any queries.

APPENDIX 5 (EXAMPLES OF NVIVO CODING)

The screenshot below shows some of the analytic codes created under theme 4, sub-theme A: legal cracks. The numbers to the right provide a snapshot of the numbers of interview excerpts tagged within a particular code.



▼ 4 Me v.d. + society - Falling between the cracks	0
▼ legal cracks	0
▼ believing the law is inadequate	0
▼ believing the law isn't clear	0
being uncertain whether I meet criteria for disability	3
feeling that 'severe' is unclear in meaning	7
▼ having to rely on charities for legal information	1
feeling that advice from non-lawyers is hard to trust	1
feeling that information on legal rights and disability status would make it easier to understand position	1
Thinking that adjustments can't be applied for v.d.	11
understanding 'visible' to mean 'noticeable'	1
▼ Disfigurement vs complex conditions	2
▼ dealing with functional aspects	12
feeling embarassed by the functional effects of my condition	1
feeling that functional impairment is used against me by managers	3
feeling that various small adjustments can or could have helped me deal with functional limitations	1
planning for future functional limitations	1
feeling that the duration requirement of the Act needs changing	1
finding that legal and medical concepts don't align	4
perceiving that the law struggles to cope with the variety of my condition	1
perceiving the severe disfigurement provision as unfair on people with functional disabilities	1
▼ Not identifying as disabled	13
being willing to call myself disabled if I meet the legal definition	4
feeling at risk of being judged as a disabled person	2
feeling that disability is treated as black and white, and I'm in between	6
▼ not knowing the definition of disability	1
feeling that knowing one's rights might change my approach	3
not knowing that severe disfigurement can be a disability	10
Seeing disability as functional inability or not coping	12
▼ Self-identifying as a bit different	5
Becoming aware that I am different as a child	1
▼ the dilemma of disclosing condition during recruitment	11
▼ believing that employers see people with illnesses as a risk or liability	3
trying to gauge whether it is safe to disclose my condition	2
believing that part-time status during recovery may hinder my recruitment prospects	1

The table below shows a small extract of one coded transcript:

INTERVIEW EXCERPT	**DOMAIN SUMMARY (TOPIC)**	**INDUCTIVE CODES**
PARTICIPANT B: It's only fair that they need to know.	Recruitment	Disclosing to be fair to employer
And plus it's a bit of an arse-covering exercise as well, because if you ever need to have any sickness or holiday in the future INTERVIEWER: Yeah PARTICIPANT B: they can't say 'well we weren't aware of it…' INTERVIEWER: Yeah.	Recruitment	Protecting one's position against employer

PARTICIPANT B: So, um, yeh, probably a more academic term than 'arse-covering exercise' INTERVIEWER: [laughs] I know what you mean – sometimes …sometimes plain-speaking describes it better than …yeah, OK. Erm…Can I…can I probe you on that point that you said, you said I don't think of myself as disabled. Why? PARTICIPANT B: Erm, because, erm…I think the definition of disabled is having a substantial impact on your ability to carry out everyday tasks	Access to justice and awareness	Seeing disability as functional inability or not coping
INTERVIEWER: mmm…yeah… PARTICIPANT B: erm…when it's at its worst, erm, I can say that I'm more socially insular, erm, and that I don't socialise as much when it's bad, and so, erm, so I would say…to a certain…why I wouldn't think of myself as disabled…because most of the time I make do INTERVIEWER: Mmmm…yeah	Strategies and Coping with reactions of others	Avoiding social situations when it's bad Seeing disability as functional inability or not coping
PARTICIPANT B: So, I'm lucky in…where I am at the moment, everyone is incredibly compassionate about my skin	Colleague relationships and colleague discrimination	Feeling grateful for understanding and good things at work

INTERVIEWER: Mmmm PARTICIPANT B: I've only ever had one comment where someone said 'I'm worried I might catch your psoriasis' and I was like [inaudible] 'it's a genetic disorder, you're not going to catch it…'	Strategies and coping with reactions of others	Dealing with contagion concerns of others Choosing to explain
INTERVIEWER: No PARTICIPANT B: Erm…er (.) but, erm, INTERVIEWER: Was it like that in previous jobs? Were they as supportive? PARTICIPANT B: Erm – when I was [role], erm, [young people] could be a bit insensitive about it INTERVIEWER: Right PARTICIPANT B: So, erm, but that's the impetuous nature of youth really. […][682]	Other discrimination experiences	Feeling that younger people are more judgmental about appearance
PARTICIPANT B: But you notice people's eyes move towards it	Colleague relationships and experiences	Feeling uncomfortable with people

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[682] Section of transcript not shown for anonymity reasons

INTERVIEWER: Mmmm PARTICIPANT B: They’re no longer looking at you in the eye, they’re looking at your skin INTERVIEWER: Yeah		staring and commenting
PARTICIPANT B: And part of that again is that balance of paranoia versus do they actually think anything	Other discrimination experiences	Being uncertain whether people are judging me on visible difference or whether I’m oversensitive

APPENDIX 6 (GUIDANCE ON WHETHER A DISFIGUREMENT IS SEVERE[683])

The following questions may be helpful in assessing whether a disfigurement is classed as 'severe' under the Equality Act 2010. It is often not necessary to satisfy all of these questions to be classed as having a severe disfigurement. You should always take individual legal advice on your rights. This list is for guidance only, and is neither exhaustive nor binding on Employment Tribunals.

