

**Face Equality International Report on Interpreting disability
Legislation to assist people with Facial Disfigurements**



FACE EQUALITY
INTERNATIONAL

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UK Equality Act 2010

Introduction

The UK Equality Act became law in 2010, providing protection to individuals in the UK who exhibit any of the following nine “protected” characteristics from discrimination, harassment and victimisation:

- (a) age;
- (b) disability;
- (c) gender reassignment;
- (d) marriage and civil partnership;
- (e) pregnancy and maternity;
- (f) race;
- (g) religion or belief;
- (h) sex; or
- (i) sexual orientation.

Such protection applies to direct and indirect discrimination or harassment in a range of areas, including (without limitation) in the workplace, use of public services, joining of clubs, use of businesses, services, and use of transportation. ⁱ

1. Are persons with facial disfigurements protected on the grounds that a facial disfigurement is a disability?

Disabled person

Section 6(1) of the UK Equality Act 2010 (the “**UK Equality Act**”)ⁱⁱ defines a disabled person as “a person who has a disability”. A person has a “disability” for the purposes of the UK Equality Act if he or she has a physical or mental impairment and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

Determination of disability

Whether a person is disabled for the purposes of the UK Equality Act is generally determined by reference to the “effect” that an impairment has on that person’s ability to carry out normal day-to-day activities. An exception to this is a person with severe disfigurement, which should be treated as meeting the definition of disability. In particular, the UK Equality Act provides that where an impairment consists of a “severe disfigurement”, it is to be treated as having a substantial adverse effect on the person’s ability to carry out normal day-to-day activities. This means that there is no need to demonstrate such an “effect” (under Schedule 1, Paragraph 3 of the UK Equality Act).

Examples of disfigurements

The UK Government have provided additional guidance on the UK Equality Actⁱⁱⁱ (the “**UK Equality Act Guidance**”), which includes examples of disfigurements which *may* be considered to fall within the definition of a disability. This includes 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 also be necessary to take account of where the disfigurement is on the body (e.g. if such disfigurement is on the back or on the face). The UK Equality Act Guidance is not designed to be comprehensive but provides a foundation to assist in interpreting and applying the UK Equality Act.

Excluded markings

Under the Equality Act 2010 (Disability) Regulations 2010 (S.I. 2010/2128) (the “**Equality Act Disability Regulations**”)^{iv}, a disfigurement which consists of a tattoo (which has not been removed) is not to be considered a severe disfigurement. Other markings which are excluded are piercings of the body for decorative purposes including anything attached through the piercing.

Parameters of the UK Equality Act

There is some academic debate regarding the lack of clear statutory guidance and case law on the meaning of ‘disfigurement’, which means that the parameters of the UK Equality Act remain uncertain^v. This is partially because the UK Equality Act Guidance sets out a list of examples of types of disfigurement, rather than detailed, comprehensive and exhaustive criteria. Additionally, there have been relatively few reported cases which explore the concept of severe disfigurement, and those that have been reported do not go much further than the examples given in the Guidance. To explain this further, whilst there has been some case law which recognises facial scarring as a disability (see Johansson^{vi}, Hand^{vii} and Griffiths^{viii}), these cases are arguably clear examples of disfigurements which will fall squarely within the definition under the Act. They do not test the parameters of more nuanced disabilities, for example, those affecting facial expressions, excessive hair growth or perspiration.

These parameters are under particular tension from the related concepts of appearance and disability, which partially overlap with disfigurement. In many cases, there will be no dispute whether a person has an impairment. Any disagreement is more likely to be about whether the effects of the impairment are sufficient to fall within the definition and in particular, whether they are long-term.

2. Are persons with facial disfigurements protected on other grounds?

A person with a facial disfigurement may be protected more widely under the UK Equality Act if it independently meets the general criteria for a disability under the UK Equality Act. This means that, in general:

- a) the person must have an impairment that is either physical or mental;
- b) the impairment must have adverse effects which are substantial;
- c) the substantial adverse effects must be long-term; and
- d) the long-term substantial adverse effects must be effects which impact normal day-to-day activities.

This definition is subject to the provisions in Schedule 1 of the UK Equality Act^{ix}. All of the factors above must be considered when determining whether a person is disabled.

Guidance on each element

Each element of this criterion has its own guidance. For example, criteria (a) requires that the effects that a person may experience must arise from a physical or mental impairment. The term physical or mental impairment should be given its ordinary meaning. It is not necessary for the cause of the impairment to be established, nor does the impairment have to be the result of an illness.

The UK's Equality Act 2010 prohibits discrimination against people with a protected characteristic (i.e. a disability) across a range of activities including the provision of goods, facilities and services; the exercise of public functions, premises, work, education, and associations. If an individual cannot demonstrate a disability under the requirements of the UK Equality Act, the UK Equality Act does provide protection for non-disabled people who are subjected to direct discrimination or harassment because of their association with a disabled person or because they are wrongly perceived to be disabled. This may provide those with facial disfigurements that do not meet all the criteria with some level of protection.

3. Must / should persons with facial disfigurements describe themselves as disabled in order to exercise their rights?

Persons with facial disfigurements generally need to meet the definition of “disability” under the UK Equality Act (as discussed in sections 1 and 2 above), in order to claim protections and exercise their rights under the UK Equality Act.

The UK Equality Act defines a “disabled person” as a person with a physical or mental impairment, which has a substantial and long-term adverse effect on such person’s ability to carry out normal day-to-day activities^x. As explained above “severe disfigurement” is deemed to be a disability for the purposes of the UK Equality Act^{xi}.

If an individual cannot demonstrate a disability under the requirements of the UK Equality Act, the UK Equality Act does provide protection for non-disabled people who are subjected to direct discrimination or harassment because of their association with a disabled person or because they are wrongly perceived to be disabled. This may provide those with facial disfigurements that do not meet all the criteria with some level of protection.

4. What are the gaps in protection?

While people with severe disfigurement are protected under the UK Equality Act, the UK Equality Act does not define or provide any further explanation as to what is considered to be a “severe disfigurement”. There is a lack of clarity as to what is “severe” and as to what is a “disfigurement”.

What is a disfigurement?

Only people with a disability and a severe disfigurement/s are generally protected under the UK Equality Act, i.e. people whose disfigurements have a substantial adverse effect on the person’s ability to carry out normal day-to-day activities – whereas people who have an imperfection of appearance or a moderate disfigurement are not protected.

What is a disfigurement is only briefly explained in the UK Equality Act Guidance^{xii}, which provides some examples of types of disfigurement (i.e. scars, birthmarks, limb or postural deformation, or diseases of the skin). It is unclear whether from the UK Equality Act or from the UK Equality Act Guidance whether other disorders, such as conditions affecting facial expressions, hair loss, excess hair growth or facial perspiration, are “disfigurements” within the meaning of the UK Equality Act.

How severe is ‘severe’?

The disfigurement has to be ‘severe’ and the UK Equality Act Guidance provides that assessing the 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.

In a recent case, 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”.^{xiii} Instead, in assessing the severity of the disfigurement, the EAT took into account the impact of the disfigurement on the claimant and recognised that the tribunal should exercise a degree of sensitivity as to the evidence required to prove the severity of the disfigurement, accepting that different forms of evidence may suffice in different cases.^{xiv} However, the test for severity is not a wholly subjective test (i.e. it is not simply that the person considers their own condition to be severe).^{xv}

While the current test for severity is beneficial to people with disfigurements, as it allows a degree of flexibility in the evidence required to meet the threshold, it could disadvantage claimants whose disfigurements are borderline in their severity, but whose life choices have been inhibited.^{xvi}

The location of disfigurement

When assessing whether the severe disfigurement threshold is met, it is necessary to take into account where the disfigurement is located (e.g. on the back as opposed to the face).^{xvii} For example, while the severe skin condition psoriasis is a disfigurement, a woman with severe psoriasis on her torso and legs was found by the employment tribunal not to be “severely disfigured”^{xviii}. Similarly, it was recognised by the tribunal that folliculitis (a chronic recurring infection of the hair follicles) is a disfigurement; however, a man with folliculitis on his scalp and posterior was not ‘severely’ disfigured.^{xix} In the tribunal’s view the “*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.*”^{xx}

Taking into consideration the location of the disfigurement in assessing its severity creates a gap in protection for people affected. It creates an expectation that a disfigurement that *can be covered, should be covered* and conflates visibility with knowledge. People with disfigurements that are on the back of the head or on the torso can still face discrimination and should be protected.^{xxi}

Disability vs Visible Differences

The UK Equality Act does not protect pure differences of appearance (without impairment) even where it produces severe disadvantages. Most people with a 'visible difference' will not be classified as "disabled" under the UK Equality Act, because such disfigurements often do not have any adverse effect on the person's ability to carry out day-to-day activities. However, people with visible differences still face social and professional barriers and discrimination, resulting in psychological suffering.^{xxii} As David Wasserman, a fellow at the Department of Bioethics, National Institutes of Health, Bethesda, Maryland, said in the book, "Americans with Disabilities" "*many physical and mental differences not classified as impairments elicit equally contemptuous, dismissive, patronizing and over solicitous responses, that can be equally handicapping*".^{xxiii} Assessing what is 'normal' or 'impaired' is difficult and currently imperfections in appearance are undefined and unprotected.

Enforcement

Finally, the UK Equality Act does not address the more subtle types of discrimination, such as colleagues making assumptions about ability or intellectual capacity of people with disfigurements, or facing general unpleasantness from strangers, such as being stared at or commented on. These forms of treatment do not fall within the scope of the UK Equality Act, but still bring a sense of helplessness and vulnerability to people.^{xxiv} There are various areas which make enforcement of the UK Equality Act difficult. For instance, social media platforms could on the one hand be strong amplifiers of campaigns to promote equality, but on the other, people with disfigurements might be more likely to be subjected to abuse online.^{xxv}

5. What legal / regulatory reforms are needed if people are to seek protection (either on the grounds that facial disfigurement is a disability, or on other grounds)?

Legal Reforms

While the UK Equality Act does offer protection for people with severe disfigurements, there is currently insufficient clarity on the definition of “disfigurement”. The government guidance should be amended to provide further definition and guidance on the existing provisions.

The requirement that only “severe” disfigurements can gain protection under the UK Equality Act should be removed. In her submission regarding amendments to the Disability Discrimination Bill in a House of Lords Committee meeting on 13 June 1995, Baroness Hollis of Heigham mentioned that: “[s]mall 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.”^{xxvi}

A “severe disfigurement” should be separated from “disability”, and a separate protected characteristic of “disfigurement” and “appearance” should be created to enable individuals to seek protection where they are discriminated against based on their appearance. The charity Changing Faces has further proposed that a separate characteristic of *facial* disfigurement should be created, which would enable individuals to seek legal protection where immediate judgements are made based on appearance.^{xxvii}

Regulatory Reforms

Relying solely on legal protection is insufficient to protect people with disfigurements, and societal level reforms are required to offer all-rounded protection. This is especially so given the lack of general awareness of discrimination against people with disfigurements and “visible differences”. Societal biases affect even the most conscientious-minded people, they take time to reduce and cannot be resolved merely through legal reforms.

Examples of possible reforms include:

- **Workplace and schools:** Guidance, training or support can be put in place to ensure people with disfigurements are informed and confident about their own legal rights. Sufficient guidance on how to deal with disfigurement in recruitment processes and during teaching should be provided to employers and teachers respectively. Policies and practices in workplaces and schools should be monitored regularly to ensure compliance with the UK Equality Act and public sector equality duty (as defined in s.149 of the UK Equality Act, where public authorities are required to have due regard to objectives such as eliminating discrimination, harassment and victimisation, advancing equality of opportunity between different groups and fostering good relations between different groups)^{xxviii}, such that people with disfigurements can enjoy a safe environment free of prejudice and harassment.^{xxix}
- **Healthcare industry:** Training and guidance for healthcare professionals are necessary to ensure all personnel have a good understanding of patients’ disfiguring conditions, and that there are adequate resources to recognise and address the psychosocial needs of patients.^{xxx}
- **Online platforms:** Guidelines and terms and conditions of various social media platforms should ensure a zero-tolerance approach in tackling abuse and bullying that targets people with disfigurements online, and complaints should be taken seriously, with decisive action taken against online bullying and abuse.^{xxxi}
- **Hate crimes:** Police and law enforcement agencies should invest in public information campaigns to increase awareness of disfigurement hate crime and on awareness as to how the UK Equality Act can protect people with disfigurements, and to ensure criminal justice personnel know how best to handle related complaints as they arise.^{xxxii}

- **Media portrayal:** The media's portrayal of people with disfigurements can heavily influence people's perceptions. Media regulators should adopt international media standards on disfigurement (e.g. regarding the use of language and editing), and on the portrayal of disfigurement in both print and broadcast media, so that the portrayal of disfigurement on media platforms is conducted sensitively in a way that is not offensive and so that complaints are handled effectively. ^{xxxiii}

6. What practical ‘protections’ are provided specifically in relation to employment, customers accessing goods and services, and citizens accessing government services?

1. Employment

The UK Equality Act protects a wide range of individuals in the employment, occupational, and vocational training contexts against **disability discrimination**, harassment and victimisation. It protects both job applicants and those "in employment" under a contract of employment, a contract of apprenticeship, or a contract personally to do work.^{xxxiv} This encompasses UK employees, UK employee shareholders, UK workers and a wider category of individuals who are self-employed, provided that they are "in employment" and that their contract obliges them to perform the work personally. However, for the purposes of this note, the terms “employer” and “employees” have been used.

Key protections provided by the UK Equality Act are:

Duty to make Reasonable Adjustments:

The UK Equality Act imposes a duty on employers to make reasonable adjustments to help disabled job applicants, employees and former employees^{xxxv}. The duty arises where a disabled person is placed at a substantial disadvantage by:

- a) A provision, criterion or practice (PCP);
- b) A physical feature of the employer’s premises; or
- c) An employer’s failure to provide an auxiliary aid.

An employer will not be obliged to make reasonable adjustments unless it knows or ought reasonably to know that the individual in question is disabled and likely to be placed at a substantial disadvantage because of their disability^{xxxvi}. Relevant factors an employment tribunal would consider when determining whether an adjustment would be reasonable for an employer to make include:

- a) whether taking any particular steps would be effective in either preventing or mitigating the substantial disadvantage;
- b) the practicability of the step;
- c) the financial and other costs of making the adjustment and the extent of any disruption caused;
- d) the extent of the employer’s financial or other resources;
- e) the availability to the employer of financial or other assistance to help make an adjustment (such as through the Government’s Access to Work^{xxxvii} scheme); or
- f) the type and size of the employer.

The Equality and Human Rights Commission’s Code (the “**ECHR Code**”)^{xxxviii} provides that the following might be reasonable adjustments for an employer to consider making:

1. A adjustment to premises, for example widening a doorway or providing a ramp or moving furniture for a wheelchair user.
2. Providing information in accessible formats, e.g. producing instructions and manuals in Braille or on audio tape.
3. Allocating duties to another worker. For example, a job involves occasionally going onto the open roof of a building, but the employer transfers this work away from an employee whose disability involves severe vertigo.
4. Altering hours of working or training. This could include allowing a disabled person to work flexible hours to enable them to have additional breaks to overcome fatigue arising from a disability, or permitting part-time working or different working hours to avoid the need to travel in the rush hour.

5. Giving, or arranging for, training or mentoring, for example, an employee who struggles with anxieties around public speaking or client facing duties might benefit from additional training or mentoring.
6. Acquiring or modifying equipment. An employer might have to provide special equipment (such as an adapted keyboard for someone with arthritis or a large screen for a visually impaired worker).
7. Providing a reader or interpreter. For example, a colleague reads mail to a person with a visual impairment at particular times during the working day. Alternatively, the employer might hire a reader.
8. Providing supervision or other support. This could include providing a support worker, arranging help from a colleague for someone whose disability leads to uncertainty or lack of confidence in unfamiliar situations, or a training course.

Direct Disability Discrimination

The UK Equality Act protects against an individual being treated less favourably than another person in a similar situation because of a disability^{xxxix}. An example of this would be where an employer rejects a job applicant with a severe facial disfigurement for a customer facing role.

Indirect Disability Discrimination

Indirect discrimination happens when an employer has a particular policy, practice or way of working (PCP) that has an adverse impact on disabled people compared to people who are not disabled^{xl}. This would be unlawful under the UK Equality Act unless the employer is able to objectively justify the PCP and demonstrate that it is a proportionate means of achieving a legitimate aim. An example would be a job advert which states that all applicants must have a driving licence. This puts some disabled people at a disadvantage because they may not have a licence because, for example, they have epilepsy or a severe disfigurement. If the advert is for a bus driver job, the requirement will be justified but that may not always be the case. The employer does not need to know about the disability in order to indirectly discriminate.

Discrimination arising from Disability

Section 15 of the UK Equality Act protects employees from being treated less favourably because of something connected to their disability, such as needing time off for medical appointments to manage a severe disfigurement. If the employer then used the employee's attendance as a criteria to select for redundancy then the employee could bring a discrimination arising from disability claim, unless the employer could objectively justify their approach.

Protection from Harassment

The UK Equality Act prohibits harassment related to a disability in the context of employment. Harassment for these purposes is where a person engages in unwanted conduct in respect of a disability which has the purpose or effect of violating another person's dignity or which creates an intimidating, hostile, humiliating or offensive environment. For the purposes of the UK Equality Act, anything done by an employee in the course of their employment is treated as having also been done by the employer^{xli}. The employer can be liable for harassment in these circumstances, whether or not the harassment is done with the employer's knowledge or approval.^{xlii}

The UK Equality Act also protects against harassment of an individual who is associated with a disability, even if they themselves are not disabled. For example, if an employee has a son with a severe disfigurement, the employee could have a claim for harassment related to disability if his work colleagues made offensive remarks to him about his son's disability.

Protection from Victimisation

Victimisation is when an employee is treated less favourably because they have raised a complaint of discrimination under the UK Equality Act, such as by raising a grievance or other complaint or lodging a complaint of disability discrimination with the UK Advisory, Conciliation and Arbitration Service (ACAS) or the UK Employment Tribunal.^{xliii}

Prohibition on pre-health questionnaires:

The UK Equality Act^{xliv} prohibits employers from asking recruits questions about their health, other than for certain prescribed reasons such as establishing whether any adjustments are required for an assessment process or whether they are able to meet the intrinsic requirements of the role. If questions related to a person's health are asked, the burden of proof will automatically shift to the employer where a job applicant brings a disability discrimination claim.

2. Customers accessing goods and services

Background

The law in the UK provides certain basic rights to all consumers of goods, facilities and services, however, a person who is "disabled", or who is "perceived to be disabled" for the purposes of the UK Equality Act, or who is associated with someone who is disabled, will also have other rights under the UK Equality Act which protect them against direct discrimination, indirect discrimination, discrimination arising from disability, disability harassment and victimisation when accessing goods and services or using certain facilities.

The UK Equality Act imposes these obligations on everyone concerned with the provision of services to the public at large, or to a section of the public, whether in the private, public or voluntary sectors. A wide range of services are covered by the UK Equality Act, including permitting access to and use of any place which members of the public are permitted to enter. Among the services covered (set out in Para 11.3 of the Equality Act 2010 Code of Practice - Services, Public Functions and Associations Statutory Code of Practice (the "**Equality Act Code**") are those provided by local authorities, such as toilet facilities; government departments and their agencies; some charities; voluntary organisations; hotels; restaurants; pubs; post offices; banks; building societies; solicitors; accountants; telecommunications organisations; public utilities (such as gas, electricity and water suppliers); services provided by bus and train operators, railway stations, airports; public parks; sports stadia; leisure centres; advice agencies; theatres; cinemas; hairdressers; shops; market stalls; petrol stations; telesales businesses; hospitals, and clinics.^{xlv} The UK Equality Act also imposes obligations on associations which have 25 or more members (see below).

The protections under the UK Equality Act apply whether or not a good or service is paid for.^{xlvi} In order to be protected by the UK Equality Act, a person must meet the UK Equality Act's definition of "disability", or be able to establish that any less favourable treatment or harassment encountered arises from a person's disability, or because a person is perceived to have a disability, for the purposes of the UK Equality Act.

However, the UK Equality Act does not require that service-providers should treat everybody in exactly the same way; in some circumstances a service-provider will need to provide services in a different way to meet the needs of disabled people so that they can receive the same standard of service as far as this is possible.^{xlvii} It is not unlawful under the UK Equality Act to treat a disabled person more favourably than a non-disabled person.^{xlviii}

Accessing goods and services

Part 3 of the UK Equality Act prohibits a person involved in the provision of services (a "service-provider"), from discriminating against a person requiring the service because of their disability by not providing the person with the service, by providing the service to that person on less favourable terms than are provided to other people, by terminating that service, or by subjecting a person to any other "detriment".^{xlix}

Part 7 of the UK Equality Act¹ imposes obligations on associations which have at least 25 members, where admission to membership is selective and regulated by the association's rules. According to guidance issued by the Government Equalities Officeⁱⁱ, examples of associations include private clubs such as golf and other sports clubs, ex-forces clubs, alumni clubs, social clubs, working men's clubs, gaming clubs and drinking clubs. Some charities also meet the definition of an association, for example, the Scout Association and Girlguiding UK. Such charities are also subject to additional provisions relating to the provision of charitable benefits. Political parties are also covered, and are subject to additional provisions dealing with the selection of election candidates. It is unlawful for a private club or other association to discriminate against, harass or victimise an existing or potential member or an associate (an associate is someone who is not a member but who has some or all of the rights of a member because they are a member of an affiliated private club). A club cannot refuse membership, or grant membership on less favourable terms (such as by applying different conditions or fees) because a person has a disability for purposes of the UK Equality Act.

Direct Discrimination^{lii}: Under the UK Equality Act, direct discrimination occurs if one person treats a person less favourably than they would treat others, because of a disability. Examples of treatment which may amount to direct discrimination^{liii} may include a restaurant insisting that a person cover up a visible impairment, so as not to make other customers feel uncomfortable.

Where the link between the impairment and the unfavourable treatment is less clear, it will be necessary to look at why the service-provider treated the service user less favourably to determine whether this was because of the person's impairment. An example might be where a restaurant insists that a person with a visible impairment sits in a separate area where there is no apparent reason to justify doing so.^{liv}

In most circumstances, direct discrimination requires that the service-provider's treatment is less favourable than the way the service-provider would treat another person who does not have a disability.^{lv}

Discrimination by Association: Direct discrimination can also apply under the UK Equality Act where a non-disabled person is treated unfairly *because of* the disability of another person, for example a family member or friend, who is disabled for purposes of the UK Equality Act.^{lvi}

Indirect Discrimination: an example of indirect discrimination occurs where a service-provider applies a practice equally to service-users, but that practice puts service-users with a disability at a particular disadvantage when compared with people who do not have that protected characteristic under the UK Equality Act. This treatment may amount to indirect discrimination under the UK Equality Act if the service-provider cannot show that the practice is justified as a proportionate means of achieving a legitimate aim.^{lvii}

Discrimination arising from a disability: The UK Equality Act says that treatment of a disabled person amounts to discrimination where a service-provider treats the disabled person "unfavourably" because of something arising as a consequence of the disabled person's disability, unless the service-provider can show that this treatment is a proportionate means of achieving a legitimate aim^{lviii}. It is not a breach of this provision of the UK Equality Act, however, if the service-provider does not know, and could not reasonably be expected to know, that the person has the disability.^{lix} For discrimination arising from disability to occur, a disabled person must have been treated 'unfavourably'. This means that the person must be put at a disadvantage.^{lx} Often the disadvantage will be obvious and it will be clear that the treatment has been unfavourable: for example, a person may have been denied a service or given a poorer service. Sometimes the unfavourable treatment may be less obvious. Even if a service-provider thinks that they are acting in the best interests of a disabled person, they may still treat that person unfavourably for the purposes of the UK Equality Act.

Protection from harassment^{lxi}: The UK Equality Act prohibits a service-provider from harassing a person to whom they are providing the service or who requires the services.^{lxii} Harassment occurs when a service-provider engages in unwanted conduct which is related to the person's disability and which has the purpose or the effect of violating the service user's dignity; or creating an intimidating, hostile, degrading, humiliating or offensive environment for the service user.^{lxiii}

Protection from Victimisation: the UK Equality Act provides protections where a person is treated unfairly because they have complained about discrimination encountered by themselves or another person, or stood up for discrimination rights.^{lxiv}

Aiding contraventions by others / Instructing, causing or inducing contraventions: Part 8 of the UK Equality Act sets out provisions which make persons liable for the acts of others in certain circumstances. In particular, the UK Equality Act makes it unlawful to knowingly help someone discriminate against, harass or victimise another person^{lxv}. A person who helps, causes or induces another to act in this way will be treated as having done the act of discrimination, harassment or victimisation themselves.^{lxvi}

Duty to make reasonable adjustments: service-providers also have an anticipatory duty to make “reasonable adjustments” for disabled people, so as not to put them at a “substantial disadvantage”^{lxvii}. Reasonable adjustments for this purpose could include taking reasonable steps to avoid a disadvantage, adopting a reasonable alternative method of providing a service or exercising a function or providing auxiliary aids. However, the UK Equality Act does place specific restrictions on the duty to make reasonable adjustments, for example, where such adjustment would fundamentally alter the nature of the service or of the service- provider’s trade or profession, or where it is out of their power to make such adjustment^{lxviii}.

Meeting obligations under the UK Equality Act

A service-provider will be liable for unlawful acts committed by their employees and agents (other than for criminal offences) unless they have taken reasonable steps to prevent such acts^{lxix}. According to the Equality Act Code, service-providers are more likely to be able to comply with their duties under the UK Equality Act and prevent their employees from discriminating against service users or customers if they take steps to create appropriate policies and communicate them to staff and implement training, monitoring and grievance and complaints procedures.^{lxx}

Contractual terms:

The UK Equality Act prevents service-providers from avoiding their responsibilities under the UK Equality Act by seeking to enter into agreements which permit them to discriminate. The UK Equality Act contains further protections enabling parties to enforce, modify or treat as void contractual terms which are discriminatory^{lxxi}.