1. Is your disfigurement on your face, hands, or other part of your body where it is likely to be visible to others?
2. Is your disfigurement large in size?
3. Is your disfigurement hard to cover completely? For example, is scarring bumpy and hard to cover with make up? Or is a postural disfigurement visible through the outline of normal clothing?
4. Is your disfigurement visible across a room to others as well as close-up?
5. Does your disfigurement make your body, or any part of it, appear asymmetrical?
6. Does your disfigurement negatively affect your confidence and / or affect how you behave in daily life?
7. Does your disfigurement affect your ability to display normal facial expressions?
8. **[Does your disfigurement make you visibly stand out as different from most people of a similar gender, age, and ethnic origin from you?]**
9. If the effect of your disfigurement is intermittent rather than constant, does it occur frequently? (For example, an involuntary **[facial twitch or]**

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[683] This checklist is drafted on the assumption that (a) the threshold of severe disfigurement remains in the Act as at present (b) additional guidance provides for disfiguring effects, disfigurement as a relative concept, and progressively disfiguring conditions are included. The square brackets indicate a point which would not be applicable if the Act and Guidance remained as currently drafted.

temporary facial paralysis is more likely to be classed as a severe disfigurement if it happens every 10 seconds, rather than once an hour).

10. **[Is your disfigurement progressive (i.e. will it continue getting worse over time)?]**

The following photographs show examples of some common conditions. For each condition, two photographs are provided; one which is likely to severe, and one which is not[684]

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[684] Photographs are not included within this thesis due to a lack of access to suitably anonymised, free-to-use, images, but could be included in formal guidance.

APPENDIX 7 (GUIDANCE ON POTENTIAL REASONABLE ADJUSTMENTS FOR VISIBLE DIFFERENCE)

The following list notes some adjustments which could be helpful for some people with a visible difference. Please note that whether a particular adjustment is reasonable depends on a variety of factors, such as the nature and severity of the disfigurement, the nature of the role, and the employer's business and resources. This should be determined on an individual basis in consultation with the employee.

The list is proposed as a starting point for discussion and not an exhaustive list or one which would be appropriate for all people with a visible difference. Some people with a visible difference also experience functional limitations – these are not addressed in the list below.

1. Adjustments to any particular aspects of the role which an individual finds difficult due to visible difference. Common examples for some (but not all) are public engagements / speaking commitments. Supporting the employee with these aspects, or adjusting the job content slightly to reduce the necessity of these aspects, could be considered if required.
2. Adjustments to recruitment processes to remove photograph / video interview requirements. Best practice may be, where possible, to provide this flexibility to all candidates to prevent the individual from feeling singled out.
3. Adjustments to application forms to enable (but not require) applicants to explain the impact of a health condition if they choose to. It is essential to include an explanation that the law does not require such disclosure at this stage, and how the information will be used if the candidate chooses to disclose it.

4. Removing requirements for the employee to have a photograph at work e.g. on email headers or work social media profile. If photographs are essential, could the employee be allowed to bring one from home?
5. Support the employee with any changes to his/her workstation e.g. alterations to the angle of lighting may make some employees feel more comfortable.
6. Time off (and perhaps funding) for the individual to access specialist external training, if desired, to further social strategies related to visible difference.
7. Flexible working – e.g. flexible start and finish times to avoid busy public transport, breaks to touch in camouflage make-up or apply medication, or the ability to work from home during a flare-up.
8. A mentor that the individual can speak to confidentially at work if problems arise.
9. Support around any information processes to colleagues – this may be relevant when an employee first joins or after a change in his / her appearance.
10. Adjustments to uniform / grooming requirements. Sometimes individuals may prefer a uniform which covers up certain areas of their body (e.g. a long-sleeved top rather than a short-sleeved top, or thick tights rather than socks), or a uniform of a different colour to hide flaking skin. Loose clothing can be helpful for people with some conditions. Requirements to wear make-up (or rules preventing the same) can also be difficult for some employees with a visible difference and should be adapted if required.
11. Sickness procedures should differentiate between absences caused by disabilities (including a severe disfigurement), and general short-term absences. The former should not be taken into account in triggering absence warnings under a disciplinary policy.