Enforcement:

A person who believes that a service-provider has committed an unlawful act against them may bring civil proceedings in the county court in England and Wales and the sheriff court in Scotland^{lxxii}. Court action must be commenced within six months (minus a day) of the alleged unlawful act. The UK Equality Act recognises that where conduct extends over a period it should be treated as being done at the end of that period for the purposes of calculating when the act of discrimination occurred. Where a claim is brought outside the time limits referred to above, the courts have discretion to hear the case if satisfied that it is just and equitable to do so.^{lxxiii}

Hate incidents/hate crime^{lxxiv}

Additional protections apply if a person is a victim of a disability hate incident or a disability hate crime. Something is a disability hate incident if the victim or anyone else *thinks* it was carried out because of hostility or prejudice against disabled people. Examples of disability hate incidents include verbal and physical abuse, teasing, threatening behaviour, online abuse, and damage to property; whether or not as a one-off incident. When hate incidents become criminal offences they are known as hate crimes. A criminal offence can be a hate crime if it was carried out because of hostility or prejudice based on disability. When a criminal offence is classified as a hate crime, the judge has powers to impose a tougher sentence on the offender under the Criminal Justice Act 2003.

3. Citizens accessing government services

Background

As noted above, the UK Equality Act imposes these obligations on everyone concerned with the provision of “services”. Among the services that are covered are those provided by government departments and their agencies.^{lxxv} In practice, the duties under the UK Equality Act imposed on persons providing a “service” and on those exercising public functions are essentially the same.^{lxxvi}

Citizens accessing government services

As noted above, Part 3 of the UK Equality Act prohibits a person involved in the provision of “services” (a “service-provider”), from discriminating against a person requiring the service because of their disability by not providing the person with the “service”, by providing the service to that person on less favourable terms than are provided to other people, by terminating that service, or by subjecting a person to any other “detriment”.

Reference should also be made to the sections above concerning:

- Direct discrimination; and
- Indirect discrimination, and how these apply to the provision of government “services”. In particular:

Indirect Discrimination

A significant factor in determining whether a public authority is able to justify what may be *indirect discrimination* is the extent to which the authority has complied with their public sector duties. For example, the government department would need to pay due regard to the positive duty to eliminate unlawful race discrimination and to promote equality of opportunity and good race relations. If the government department has not properly carried out these duties, it will be more difficult for it to justify the criteria.^{lxxvii}

Discrimination arising from a disability:

As noted above, the UK Equality Act says that treatment of a disabled person amounts to discrimination where a service-provider treats the disabled person “unfavourably” because of something arising in consequence of the disabled person’s disability, unless it can be objectively justified, or unless the service-provider did not know or could not reasonably have been expected to know that the person was disabled^{lxxviii}. For example, the provision of the Services, Public Functions and Associations Statutory Code cites an example where a member of staff at Jobcentre Plus refused to interview a member of the public who wished to complete an application for Jobseeker’s Allowance because he was swearing. However, his swearing was a result of him having Tourette syndrome. The refusal to interview is unfavourable treatment, which is because of something that arises in consequence of the disabled person’s disability.^{lxxix}

Reference should also be made to the provisions discussed in the section on customers accessing goods and services above concerning the descriptions of:

- Protection from harassment;
- Protection from Victimisation;
- Aiding contraventions by others/instructing, causing or inducing contraventions;
- Duty to make reasonable adjustments; and
- Meeting obligations under the UK Equality Act.

General public sector equality duty (PSED)

In addition to the above, section 149 of the UK Equality Act also includes a single general public sector equality duty (“PSED”), which applies to “public authorities” exercising “public functions”. The PSED requires public authorities to have “due regard” to the need to:

- eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by the UK Equality Act;
- advance equality of opportunity between persons who share a relevant protected characteristic (eg disability) and persons who do not share it;
- foster good relations between persons who share a relevant protected characteristic (eg disability) and persons who do not share it.

The “public authorities” who are subject to the PSED are set out in Schedule 19 to the UK Equality Act. These fall under the headings:

- Ministers of the Crown and government departments;
- Armed forces;
- Broadcasting (i.e. the BBC, Channel Four Television Corporation and The Welsh Authority);
- Citizens’ rights (i.e. The Independent Monitoring Authority for the Citizens’ Rights Agreements);

- Civil liberties (i.e. The Commission for Equality and Human Rights and The Information Commissioner);
- Court services and legal services;
- Criminal justice;
- Environment, housing and development (i.e. The Homes and Communities Agency and Natural England);
- Health, social care and social security (e.g. the NHS);
- Industry, business, finance (e.g. the Bank of England, the Civil Aviation Authority and the Financial Conduct Authority);
- Local government;
- Other educational bodies;
- Parliamentary and devolved bodies;
- Police;
- Regulators (e.g. The Institute of Chartered Accountants in England and Wales, The Law Society of England and Wales and the Pensions Regulator); and
- Transport (e.g. Network Rail Limited).

The PSED applies to “public authorities” exercising “public functions”, where the “public functions” may include:

- determining frameworks for entitlement to benefits or services;
- law enforcement;
- receiving someone into a prison or immigration detention facility;
- planning control;
- licensing;
- enforcement of parking controls, trading standards;
- exercise of statutory powers under mental health and children legislation;
- regulatory functions; and
- the investigation of complaints.

Whether an activity is a “service” to the public or a “public function” will depend on the circumstances. Many activities that a public authority carries out are “services” to the public – for example, the provision of social care, library or leisure services. Accordingly, activities such as these will be subject to the provisions of the UK Equality Act relating to the provision of a “service”.

Exclusions

The UK Equality Act excludes certain types of functions and certain “public authorities” from the prohibition of discrimination, harassment and victimisation in the exercise of “public functions”. For example, the UK Equality Act excludes the Security Service, the Secret Intelligence Service and the Government Communications Headquarters from the prohibition of discrimination, harassment and victimisation.

Enforcement

Section 156 of the UK Equality Act provides that a failure in respect of the performance of a duty imposed under Chapter 11 of the UK Equality Act does not confer a cause of action at private law. Legal proceedings may only be brought by the Equality & Human Rights Commission (“EHRC”).

Americans with Disabilities Act 1990

Introduction

The Americans with Disabilities Act was signed into law on 26 July 1990. The Americans with Disabilities Act was subsequently amended pursuant to the American with Disabilities Act Amendments Act of 2008 (the “**ADAAA**” and together with the Americans with Disabilities Act, the **ADA**), became effective on 1 January 2009.^{lxxx} The ADAAA made a number of significant changes to the definition of disability under the Act^{lxxxi} following rulings made by lower courts and the Supreme Court, which began to narrow the definition of disability under the Act. The signing of the ADAAA into law effectively overturned such Supreme Court cases.^{lxxxii}

The ADA is split into five sections called titles. Each title prohibits discrimination on the basis of disability in a specific area and each title is overseen by a particular agency or organisation. Title I covers employment. Title II covers state and local government activities and public transportation. Title III covers public accommodations, Title IV covers telecommunications and Title V has several miscellaneous provisions that cover matters such as retaliation against employees and attorney fees – these miscellaneous provisions will not be addressed in detail within this report.^{lxxxiii}

1. Are persons with facial disfigurements protected on the grounds that facial disfigurement is a disability?

Persons with facial disfigurements can be protected under the ADA where (i) their facial disfigurement qualifies as a 'disability' within the meaning of the ADA and where (ii) they meet the specific conditions for the protection laid down in the relevant ADA Title.

Disfigurement as a potential 'disability' under the ADA

To seek protection under the ADA, a person must have a disability, or have a relationship or association with an individual with a disability. An example of a person who has a relationship or association with an individual with a disability is a carer (who does not have a disability) looking after a person who has a disability.^{lxxxiv}

The ADA defines an individual with a disability as any one of the following^{lxxxv}:

(a) a person who has a physical or mental impairment that substantially limits one or more major life activity (prong 1).

The ADA does not specifically name all of the impairments that are covered. It was however clarified in various communications, such as the Interpretive Guidance on Title 1 of the Americans with Disabilities Act (the "**Guidance**")^{lxxxvi} that an impairment under the ADA includes a physiological disorder or condition, cosmetic disfigurement or anatomical loss affecting one or more of the body systems (neurological, musculoskeletal, special sense organs, respiratory, including speech organs, cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin, and endocrine) or any mental or psychological disorder.^{lxxxvii}

Major life activities are functions that are crucial to most people's daily lives. These can include breathing, walking, talking, hearing, seeing, sleeping, caring for one's self, performing manual tasks and working. "*Major life activities*" can also be extended to include major bodily functions such as immune system functions, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions; or

(b) a person who has a history or record of such an impairment, even if they do not currently have a disability (prong 2). Record of a disability means that the person has a history or has been misclassified as having, a mental or physical impairment that substantially limits one or more major life activities even though the person does not currently have a disability; or

(c) a person being regarded as having such an impairment, whether or not the impairment limits or is perceived to limit a major life activity (prong 3). This covers situations where (i) the person has an impairment that does not substantially limit a major life activity, (ii) the person has an impairment that substantially limits a major life activity only as a result of the attitudes of others toward them or (iii) the person does not have any impairment but is treated as having an impairment by others, including individuals and/or organisations. Impairments that are both transitory and minor are however not included. The ADA defines a 'transitory impairment' as an impairment with an actual or expected duration of 6 months or less.^{lxxxviii}

The concept of 'minor' impairment is however not defined and is subject to a case-by-case assessment, which can take into account various factors such as the symptoms and severity of the impairment, the type of treatment required, the risk involved, whether any kind of surgical intervention is anticipated or necessary or the nature and scope of any postoperative care.^{lxxxix} Examples of conditions that were considered to be both

transitory and minor include a broken finger, broken bones that healed within two months or injuries from a car accident that were recovered within a week.^{xc} The 2008 House Judiciary Committee Report also clarified that the exception relating to 'transitory and minor' impairments was introduced to exclude "***common ailments like the cold or flu***".^{xc} Since the exclusion only covers impairments that are both transitory and minor, an individual with a permanent face disfigurement (or one that lasts more than 6 months) could benefit from the protection, regardless of whether his/her disfigurement is considered 'minor'.

The EEOC also gives the example of an individual with a severe facial disfigurement who is excluded from staff meetings because the employer does not like to look at the employee or of an experienced assistant manager of a convenience store, with a prominent facial scar, who was passed over for promotion to store manager, because the employer believed that customers or vendors would not want to look at this person.

The third prong may be particularly relevant for people with facial disfigurement, who are not substantially limited in major life activities. It is worth noting that the ADAAA broadened the scope of the definition of individuals "regarded as" disabled. It superseded previous US Supreme Court rulings that had made it particularly difficult for plaintiffs to seek protection under the third prong.^{xcii} The US Supreme Court had notably ruled that a claimant was required to prove not only that a given entity believed she/he had an impairment, but also that this entity considered that this impairment substantially limited a major life activity. This very high standard led, for instance, to the dismissal of an action brought by an individual with facial palsy on the ground that he had failed to demonstrate that his employer regarded his palsy as a condition substantially affecting the major life activity of work.^{xciii} Under the revised version of the ADA, individuals now only need to show that they are "regarded as" having an impairment, regardless of whether the impairment is perceived to limit a major life activity or perceived to be substantially limiting. Reports have shown that the ADAAA significantly improved the success rates of claimants in establishing a disability under the ADA.^{xciv}

Based on the above description of how the ADA captures a person with disability, it is therefore possible for a person with facial disfigurement to be considered a person with disability and to fall within the scope of protection of the ADA. A facial disfigurement may be an actual disability, for instance where it affects an individual's ability to see, speak or hear (prongs 1 and 2) or be deemed to be a disability only based on the perception of others (prong 3).

2. Are persons with facial disfigurements protected on other grounds?

The ADA specifically prohibits discrimination on the basis of disability.

“in enacting the Americans with Disabilities Act of 1990 (ADA), Congress intended that the Act “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities”^{xv}.

Persons with facial disfigurements will hence be protected under the ADA on the ground that they have an actual or perceived disability as discussed in question 1 above and, with regards to Title IV of the ADA, where their facial disfigurement generates a hearing or speech impairment:

- **Employment (Title I):** *“No covered entity shall discriminate against a **qualified individual on the basis of disability** in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment”^{xvii};*
- **Public services (Title II):** *“Subject to the provisions of this subchapter, no **qualified individual with a disability** shall, **by reason of such disability**, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity”^{xviii};*
- **Public accommodations and services operated by private entities (Title III):** *“No individual shall be discriminated against **on the basis of disability** in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation”^{xix}; and*
- **Telecommunications (Title IV):** *“In order to carry out the purposes established under section 151 of this title, to make available to all individuals in the United States a rapid, efficient nationwide communication service, and to increase the utility of the telephone system of the Nation, the Commission shall ensure that interstate and intrastate telecommunications relay services are available, to the extent possible and in the most efficient manner, to **hearing-impaired and speech-impaired individuals** in the United States”^{xx}.*

Titles I, II and III of the ADA also protect individuals, who do not have a disability, but who have a relationship or association with an individual with a disability, against discrimination (sometimes referred as “association discrimination”).^c

Title I prohibits excluding or otherwise denying access to jobs or benefits to a qualified individual *“because of the known disability of an individual with whom the qualified individual is known to have a relationship or association”*.^{ci}

In its Guidance, the EEOC clarified that this protection is not limited to those who have a familial relationship with an individual with a disability.

Association discrimination under Title I covers three themes^{cii}:

- expense: when an employer takes an adverse action against an employee because of the costs potentially related to the individual with a disability, e.g. an employer reduces the level of health insurance benefits to an employee simply because that employee has a dependent with a disability;
- disability by association: when an employer fears that the employee may contract the associate’s disability or is genetically predisposed to developing the disability. The EEOC gives the example of an employer who discharges an employee because the employee does volunteer work with people who have AIDS, and the employer fears that the employee may contract the disease;
- distraction: when an employer fears that an employee will be inattentive at work or will need leave to care for their associate. For instance, this would be the case where an employer declines to hire an applicant,

whose spouse has a disability, because the employer believes that the applicant would have to miss work or frequently leave work early in order to care for his/her spouse.

Title II does not contain a specific provision prohibiting association discrimination. However, it provides in its enforcement section a remedy to *“any person”* alleging discrimination on the basis of disability^{cii}.

Title III prohibits excluding or otherwise denying equal goods, services, facilities, privileges, advantages, accommodations, or other opportunities to an individual or entity *“because of the known disability of an individual with whom the individual or entity is known to have a relationship or association”*^{civ}.

3. Must/should persons with facial disfigurements describe themselves as disabled in order to exercise their rights?

Persons with facial disfigurements do not have to describe themselves as disabled in order to exercise their rights under the ADA.

They can seek protection under the ADA on the ground that they are only “regarded” as having an impairment (see prong 3 as set out in question 1 above).

The US Supreme Court noted that Congress specifically included the third prong in the ADA’s definition of disability in order to protect people who are subject to discriminatory treatment based on society’s accumulated myths, fears and stereotypes about disability, which are in practice as limiting as the physical limitations that flow from actual impairment.^{cv}

4. What practical ‘protections’ are provided specifically in relation to employment, customers accessing goods and services, and citizens accessing government services?

Introduction

A person who meets the definition of disability under the ADA may not have rights under particular Titles of the ADA - in order to be protected, a person with a disability will have to prove that the conditions for the protection provided for by the relevant Title of the ADA are met. Titles I, II and III of the ADA provide protections in the areas of employment, government services, and services provided by private entities to those with disabilities. The ADA works to provide a clear and enforceable national mandate to ensure that the rights of those with disabilities are protected, and discrimination against individuals with disabilities is restricted.^{cvii}

Title I: Employment protections^{cvi}

The ADA provides, as a general rule^{cvi}, that no employers, employment agencies, labour organisations or joint labour-management committees shall discriminate against a qualified individual on the basis of disability. Qualified individuals who receive protections under the ADA include individuals who, with or without reasonable accommodations, can perform the essential functions of a given position. When deciding the essential functions of a role, consideration is given to the employer’s judgement, as well as written job descriptions. This rule covers the process from application, hiring, advancement, discharge, compensation, training and other privileges of employment.

Reasonable accommodations are modifications or adjustments in the work environment or in the way things are done that enable an individual with a disability to enjoy equal employment opportunities, whether during the application process or during the performance of the job.^{cix}

Employers that are required to comply with the ADA are those engaged in an industry affecting commerce who have 15 or more employees for each working day in each of 20 or more calendar weeks in the current or previous calendar year. Employers do not include a corporation wholly owned by the government of the US or an Indian Tribe or a bona fide private members club exempt from taxation.^{cx}

Examples of discrimination against a qualified individual given within the ADA include^{cx}:

1. Limiting, segregating or classifying an individual due to their disability in a way that negatively affects their opportunities or status.
2. Entering into a contract or arrangement that has the effect of subjecting a qualified individual to discrimination that is prohibited under the ADA e.g. through engaging sub-contractors, or a labour union or benefits provider that discriminates on the basis of disability.
3. Adopting standards, a criteria or administrative system that discriminates on the basis of disability, or facilitates the discrimination of others.
4. Allowing an employee’s job or benefits to be dictated by their disability rather than their qualifications.
5. Failing to make reasonable accommodations to known limitations of an otherwise qualified individual unless the accommodation would cause undue hardship for the business, or denying a qualified employee a job to avoid the need to make accommodations.
6. Imposing criteria when selecting employees that are hard for people with disabilities to meet, for example, qualification standards. The only exception to this is if the criteria required for the position are a necessity for the business.
7. Failing to ensure that sensory, manual or speaking skills do not impede test results and that such results accurately reflect the skills and aptitude of the employee.

Employer's rights to require medical examination and information surrounding the nature of disability^{cxii}:

- Employers are not allowed to conduct medical examinations or ask an employee if they have a disability. Employers cannot enquire as to the nature or severity of a disability. However, an employer can ask a potential employee about their ability to perform a role and job-related functions.
- An employer can ask an employee to complete a medical examination, but only after an offer of employment has been made and before an employee commences the role. An offer of employment can be made conditional upon the results of such an examination if:
 - a) All new employees have to take the medical exam.
 - b) All medical information and medical history collected is maintained in a separate confidential medical file with access limited to the following:
 - a. supervisors and managers may be informed of necessary restrictions relevant to the role;
 - b. first aid and safety personnel may be informed to ensure the employee is safe within the workplace; and
 - c. government officials investigating compliance with the ADA.

Defences for employers against a charge of discrimination:

- It may be a defence for an employer against the allegation that requirements for qualification standards, tests, or selection criteria screen out individuals with disabilities if these criteria have been shown to be related to the role and are consistent with what the business requires, and such performance could not be achieved through providing reasonable accommodations.
- Qualification standards include a requirement that an employee does not pose a health and safety threat to other individuals in the workplace.
- Religious corporations, associations, educational institutions or societies can give preference to individuals of that religion. Further, the ADA allows religious organisations to require that all applicants and employees conform to the beliefs of the organisation.

Illegal use of drugs and alcohol:

Rights and protections under the ADA do not extend to any employee or applicant currently engaging in the illegal use of drugs when the employer acts on the basis of such use. However, an individual with a disability will not be excluded from the ADA if they have successfully rehabilitated and are no longer engaging in the use of illegal drugs, or the employee is regarded as using illegal drugs in error. Employers are permitted to impose reasonable policies or procedures e.g. drugs testing to ensure an individual is no longer engaging.

Employers may prohibit the use of illegal drugs and alcohol in the workplace, and require that employees are not under the influence of alcohol. Under the ADA a drugs test shall not be considered a medical examination.

Posting notices:

All employees must post notices in an accessible format to applicants, employees and members explaining the applicable provisions of the ADA.

Title II: Accessing government services

Title II (state and local government activities) of the ADA is implemented by the Department of Justice (**Title II – State and Local Government**)^{cxiii}. The Attorney General published the regulations implementing Title II – State and Local Government in 2010.^{cxiv}

The aim of Title II – State and Local Government is to ensure that a person with a disability under the ADA has equal access to civic life and must be provided with an equal opportunity to benefit from all of their programmes, services,

and activities (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

The ADA prevents a qualified individual from being excluded from participating or benefitting from a service, program or activity of a public entity, or from being discriminated against due to their disability. Public entity is widely defined in the ADA to include any state or local government, department, agency, special purpose district, or other instrument of a state. Qualified individuals who receive protections under the ADA include individuals who with or without reasonable accommodations can perform the essential functions of a given position.^{cxv}

State and local governments are required to follow specific architectural standards in the new construction and alteration of their buildings. They also must relocate programmes or otherwise provide access in inaccessible older buildings, and communicate effectively with people who have hearing, vision, or speech disabilities. Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, programme, or activity being provided.

Public transport protections under the ADA^{cxvi}:

Title II (public transportation) of the ADA covers public transportation, it is implemented by the Federal Transit Administration (**FTA**) which published specific guidance in 2015 providing practical steps and guidance to ensure compliance.^{cxvii}

The ADA applies to all public transport with the exclusion of aircraft, intercity or commuter rail and public school transportation.^{cxviii} It is deemed discrimination under the ADA to fail to provide vehicles that are not readily accessible and usable by those with disabilities, unless evidence can be provided to demonstrate that good faith efforts have been made to obtain such vehicles, or vehicles are excluded due to their historic characteristics. Additionally, it is considered discrimination for a public entity operating a fixed route, commuter rail transportation or services provided by the National Railroad Passenger Corporation to not provide services that accommodate individuals with disabilities, when providing a comparable service to those without disabilities in terms of response and timing.^{cxix}

When public entities purchase new vehicles they must be accessible unless unavailable from manufacturers, however, any exemption must be limited by a specified date. All new facilities built to provide public transport must have a clear path to accessible bathrooms, telephones, drinking fountains and general areas accessible to those with disabilities. Existing key stations must also be altered to make them accessible and suitable to the needs of people with disabilities.^{cxx} There is a time-based exemption to the requirement to make facilities accessible if this would require structural changes.^{cxxi}

Title III: Services operated by private entities

Title III (public accommodation) of the ADA is implemented by the Department of Justice. The Attorney General published the regulations implementing Title III in 2010.

Title III applies to the following private entities:^{cxxii}

- a. Inn, hotel, place of lodging (except establishments within buildings containing five rooms or less that is also the residence of the owner);
- b. Restaurants, bars or other establishments serving food or drink;
- c. Motion picture house, theatre, concert hall, stadium or place of exhibition entertainment;
- d. Auditorium, convention centre, lecture hall, or other place of public gathering;
- e. A bakery, grocery store, clothing store, hardware store, shopping centre or other sales or rental establishment;

- f. Laundromat, dry-cleaner, bank, barber shop, beauty shop, travel service, shoe repair service, funeral parlour, gas station, office of accountant or lawyer, pharmacy, insurance office, professional office of health care provider, hospital, or other service establishment;
- g. Terminal, depot or other station used for specified public transportation;
- h. Museum, library, gallery, or other place of public display or collection;
- i. Park, zoo, amusement park, or other place of recreation;
- j. Nursery, elementary, secondary, undergraduate, or postgraduate private school, or other place of education;
- k. Day care centre, senior citizen centre, homeless shelter, food bank, adoption agency, or other social service centre establishment; and
- l. Gymnasium, health spa, bowling alley, golf course, or other place of exercise or recreation.

As a general rule, the ADA prohibits discrimination on the basis of disability preventing the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any of the entities listed above.^{cxxiii} These shall be provided to individuals with disabilities in the most appropriate setting to suit the needs of that individual. Further to this, the ADA makes clear that an individual with a disability shall not be denied the chance to participate in the above programmes or activities on equal grounds to those without a disability.^{cxxiv}

The above entities and associated third parties must ensure that standards, criteria or administrative methods do not have a discriminatory effect or perpetuate discrimination against those with disabilities. Additionally, those with disabilities must not be denied equal goods, services, facilities, privileges, advantages, accommodation, or other opportunities available to an individual due to a disability.

The ADA specifies that discrimination relating to the above list of organisations includes adopting criteria that would have the impact of screening out individuals with disabilities from fully enjoying any goods, services, facilities, privileges, advantages, or accommodations unless the criteria is necessary to provide such services. Failure to make reasonable modifications, and take steps to ensure that those with disabilities are not excluded, segregated, denied services or treated differently is also discriminatory, unless an entity can demonstrate that such modifications would fundamentally alter the nature of the good, services, facilities, privileges, advantages or accommodations they supply.

For the organisations listed above there is a requirement for all shopping centres, malls or professional offices of a health care provider, and all organisations with more than three stories each with more than 3,000 square foot per storey to install an elevator to assist those with disabilities.

The ADA also provides that private entities providing public transportation services must not discriminate on the basis of disability. Eligibility criteria must not be adopted that tends to screen out individuals with disabilities, and reasonable modification (including the removal of barriers) and auxiliary aids must be provided to accommodate those with disabilities in using the service. Any purchase, lease or modification of a vehicle with a seating capacity of 8 or more passengers inclusive of the driver must accommodate those with disabilities, with the exception of historical vehicles where remanufacture would significantly alter the historic character.

It would be considered discrimination under Section 304 of the ADA if a new vehicle with a seating capacity of 8 or more passengers was purchased or leased in order to provide specified public transportation that is not accessible and usable by those with disabilities. There is an exception to this requirement if the vehicle is intended to be used solely in a demand responsive system, and the level of service provided to those with disabilities can be shown to be equivalent to the level of service provided to the general public.

Private clubs or establishment are exempt from coverage under Title II of the Civil Rights Act of 1964 and religious organizations including places of worship are not required to comply with the ADA.^{cxxv} A clear definition of Private establishments has not been provided by the courts, however, the Supreme Court decision in *Wright v. Cork Club*^{cxxvi} indicates that private clubs are non-profit, member owned and controlled and operate a selective membership system, and examples may include sororities and fraternities.^{cxxvii}

Telecommunications (Title IV)

Title IV (Telecommunications) of the ADA addresses telephone and television access for people with hearing and speech disabilities. It requires common carriers (telephone companies) to establish interstate and intrastate telecommunications relay services (**TRS**) 24 hours a day, 7 days a week. TRS enables callers with hearing and speech disabilities who use text telephones (**TTYs**) (also known as telecommunication devices for deaf persons (**TDDs**)), and callers who use voice telephones to communicate with each other through a third party communications assistant. Title IV is overseen by the Federal Communications Commission (**FCC**), which has set minimum standards for TRS services.

A person with speech disabilities due to facial disfigurement should be able to assert their rights in accordance with the provisions under Title IV of the ADA.

Enforcement and remedies available under the ADA

The remedies and rights to enforcement under the ADA are documented under section 42 of the United States Code § 2000e – 4 to 2000e - 9. Section 42 of the United States Code of Federal Regulations “the **United States Code**” details public health, social welfare and civil rights.

An Equal Employment Opportunity Commission (“the **ADA Commission**”) has been created to handle complaints and breaches under the ADA. Under § 2000e – 5 of the United States Code, whenever a charge is filed by or on behalf of an aggrieved individual, a member of the ADA Commission shall serve a notice of charge, and make investigations.^{cxxviii}

Charges are investigated under State or local law and these findings guide the ADA Commission’s investigations. If there is reasonable cause to believe that a charge is true, the ADA Commission will endeavour to eliminate such unlawful employment practice through informal conference, conciliation and persuasion. The process can largely be guided by the aggrieved party from this stage, dependent on the outcome they are seeking. This information will not be made public without the written consent of the persons concerned. Alternatively, the ADA Commission may provide the aggrieved party with a right-to-sue letter; the individual can then provide this to the party committing the wrongdoing under the ADA and pursue their own case.

The ADA Commission must make a determination as to whether a claim has reasonable cause within 120 days from the filing of the charge. If the alleged unlawful employment practice occurs in a state where local state law prohibits such practices, relief may be sought under the relevant state laws, or criminal proceedings initiated.^{cxxix}

The Attorney General also has the right to bring a civil action in the appropriate district court of the United States including an application for an injunction where there is reasonable cause to believe the full rights of an individual under the ADA are not being observed.^{cxxx} A successful injunction will obligate the person or organisation violating the ADA to rectify their actions, and ensure compliance with the protections provided.

The ADA also confers on the ADA Commission the investigatory powers they require to access evidence to facilitate this process^{cxxxi} and powers to facilitate the collection of documentary evidence through summoning witnesses and taking testimony in order to prove violations of the ADA.^{cxxxii}

5. What are the gaps in protection?

What are the gaps in the provision of ‘reasonable accommodations’?

As detailed in section 1 above, The ADA definition of disability distinguishes between (1) persons who have a physical or mental impairment that substantially limits one or more major life activity, (2) persons who historically had such an impairment, and (3) those persons who are ‘regarded as’ having such an impairment by others. The distinguishing of impairment includes differences in the scope of accommodation that is required to be provided under the ADA with individuals with impairments that fall within the ‘regarded as’ or ‘historic limbs’ having no reasonable accommodation rights. For example, a plaintiff who had surgical treatment for a cleft palate requested accommodation from her employer to take into account frequent illness (sinus infections) associated with cleft palate. The court held that the plaintiff was not entitled to reasonable accommodation on the basis that (1) she could not prove any impairment to her life, and (2) her injuries were ‘invisible to the lay observer’ on account of her surgery.^{cxxxiii}

Moreover, assuming a person with a facial disfigurement could meet the first prong definition of disabled and thus, could be entitled to a reasonable accommodation, the threshold to demonstrate impairment that qualifies a person to reasonable accommodation is high. For example, an Alabama federal court dismissed a plaintiff’s claim for reasonable accommodation under the ADA because the plaintiff did not plausibly allege a disability substantially limiting his major life activity (working). Quoting from a Florida case, the court held that *“To show that a disability affects the major life activity of working, a plaintiff must demonstrate that the disability precluded him or her from working in a “class of jobs” or a “broad range of jobs.”*^{cxxxiv} Because the plaintiff was unable to demonstrate that his facial deformity precluded him from performing a broad range of jobs, the court held that he did not have a disability substantially limiting his major life activity of working, and therefore was not entitled to any accommodation.^{cxxxv}

Application (i.e. case law) of the Act?

To date, very few cases have been brought under the ADA that relate to facial disfigurement. The focus of most of those cases has been the causative factor of the facial disfigurement (eg. cellulitis, psoriasis, cleft palate) in order to categorise it as a disability for the purposes of the ADA,^{cxxxvi} rather than being “regarded as” having a disability. A plaintiff’s case has a far greater chance of success under the ADA if they can point to the recognizable disability that they suffer from, and the way in which they are qualified for protection under the ADA.

Differences in the application of the ADA between states

States may expand protections beyond those provided by the ADA. For example, in California, “cosmetic disfigurements” are specifically included in the definition of physical disability. New York State Human Rights Legislation has also been expanded to include genetic conditions. This means that, in both California and New York, the scope of protections has been broadened beyond those specifically enumerated in the ADA.^{cxxxvii} The ADA is far less inclusive in its definitions, partially due to its lack of amendments over the last decade. Before the ADA’s last amendment in 2008, the ADA would not cover for example a facial scar if it did not actually impair the individual’s major life functions. Offering a static category of discrimination on the basis of cosmetic disfigurements, as in California, would protect individuals with facial deformities more comprehensively, making cases more successful when the disability is not one which features a major impairment.

6. What legal/regulatory reforms are needed if people are to seek protection (either on the grounds that facial disfigurement is a disability, or on other grounds)?

Legal Reforms

While the ADA offers varying levels of protection for people with facial disfigurements, a protection likely to be helpful to those with facial disfigurements – a reasonable accommodation – requires a high threshold in order to be available. Additionally, because protections for people with facial disfigurements are contained within the ADA, there is a focus in the courts on the causative factor of facial disfigurement i.e. to establish facial disfigurement as a ‘disability’ for the purposes of bringing it within scope of the ADA.

One possible reform that would remove the requirement to establish facial disfigurement as a disability and associated threshold requirements is the re-working of the ADA into language more reminiscent of the EEOC’s Coverage under Civil Rights Act of 1964. For example:

*“(h) Physical or mental impairment means—
(1) Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more body systems, such as neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, immune, circulatory, hemic, lymphatic, skin, and endocrine; or
(2) Any mental or psychological disorder, such as an intellectual disability (formerly termed “mental retardation”), organic brain syndrome, emotional or mental illness, and specific learning disabilities.”^{cxviii}*

Another possible reform would be to allow reasonable accommodation for prong 3 impairments (as discussed above). This would enable plaintiffs to engage in the process of determining necessary reasonable accommodations with their employer, coming to an appropriate resolution. There may be scenarios where this remedy is ineffective, or the relationship between parties has degraded due to discrimination, to the point that engaging in the accommodations process is unproductive. However, this is an avenue offered under other prongs of the ADA, and it would make sense to expand this area.^{cxvix}

Further to the above, several states have expanded protections beyond those provided by the ADA. Groups interested in expanding the rights and protections to those with facial disfigurements may consider grassroots, state-based reform options, such as advocating for further legislation and advocating for agencies designed to assist those with disabilities or disfigurements.

Examples of other possible reforms include:

- **Workplace and schools:** Guidance, training or support to ensure that people with disfigurements are informed and confident about their own legal rights. Providing guidance on how to deal with disfigurement in recruitment processes and during teaching for employers and teachers respectively. Policies and practices in workplaces and schools should also be monitored regularly to ensure compliance with the ADA and state level legislation, such that people with disfigurement can enjoy a safe environment free of prejudice and harassment.
- **Healthcare industry:** Training and guidance for healthcare professionals is necessary to ensure all personnel have a good understanding of patients’ disfiguring conditions, and that there are adequate resources to recognise and address the psychosocial needs of patients.
- **Online platforms:** Guidelines and terms of conditions of various social media platforms should ensure a zero-tolerance approach in tackling abuse and bullying that targets people with

disfigurements online. Complaints should be taken seriously, with decisive action taken against online bullying and abuse.

- **Hate crimes:** Police and law enforcement agencies should invest in public information campaigns to increase awareness of disfigurement hate crime and awareness on how the ADA and state level legislation can protect people with disfigurements - whilst ensuring that criminal justice personnel are capable of handling related complaints as they arise.
- **Media portrayal:** The media's portrayal of people with disfigurements, including facial disfigurements can heavily influence people's perception. Media regulators should take steps to adopt international media standards on disfigurement (e.g. regarding the use of language and editing) on the portrayal of disfigurement in both print and broadcast media. This would ensure that the portrayal of disfigurement on media platforms would be conducted sensitively and non-offensively and that complaints would be handled effectively.

EU Charter of Fundamental Rights 2000

Introduction

Generally, the fundamental values of the European Union (“EU”) are based on the indivisible, universal values of human dignity, freedom, equality and solidarity together with the principles of democracy and the rule of law. The EU focuses on the individual rights of its citizens by creating “*an area of freedom, security and justice*”. It seeks to promote balanced and sustainable development as well as to ensure free movement of persons, services, goods and capital, along with the freedom of establishment. The European Union Charter of Fundamental Rights (the “**EU Charter**”)^{cxl}, was created in 2000, but only obtained legal status and came into effect when incorporated into the Treaty of Lisbon on 1 December 2009. Article 6(1) of the Treaty on the European Union (the “**TEU**”) provides that “[t]he Union recognises the rights, freedoms and principles set out in the Charter of Fundamental Rights of the European Union [...], which shall have the same legal value as the Treaties”.^{cxli} The EU Charter sets out the basic rights that must be respected both by the EU and by its member states (“**Member States**”), which are all bound by the EU Charter through the doctrine of the supremacy of EU law, when implementing EU law nationally and across the EU.

The EU Charter is binding on the 27 EU Member States, such that any national laws that contravene the EU Charter will be held invalid by the relevant nation’s courts, and any EU Law that contravenes the EU Charter will be held to be invalid by the CJEU.

Any person (regardless of their nationality) may apply to the relevant courts for a declaration that a particular law is in contravention of the EU Charter. The particular law however would need to be one enacted by a Member State, or by the EU itself. The EU Charter has no status under English law, as it was deliberately not transposed into UK legislation as part of the Brexit arrangements. The UK legislature has therefore been free to ignore the EU Charter when enacting new laws (or repealing existing ones) as of January 2021. The rights afforded by the EU Charter will not be affected by Brexit. The European Union (Withdrawal) Act 2018^{cxlii} preserves domestic laws based upon EU law. Where there may be a conflict between UK and EU law rights, UK rights will have to be balanced against other rights in the EU Charter.

The Preamble of the EU Charter^{cxliii} notes that rights arise from: (i) the constitutional traditions and international obligations common to Member States, (ii) the European Convention on Human Rights (the “**ECHR**”)^{cxliv} and (iii) the Council of Europe and the case law of the Court of Justice of the European Union (the “**CJEU**”)^{cxlv} and of the European Court of Human Rights (the “**ECHR Court**”)^{cxlvi}. The decisions on how to implement rights are retained at Member State level unless it is necessary for the EU to intervene.

Article 51 of the EU Charter limits its application to EU institutions and bodies and to Member States when they are implementing EU law. This provision helps to draw the boundary between the scope of the EU Charter and that of national law and the ECHR. The EU Charter, therefore, does not create new rights, but rather reaffirms rights that already existed in EU law.

The majority of the EU Charter represents a series of principles, rather than rights that are directly enforceable. Hence, the provisions of the EU Charter do not actually provide legal protection, which is delegated to Member States at the national level. Thus, individuals seeking legislative protection will have to depend on national legislation implementing the Charter in order to enforce their rights in a court of law.

1. Are persons with facial disfigurements protected on the grounds that facial disfigurement is a disability?

Article 21 (1) of the EU Charter^{cxlvii} states:

“Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.”

Article 26 of the EU Charter states:

“The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.”

The protection afforded under Articles 21(1) and 26 will assist persons with disabilities, because any laws that fail to prohibit discrimination on the grounds of disability may be set aside in this way. However, it is less clear (i) whether facial disfigurement would be regarded as a disability by the courts, and (ii) whether the courts would set aside a law on the basis that it fails to prohibit discrimination based on some other ground not specified in Article 21(1), despite the Article providing examples, and not being exhaustive.

What is a “disability”?

The EU Charter does not offer a definition of “disability”. The definition of disability has evolved through case law. In joined cases C-335/11 and C-337/11, concerning *HK Danmark (Ring and Skouboe Werge)* (2013),^{cxlviii} known as the *HK Danmark Ring Case*, the CJEU defined disability 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”.^{cxlix}

This definition specifically took into account the UN Convention on the Rights of Persons with Disabilities (“**UNCRPD**”)^{cl}, to which all Member States signed up in 2010.

This definition recognises the relevance of social and environmental factors in limiting (or disabling) people. It recognises that disability results from the interaction between an impairment of an individual and the environment in which the individual exists. The CJEU recognised that the impairment does not need to be the cause of a restriction of the functional ability of the individual, but instead that the attitudes of others can lead to limits being placed on the individual’s choices that have the effect of disabling the person. However, the CJEU has not always applied this definition consistently in subsequent cases.

In the *Kaltoft* case,^{cli} Mr Kaltoft was dismissed from his job and claimed that the reasons for this included the fact that he was obese. The CJEU considered whether obesity, in and of itself, fell within the definition of disability adopted in the *HK Danmark (Ring and Skouboe Werge)* case.^{clii} The Court focussed on the notion that the condition would need to lead to a limitation, which hinders the full and effective participation of the person concerned in professional life on an equal basis with other workers. It fell short of clarifying whether the attitudes of others (i.e. discrimination) could be counted as creating those limitations, as opposed to the condition of obesity itself. On the facts, Mr Kaltoft did not regard his obesity as directly causing any limitations that affected his ability to carry out his job as effectively as anyone else did.

The CJEU seemed to require that, in order for Mr. Kaltoft to be protected from discrimination by the European Employment Directive^{cliii}, he must first be classed as disabled, and that in order to be so, he must have an impairment and must experience a limitation directly related to that impairment. A limitation caused solely by socially created barriers, such as false assumptions and prejudices, would seem to not count for these purposes. In doing so, the CJEU has not fully embraced the model of disability envisioned by the UNCRPD, which in contrast does seem to recognise that a disabled person's limitation may be caused solely by the social barriers created by the prejudiced attitudes of others.

Current case law suggests that the CJEU would not regard facial disfigurement by itself as a "disability", unless the disfigurement itself leads to a limitation on the person's ability to carry out certain functions (for example a specific role in employment) and the fact that other people may place barriers (such as discrimination) on the person (thereby leading to a limitation on the person) may not be sufficient on its own for the CJEU to rule that such person should be entitled to benefit from the protection that a disabled person would be entitled to under the EU Charter. This is at odds with the approach taken in the UNCRPD. The CJEU may develop its own line of interpretation in new case law, in order to become consistent with the UNCRPD (see below). Until then however, in the absence of new case law, the EU Charter appears to offer limited substantive legal protection to people with facial disfigurements.

2. Are persons with facial disfigurements protected on other grounds?

Other grounds on which persons with facial disfigurements may be protected is discrimination by association or perception. Discrimination by association refers to a situation in which an individual is discriminated against because of the protected characteristic of another person, namely someone with whom they are associated.

In the CJEU case of *Coleman*, the claimant, who was the primary carer for her disabled son, claimed that she had been treated less favourably on account of her son's disability and therefore discriminated against on the basis of disability. In this case the court explained that:

“An interpretation limiting its application only to people who are themselves disabled is liable to deprive the directive of an important element of its effectiveness and to reduce the protection which it is intended to guarantee.”^{cliv}

Following this judgment it should not be necessary for an employee to be disabled to bring a claim for direct disability discrimination if he or she is discriminated against because of an association with a disabled person.

The availability of a claim for perception discrimination was confirmed in the *Coffey case*.^{clv} In this case it was accepted that the perpetrator of the discrimination must believe that the elements of statutory disability are present although it is not necessary for him to attach the label to them, and that the impairment at issue must be serious and long term enough to meet the relevant statutory definition. It has been noted obiter^{clvi} that perceived injury or depression may enter peoples' minds unconsciously and they may not recognise the basis on which they are discriminating.

Direct discrimination claims based on association or perception should now be allowed in respect of disability under the Equal Treatment Framework Directives^{clvii} as implemented in the Member States. The effect is that an individual is now not only able to bring a claim for direct discrimination solely on the grounds of their protected characteristic, but simply because of a protected characteristic, whether it is theirs or someone else's.

3. Must / should persons with facial disfigurements describe themselves as disabled in order to exercise their rights?

There is no requirement for persons with disabilities or other differences (including facial disfigurements) to describe themselves as disabled in order to benefit from the rights and protections described in the EU Charter. The EU Charter does not provide a definition of what is considered a disability. Indeed, different countries around the world have adopted different definitions, depending on severity and long-term impacts. For example, under the UK Equality Act 2010, people with a disability or a severe disfigurement are granted equality rights, while people with mere disfigurements (imperfection in appearance) are not.^{clviii} Therefore, if the facial disfigurement meets the severity threshold amounting to disability, describing oneself as 'disabled' may reduce the barriers to receiving the same protection as other disabled people under the EU Charter. This may include enforcement of positive actions promoting tolerance, as well as adjustments to improve the work and office environment; thus pre-empting the possibility of unlawful discrimination and other unfair practices *HK Danmark (Ring and Skouboe Werge) (2013)*.^{clix} Examples of such positive actions include reduction in working hours or adjustments to office equipment.

Currently, there are no discrimination-related cases at the CJEU, which relate specifically to facial disfigurements.

4. What are the gaps in protection?

Scope of applicability

While the EU is obliged under the EU Charter not to take measures that violate human rights (including the prohibition of discrimination)^{clx}, the EU Charter applies to Member States only in the limited context of the interpretation and implementation of EU law^{clxi}. The EU's administrative system leaves the implementation of EU laws to the Member States. Thus, the protection of persons with facial disfigurements also depends on the implementation of EU law into national law by the respective Member State.

Generally, if a Member State fails to implement EU law in full or in part, an individual who has been unlawfully discriminated against, on the basis of a facial disfigurement could bring a claim based on the violation of Art. 21 para. 1 of the EU Charter^{clxii}. However, the claim could only be pursued on the grounds that the Member State in which the discrimination took place did not implement the right to protection from discrimination in full or in part and thus, that a particular law may be in contravention of the EU Charter.^{clxiii} This is likely to be a lengthy procedure.

Despite the aforementioned limited scope^{clxiv} and despite controversial discussions in literature^{clxv}, the CJEU in its recent judgments^{clxvi}, has established the binding effect of Art. 21 paragraph 1 of the EU Charter among private individuals due to its specific character, which enables direct assertion by private individuals. Irrespective of whether or not Art. 21 para. 1 of the EU Charter grants direct or indirect horizontal effect, private (national) laws must be interpreted in conformity with fundamental rights.^{clxvii} Provisions that violate Art. 21 para. 1 are inapplicable.^{clxviii} Nevertheless, court proceedings are likely to take a long time.

Scope of protection

As discussed above, Article 21 para. 1 prohibits discrimination based on “*any ground such as [...] genetic feature, [...] disability, [...]*”. Thus, a person with a facial disfigurement may be protected against discrimination where and to the extent such facial disfigurement is based on genetic features and/or defined as disability and/or other features, as discussed below.

(i) Genetic features

The EU Charter prohibits discrimination based on genetic features. The inclusion of this personal characteristic draws on Art. 11 of the Convention of Human Rights and Biomedicine which prohibits any form of discrimination based on genetic heritage.^{clxix} This characteristic was implemented in the EU Charter in view of the progress of medicine: the prohibition of discrimination on the basis of genetic characteristics was seen as a forward-looking provision in the Charter.^{clxx} The EU Charter, however, does not provide for a definition of genetic features. Unlike for the characteristic “disability”, a definition has also not been formed through case law.^{clxxi} This leaves legal uncertainty as to the interpretation of the scope of protection of genetic features as well as to implementation into national laws. The definition and/or more specific features of protection will need to be defined and filled by case law.

(ii) Disability

Since the EU Charter does not provide for a definition of disability, such definition has been formed through case law (see above):

“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”.

This definition, however, still leaves legal uncertainty. As of yet, there is no case law stating that the definition of disability covers facial disfigurement. The terms of the above definition will need to be defined and filled by case law. This will most likely be done on a case-by-case basis determining whether the particular facial disfigurement at stake will be protected on the grounds that it falls within the category of such disability.

(iii) Other features

If and to the extent facial disfigurement is not protected on the grounds of genetic features and/or disability, Art. 21 para. 1 of the EU Charter still leaves room for interpretation. The list of protected grounds is not conclusive. Rather, any other individual feature is protected if it is considered equal to the listed grounds of protection^{clxxii}. As there is no court ruling with regard to facial disfigurement confirming that such individual features will fall under the scope of Art. 21 para. 1 of the EU Charter, this gap will need to be filled with the Member State's implementation of the EU Charter into national law and the national court's interpretation. This will leave legal uncertainty until a court ruling can give guidance on how such cases may be resolved.

Other gaps in protection - UK

Whilst the vast majority of EU law has been transposed into UK domestic law under the European Union (Withdrawal) Act 2018^{clxxiii}, section 5 of that Act specifically states that the EU Charter ceases to be part of UK law after Brexit. UK citizens therefore no longer have a mechanism to challenge UK domestic laws on the basis that they conflict with the EU Charter. The UK is still a signatory to and therefore bound by the ECHR, however the rights under the ECHR are not as wide or strong as those under the EU Charter.

5. What legal / regulatory reforms are needed if people are to seek protection (either on the grounds that facial disfigurement is a disability, or on other grounds)?

Scope of applicability

The EU Charter's limited scope of applicability means an individual is not able to derive individual rights directly from the EU Charter itself or from its regulations, including its Article 26 (Integration of persons with disabilities). This stems from Article 51 of the EU Charter^{clxxiv}, according to which it is only binding on Member States "when they implement Community rules".^{clxxv}

However, a reform to Article 51 of the EU Charter, according to which individuals would be entitled to directly claim for rights under the EU Charter, is not feasible. Such a reform would be in conflict with the principle of subsidiarity and the fact that the EU only has those powers which have been conferred upon it. Therefore, as confirmed in the explanation relating to the EU Charter, "the Charter may not have the effect of extending the competences and tasks which the Treaties confer on the Union".^{clxxvi} By granting individuals directly claimable rights under the EU Charter, the EU would exceed these competences and tasks.

Scope of protection

Reforms could however be implemented to enhance the EU Charter's scope of protection, particularly to Art. 26 of the EU Charter, in order to grant persons with facial disfigurements the same equality rights as persons with disabilities or other impairments. This could be achieved by either (i) mentioning persons with facial disfigurements explicitly within the relevant articles, or by (ii) clarifying that facial disfigurements can or do fall under the definition of disability.

(i) Mention of facial disfigurements as being protected under the relevant Articles of the EU Charter

The former option (explicitly mentioning facial disfigurements alongside disabilities) however, might again fall in conflict with the principle of subsidiarity as discussed in the Scope of applicability section above. By mentioning facial disfigurements alongside disabilities, the EU Charter would indicate that these two conditions are not the same and that persons with facial disfigurements had not been protected in the past. Such an expansion of the scope of protection may act as a contradiction to the EU Charter's nature as evident from its preamble: The EU Charter's intention is to reaffirm established rights rather than create new ones.^{clxxvii}

(ii) Clarification that facial disfigurement can fall under the definition of disability

The latter option (clarifying that facial disfigurements can or do fall under the definition of disability) could be a feasible way to strengthen the rights of persons with facial disfigurements. Amendments would not necessarily have to be made to the wording of the EU Charter itself; instead, such clarification could be included in the EU Charter's Explanations,^{clxxviii} where it could be expressly stated that the limitations or impairments required in order to define a condition as a disability don't have to derive from physical, mental or psychological impairments, but rather can also result from the attitudes of others (i.e. discrimination).

As stated above, such understanding of the definition of "disability" had been assumed by the CJEU in the past,^{clxxix} therefore it would not necessarily be seen as a prohibited expansion of the rights envisioned under the EU Charter, but instead as a valid confirmation and clarification of rights that already existed.

Another argument that a definition of disability should not be seen as a prohibited expansion of rights is the fact that several Member States have implemented national regulation, according to which facial disfigurements fall within the scope of disability legislation or policy,^{clxxx} and lead to a disability according to the applicable Barema (where Member States apply the Barema method: an arbitrary ordinal scale which attaches progressive

percentage values to define disabilities. The disabilities of the claimant are compared to those for which there are scale values and a percentage is thereby obtained)^{clxxxi}. Examples for such regulations are the following:

- **Ireland:** A definition of disability is in section 2.1 of the Employment Equality Act (1998),^{clxxxii} which states that disability means (i.a.) "... (d) the malfunction, malformation or disfigurement of a part of a person's body..."
- **Belgium:** A disfigurement in the head area can lead to a Barema of 10 to 100%.^{clxxxiii}
- **Germany:** a "*high degree of facial disfigurement*" can lead to a disability Barema of 50%.^{clxxxiv}

Thus, considering that several EU Member States have already implemented regulation, according to which facial disfigurements can be qualified as a disability, it can be argued that the definition of disability according to the EU Charter is able to include persons with facial disfigurements as well.

6. What practical ‘protections’ are provided specifically in relation to employment, customers accessing goods and services, and citizens accessing government services?

General protections

The provisions of the EU Charter discussed below are some of the overarching principles that constitute key protections and standards for any national legislation. Hence, any provisions must be read in conjunction with these principles as well as the ECHR and the European Social Charter.^{clxxxv}

Article 1 of the EU Charter^{clxxxvi} states:

“Human Dignity is inviolable. It must be respected and protected.”

Human Dignity is the real basis of fundamental rights. Dignity is the right of a person to be valued and respected for who they are, and hence, must be protected. The dignity of a person can be violated through humiliation and degradation, among others. This is something that people with facial disfigurements may experience often in many different situations. Therefore, it is important to be aware of the protection that the EU Charter provides in this respect. It specifically states that none of the rights laid down anywhere may be used to harm the dignity of another person even where a right is restricted. The right to human dignity also exists independently of the EU Charter.^{clxxxvii}

In addition, the right to the integrity of the person *“pervades all areas of EU law and policy”* and must be respected. Article 3 of the EU Charter^{clxxxviii} states that:

“Everyone has the right to respect for his or her physical and mental integrity.”

This is a general principle of EU law, and as such, exists independently of the Charter.^{clxxxix} Hence, respect for physical and psychological integrity forms part of the right to respect for private life and is also incorporated in Article 8 of the ECHR.^{cxc}

The violation of an individual’s physical and mental integrity is treated as an unethical infringement, intrusive, and may be a criminal offence. Being different in appearance can lead to situations that can affect the physical and mental integrity of the person. Thus, protection through this provision is of fundamental importance.

1. Employment, goods & services and government services

Employment

Fundamental rights in relation to employment were created to ensure equal opportunities for all European citizens and those who may have a right to live and work in the EU. While these provisions of socio-economic focus are of great importance to all, these are of even more significance for people with facial disfigurements who may be discriminated against or experience lack of opportunity as a result of their facial disfigurement.

Article 15 of the EU Charter^{cxc} states:

“Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation...Every citizen of the Union has the freedom to seek employment, to work, to exercise the right of establishment and to provide services in any Member State...”

The ‘right to work’ is also a fundamental human right^{cxcii} as well as being included in the EU Charter. The freedom to choose an occupation exists independently of the EU Charter.^{cxciii} The longstanding EU case law on the right to pursue

a trade or profession is part of EU law. It applies to “everyone”, employees and self-employed persons, regardless of the nature of their employment relationship. The importance given to the right to work, in significance and scope, can include the individual’s freedom to work as well as the right for individuals to claim the right to work from the Member State. This establishes not only the freedom to work or not to work, but also the freedom to choose and to pursue their choice of professional activity. Hence, people with facial disfigurements are not only entitled to apply for jobs and be considered for any job without discrimination, but also to claim the right to work from the Member State.

Similar protections are available under the EU Charter to people who may want to start their own business as long as it is conducted “in accordance with Union law and national laws and practices”.^{cxciv} The right to carry on economic or commercial activity exists independently of the EU Charter.

People with facial disfigurements may face discrimination in any aspect of their everyday lives, whether in an employment context, when trying to obtain access to goods and services and when trying to obtain government assistance. It is, therefore, important to reiterate that Article 20 of the EU Charter^{cxcv} guarantees equality before the law while Article 21 of the EU Charter^{cxcvi} provides a right to be protected against discrimination on a non-exhaustive list of grounds, as discussed above.

In general, “discrimination” refers to violation of specific individual rights. However, it may also include the obligation to eliminate anything that has the effect of producing unlawful distinctions that disadvantage certain individuals in society or create hurdles to achieving equality.^{cxcvii} A similar approach on discrimination is evident in EC Directives 2000/43 (implementing the principle of equal treatment between persons irrespective of racial or ethnic origin)^{cxcviii} (the “**Racial Equality Directive**”) and EC Directive 2000/78 (establishing a general framework for equal treatment in employment and occupation)^{cxcix} (the “**Employment Equality Directive**”). The Racial Equality Directive prohibits discrimination on the ground of racial or ethnic origin in the areas of employment, social protection and social advantages, education, and goods and services available to the public and the Employment Equality Directive relates to the field of employment and occupation covering the grounds of religion or belief, disability, age and sexual orientation. The provisions of these Directives have been transposed into existing legislation of many EU Member States to specifically regulate the prohibition of discrimination in accordance with these Directives’ requirements.

Article 21 of the EU Charter provides for a non-exhaustive list of grounds of discrimination, which are examples of the prohibition on “any ground” of discrimination. “[A]ny discrimination is prohibited, including acts or omissions, direct and indirect, manifest and hidden, both individual and collective discrimination practices.”^{ccc} In the work context, this covers the worker as an individual or as a member of a group. It may also equally apply when trying to access goods and services or government assistance.

Article 21 of the EU Charter is wider in scope and application when compared with Article 19 of the Treaty on the Functioning of the European Union (“**TFEU**”)^{ccci} that confers powers on the EU to legislate to combat discrimination. Nevertheless, the “*applicability of EU law entails applicability of the fundamental rights guaranteed by the EU Charter*”, resulting in a wide range of new grounds such as genetic features, social origin, political opinion or property status that fall within the scope of Article 21 of the EU Charter.^{cccii}

Most rights are accessible to people with facial disfigurements as part of being an EU citizen or having the right to live and work in a Member State. However, if a person with a facial disfigurement is regarded as being disabled, they will also be able to rely on the protection provided by Article 26^{cciii} of the EU Charter, which compels that the EU and each Member State:

“...[recognise] and [respect] the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.”

Article 26 of the EU Charter is based on the European Social Charter (“**ESC**”)^{cciv} and draws on the Community Charter of the Fundamental Social Rights of Workers (“**CCFSRW**”).^{ccv} These cover a wide range of fundamental rights in relation to employment, working conditions, training, housing, education, health, social security, social protection

and medical assistance, within a framework of non-discrimination, and specific protection for vulnerable persons such as the elderly, children, the disabled and migrants. The ESC is seen as the social constitution of Europe whereas CCFSRW represents a commitment by the Member States to a set of social policy and labour law objectives.

Dismissal

People with facial disfigurements may find themselves subject to unfair treatment that could lead to unjustifiable dismissal, in breach of Article 30 of the EU Charter, which provides that:

“Every worker has the right to protection against unjustified dismissal, in accordance with Union law and national laws and practices.”

Recognition of protection against unjustified dismissal, as a fundamental right, indicates that any legislation that limits employers’ obligations not to discriminate must also balance and give significant importance to the individual employee’s interest in their own security of employment. Nearly all Member States have national regulations in relation to unjustified dismissal. Article 30 of the EU Charter simply reflects the existing EU legislative framework in relation to safeguarding of employees' rights in the event of transfers of undertakings^{ccvi} and leaves it entirely to the Member States to decide whether to give any rights that go beyond the legislation.

Some procedural requirements also need to be complied with in the process leading to a dismissal. For instance, the right to be heard and consulted on an individual level and/or the right to information and consultation on a collective level form a part of the procedures that are necessary in order to ensure adequate protection. Also, in order for the protections under the EU Charter to be effective, national legislation providing legal protection at a Member State level should contain not only compensatory measures, but also include preventative measures that the employer must follow in order for a dismissal to be justifiable. However, Article 30 of the EU Charter is engaged only in cases of an unjustified dismissal, not “unlawful”, or “unfair” dismissal. Nevertheless, protection against “unlawful” dismissal requires that the reasons for dismissal must be defined in substance and provided for in the national legislation or constitution. An example of such a protection can be seen in the Finnish and Portuguese constitutions.^{ccvii}

Any sanctions imposed by the courts at a Member State level have to be effective, proportionate and adequate. Failure of the employer to adopt adequate preventive measures should be taken into account when considering appropriate remedies. Financial compensation is the most common, but may not always be adequate.

Working Conditions

Ensuring fair and just working conditions are important for everyone but are of far greater significance for people with facial disfigurements who, may feel they need to accept conditions that would otherwise be considered unjust or unfair. It is possible that this will affect the dignity and integrity of the individual, impacting their mental and/or physical health. Article 31 of the EU Charter ensures that:

“Every worker has the right to working conditions, which respect his or her health, safety and dignity.”

This not only includes working hours, “...the right to limitation of maximum working hours, to daily and weekly rest periods and to an annual period of paid leave...”,^{ccviii} but also remuneration and all other working conditions. Even though not explicitly mentioned in the EU Charter, these may also include sexual harassment, offensive actions against workers (e.g. verbal/physical abuse) and violations to whole personality of the worker in the context of unequal power in determining conditions of employment.^{ccix} The information and consultation procedures are also included within the scope of fair and just working conditions.

Government services

“Everyone residing and moving legally within the European Union is entitled to social security benefits and social advantages in accordance with Union law and national laws and practices”.^{ccx}

The importance of such services cannot be underestimated, especially for people who may otherwise be marginalized or socially excluded. The EU *“recognises and respects the entitlement to social security benefits and social services providing protection in cases such as maternity, illness, industrial accidents, dependency or old age, and in the case of loss of employment, in accordance with the rules laid down by Union law and national laws and practices”.*^{ccxi}

Individuals have a right to social, housing and other assistance to ensure that all those who lack sufficient resources or means are also able to access a decent quality of life.^{ccxii} Nevertheless, Article 34 of the EU Charter^{ccxiii} does not create a general entitlement to social security or welfare benefits where such a right is not conferred under EU or domestic law. EU social security is based on the coordination rather than the harmonisation of national law. Each country remains responsible for its own legislation determining what benefits it pays and to whom.

Article 29 of the EU Charter^{ccxiv} that provides that *“everyone has the right of access to a free placement service”*, is of paramount importance to those who may find it difficult to find employment on their own, especially due to physical differences or limitations. Based on the ESC and the CCFSRW, the term ‘placement services’ as used in the EU Charter refers to job placement services, such as Jobcentre Plus.^{ccxv}

Additionally, Article 35 of the EU Charter provides that *“everyone has the right of access to preventive health care and the right to benefit from medical treatment”*^{ccxvi} under the conditions established by national laws and practices. A high level of human health protection is ensured in the definition and implementation of all policies and activities of the EU.

In addition, the EU *“recognises and respects access to services of general economic interest as provided for in national laws and practices, in accordance with the Treaties, in order to promote the social and territorial cohesion”.*^{ccxvii} These are services of general interest subject to specific public service obligations and can be provided by both state and private sector, e.g. public transport, postal services, and health care.

The EU, through its policies, seeks to promote consumers' health, safety and economic interests, as well as to protect other rights for the benefit of its citizens. It also requires consumer protection to be taken into account when defining other EU policies.

Goods and Services

Specifically, in relation to the access of goods and services, Article 38 of the EU Charter,^{ccxviii} and also national law, provides the basic right of consumer protection against unfair treatment.

2. General provisions governing citizens' rights

The provisions in the EU Charter are directed towards EU citizens as well as *‘any natural or legal person residing or having its registered office in a Member State’*,^{ccxix} such as the right of referral to the European Ombudsman^{ccxx} and the right to petition the European Parliament.^{ccxxi} The right to petition the European Parliament^{ccxxii} will continue to exist for any UK nationals residing in the EU or for EU citizens resident in the UK (even after Brexit).

Article 41 of the EU Charter^{ccxxiii} states that:

“Every person has the right to have his or her affairs handled impartially, fairly and within a reasonable time by the institutions, bodies, offices and agencies of the Union.”

It also ensures that:

- a) every person has a right to be heard before any individual measure is taken that would affect him or her adversely;
- b) every person has access to his or her file, while respecting the legitimate interests of confidentiality and of professional and business secrecy; and
- c) the administration has the obligation to give reasons for its decisions.

This right to good administration is addressed to ‘every person’, thus not only EU citizens or residents.

3. General provisions governing the interpretation and application of the EU Charter

The EU Charter contains a number of provisions that apply to all rights, freedoms and principles. These regulate the relationship of the EU Charter to other international and regional human rights instruments, in particular the ECHR, as well as serving as important guidance on the interpretation and application of the EU Charter.

Article 51 of the EU Charter^{ccxxiv} defines the important distinction between ‘rights’ and ‘principles’, i.e. the parties are to “*respect the rights, [and] observe the principles*”. Hence, principles only become relevant where they have been legislatively enacted and do not by themselves give rise to direct claims for positive action. The implementation of the principles in the EU Charter have been left to particular Member States or the EU depending on competency. Therefore, in order to allege the violation of a ‘principle’ set out in the EU Charter in any court, it is necessary to invoke the legislation implementing the principle because they are not directly enforceable.

Articles 52 and 53 of the EU Charter ensure that any limitation on the exercise of the rights and freedoms recognised by the EU Charter must be made in accordance with the principle of proportionality, respecting the essence of those rights and freedoms. Limitations may be made only if they are necessary and genuinely meet objectives of general interest recognised by the EU or where there is a need to protect the rights and freedoms of others.^{ccxxv} Furthermore, provisions of the EU Charter will not conflict with human rights and fundamental freedoms that are guaranteed under international law and conventions as well as national constitutions and Member States’ conventions. Therefore, the EU Charter maintains the level of protection currently afforded by EU law, national law and international law.^{ccxxvi}

7. Areas for potential further research

1. The European Convention on Human Rights

An area of potential further research could be whether the ECHR provides wider or more effective protection for persons with facial disfigurements than the EU Charter.

The ECHR and the ECHR Court are part of a different legal system to the EU, namely they are part of the Council of Europe, which has 47 member states ("**Council Member States**"). However, the EU and Council of Europe systems are intertwined because all 27 Member States are also Council Member States and the ECHR lies behind many of the general principles of EU law. Furthermore, the ECHR provisions have been used as a basis for the EU Charter.

The ECHR prohibits discrimination:

"on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status"^{ccxxvii} for the enjoyment of rights and freedoms set forth in the ECHR.

The wording does not explicitly mention facial disfigurements or disability as a ground of protection. However, the list of protective grounds is "illustrative and not exhaustive, as is shown by the words "any ground such as" and the inclusion in the list of the phrase "any other status".^{ccxxviii} Thus, the provision itself is subject to wide interpretation. In *Clift v. the United Kingdom*, the ECHR Court recalls that "the words "other status" have generally been given a wide meaning".^{ccxxix} According to the ECHR Court, "Article 14 does not prohibit all differences in treatment but only those differences based on an identifiable, objective or personal characteristic, or "status", by which persons or groups of persons are distinguishable from one another".^{ccxxx} In *Glor v. Switzerland*, the ECHR Court held that physical disabilities fell within the phrase "other status".^{ccxxxi} In addition, the ECHR is considered to be a living instrument whose interpretation is based on the current social and economic conditions. Consequently, facial disfigurement may easily fall into the "other status" category and be recognised as a characteristic to be protected under Article 14 of the ECHR if it has been used as a ground of discrimination. However, there is currently no case law of the ECHR Court explicitly dealing with facial disfigurement confirming such interpretation.

The main weakness of Article 14 is that it prohibits discrimination only to the extent that such discrimination takes place in connection with the "*enjoyment of [other] rights and freedoms set forth in this Convention.*"^{ccxxxii} Thus, the discrimination prohibition of the ECHR operates in a similar way to the EU Charter, in that it does not confer a stand-alone right, but provides protection only when other basic rights and freedoms of the Convention are exercised by a person, i.e. on accessory basis.^{ccxxxiii} The ECHR helps remedy these weaknesses by extending the prohibition of discrimination in connection with the "*enjoyment of any right set forth by law.*"^{ccxxxiv} As a result, the ECHR now protects individuals from discrimination by the exercise of any legal right codified in a Member State rather than the original rights and freedoms set forth in the ECHR. However, this wider protection is only available in 19 Member States.^{ccxxxv} Nineteen other Member States, which have signed Protocol No. 12, among others Germany, France, Italy, Russia and the United Kingdom, have not ratified it into national law.^{ccxxxvi ccxxxvii} Another gap in protection is that the general prohibition of discrimination applies only to public authorities and not to private persons or corporations.

Under the ECHR, persons with facial disfigurements may require protection from a state not only if they are subject to direct unequal treatment but also in cases where they are given equal treatment to persons without facial disfigurements, and this is not an appropriate response and where the state fails to compensate for the disadvantage to affected individuals through active legislative measures or de facto affirmative action. According to the case law of the ECHR Court, even a general policy based precisely on uniform treatment may, like an individual measure, be discriminatory because of disproportionately adverse effects on a particular group of persons, even if a measure is

generally not aimed at that group. Discrimination may then arise from the circumstances,^{ccxxxviii} for example, when people with facial disfigurements are statistically underrepresented in public service jobs because their disadvantage is not recognized as such in the selection of applicants and they end up in the same comparison group with people without facial disfigurements. While such a case is often cited as an example of indirect discrimination, and the ECHR Court itself also speaks of indirect discrimination,^{ccxxxix} strictly speaking it is a case of “*discrimination by equal treatment*”,^{ccxl} since even mere indirect discrimination implies unequal treatment..

Systematic equal treatment may also result in discriminatory effects. As a result, the ECHR Court considers Article 14 of the ECHR to be violated if the state does not treat differently persons in clearly different situations without reference to the specific factual circumstances, and without reasonable justification for the action taken/inaction. Furthermore, it should be noted that Council Member States have discretion in assessing whether and to what extent differences in otherwise identical situations justify different treatment. The extent of this discretion varies depending on the circumstances, the case and its background.

Generally, the scope of protection against discriminatory treatment is comparable under the ECHR and the EU Charter. However, there is no relevant case law of the ECHR Court and the legal literature available in connection with the ECHR does not discuss facial disfigurements specifically as a feature of potential discrimination.

2. Compatibility of CJEU jurisprudence regarding disability with the UN Convention on the Rights of People with Disabilities (“UNCRPD”)

According to the European Commission’s paper on “*Combatting disability discrimination and realising equality*”^{ccxli} (2018) the “*EU law is in breach of its obligations under the CRPD regarding elements of the definition of disability.*” As elaborated by the CJEU in the *HK Danmark (Ring and Skouboe Werge)* case^{ccxlii} and affirmed in subsequent case law, a person is only regarded as disabled if they are potentially hindered in carrying out activities required in their professional life. By contrast, the UNCRPD adopts a broader perspective and recognises as disabled individuals whose participation is hindered more generally in carrying out daily activities. As a result, those individuals who are not disabled in their professional activities but who are disabled in other areas of life will not be deemed to fall under the CJEU’s definition of disability. The report argues that the definition of disability developed by the CJEU for the purposes of the Employment Equality Directive^{ccxlili} does not fully comply with the UNCRPD in this regard.

The report further argues that EU law breaches the UNCRPD, to the extent that the CJEU’s definition of disability fails to embrace the human rights model of disability embodied by the UNCRPD. According to the *HK Danmark (Ring and Skouboe Werge)* case^{ccxliv}, EU law requires that an individual not only has an impairment but also experiences a limitation directly related to that impairment in order to fall within the definition of disability. However, the report contends that the CJEU appears to exclude from the definition of disability individuals who are disabled, simply on account of socially created barriers, such as false assumptions and prejudices about an individual’s ability, and possibly even barriers in the physical environment, which may significantly impact on a person with facial differences to seek protection from discrimination through proceedings in the CJEU. By way of contrast, the UNCRPD does acknowledge as disabled those individuals with an impairment who are disadvantaged purely by environmental factors. While the CJEU has dealt with a number of cases concerning the definition of disability since the *HK Danmark (Ring and Skouboe Werge)* case^{ccxlv}, including the *Kaltoft* case^{ccxlvi}, it has not clarified this point (and *Kaltoft* is open to the same interpretation outlined above). Therefore, this is an area where, on the basis of current case law, EU law and the UNCRPD are not in line, and clarification is required by the CJEU on this point.

United Nations Convention on the Rights of Persons with Disabilities 2007

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (the “**UNCRPD**”) is an international treaty that safeguards the human rights of persons with disabilities in various areas, such as employment, education and access to services. Persons with facial disfigurements are likely to be protected under the UNCRPD, which adopts an open description of “disability”. There is no need for a person to describe themselves as “disabled” to enjoy the protection therein. While the UNCRPD provides a strong theoretical foundation for protecting the rights of people with facial disfigurements through its wide definition of disability, in reality, it has had more limited practical success, owing to the limited accountability measures in place and the reliance on countries that have signed up to the UNCRPD (“**State Parties**”) to give effect to the UNCRPD in national law in order for relevant rights to be given legal protection.

What is the UNCRPD?

The UNCRPD^{ccxlvii} is an international human rights treaty established pursuant to a resolution adopted by the United Nations General Assembly on 13 December 2006^{ccxlviii}. An unprecedented 81 countries signed the UNCRPD in March 2007. Following the ratification by the 20th State Party in accordance with its Article 45(1), the UNCRPD came into force on 3 May 2008. As of May 2021, the UNCRPD has 164 signatories and 182 parties.^{ccxlix} The United Kingdom ratified the UNCRPD in 2009.

The purpose of the UNCRPD 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*”.^{cc} The UNCRPD adopts a broad categorization and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms^{ccii}.

The eight guiding principles which underlie the UNCRPD are as follows^{cciii}:

- Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women; and
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The UNCRPD sets out specific human rights and fundamental freedoms for persons with disabilities and the specific obligations of states signatory to the UNCRPD (i.e. the State Parties) in relation to such rights and freedoms. The rights and freedoms protected by the UNCRPD mirror the rights and freedoms affirmed in other United Nations human rights conventions such as the International Covenant on Civil and Political Rights^{ccliii} and International Covenant on Economic, Social and Cultural Rights.^{ccliv} However, the UNCRPD sets out in greater detail the specific

obligations of the State Parties to ensure that these rights can be fully realised by persons with disabilities. The UNCRPD also contains certain rights which are specific to it such as the right of access to the physical environment, to transportation, to information and communication, and to other facilities and services open to the public^{cclv}; the right to personal mobility^{cclvi} and the right to habilitation and rehabilitation.^{cclvii}

As with all other UN human rights treaties, the UNCRPD imposes on State Parties three types of obligations, being the obligations to respect, protect, and fulfil.^{cclviii} The obligation to respect means the State Parties must refrain from interfering with, whether directly or indirectly, the enjoyment of rights set out in the UNCRPD whereas the obligation to protect requires State Parties to take active measures to prevent violation by third parties of the rights of persons with disabilities.^{cclix} As for the obligation to fulfil, it requires the State Parties to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to fully realise the rights of persons with disabilities.^{cclx} State Parties that have signed up to the UNCRPD are required to fulfill these obligations by:

- adopting all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the UNCRPD;
- taking all appropriate measures to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- taking into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
- refraining from engaging in any act or practice that is inconsistent with the UNCRPD and ensuring that public authorities and institutions act in conformity with the UNCRPD; and
- taking all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise.^{cclxi}

1. Are persons with facial disfigurements protected on the grounds that facial disfigurement is a disability?

Paragraph 2 of Article 1 of the UNCRPD provides that *“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”*. This is an *“open description or non-definition of disabilities”*.^{cclxii} Paragraph (e) of the Preamble to the UNCRPD recognises that *“disability is an evolving concept”*^{cclxiii} and that *“disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”*.^{cclxiv}

This open description of disability makes no mention of any functional limitation and this concept applies to disabilities *“that may or may not come with functional limitations”*.^{cclxv} This reflects a social model of disability rather than a medical model of disability which is built on the concept of a *“broken body”* and clarifies that disability results from the interaction between persons with impairments and external barriers that hinders their participation in society^{cclxvi}.

Thus, it appears that facial disfigurements would qualify as a ‘disability’ under the UNCRPD because facial disfigurements would likely be a long-term physical impairment and that disability may result from the interaction between a person with facial disfigurements and the overall context in which such person lives, which in turn may hinder such person’s full and effective participation in the society on an equal basis with others.

2. Are persons with facial disfigurements protected on other grounds?

The UNCRPD aims to “*promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by **all persons with disabilities***^{cclxvii}, and to promote respect for their inherent dignity”^{cclxviii}.

Article 6 and Article 7 of the UNCRPD make express reference to women, girls and children with disabilities and paragraph (p) of the Preamble of the UNCRPD states that there are concerns “*about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status*”. However, it should be noted that the protection under the UNCRPD is essentially based on the ground of disability and not on other grounds such as gender^{cclxix} and race.

Discrimination based on other grounds is addressed by other United Nations treaties such as the Convention on the Elimination of All Forms of Discrimination against Women^{ccclxx} and the International Convention on the Elimination of All Forms of Racial Discrimination^{ccclxxi}.

3. Must / should persons with facial disfigurements describe themselves as disabled in order to exercise their rights?

The terminology used in the UNCRPD is “**persons with disabilities**”. Unlike the United Nations Declaration on the Rights of Disabled Persons^{cclxxii}, the term “disabled person” is not used in the UNCRPD.

As discussed above, the term “person with disability” used in the UNCRPD is an open description rather than a closed definition of “disability” and “disability” for the purpose of the UNCRPD results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders the relevant person’s full and effective participation in society on an equal basis with others.^{cclxxiii}

4. What practical protections are provided specifically in relation to employment, customers accessing goods and services, and citizens accessing government services?

The UNCRPD establishes a set of general principles which guide the interpretation and application of its provisions^{cclxxiv}. The general principles include non-discrimination, equality of opportunity and full and effective participation and inclusion in society^{cclxxv} for people with disabilities. The general rights of autonomy and independence, which are included amongst the general principles, consolidate and strengthen the more explicit rights in the UNCRPD such as the right to choose where to live, the right to dispose of property and to enter into financial arrangements, which have historically been violated^{cclxxvi}.

Pursuant to Article 2, paragraph 3, of the UNCRPD, discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others by a person with a disability, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

The Article 2 definition of “discrimination on the basis of disability” includes “all forms of discrimination”. Common forms of discrimination include:

- Direct discrimination: It occurs when a person is treated less favourably than another similarly situated person because of disability, unless there is an accepted justification for the differential treatment ;
- Indirect discrimination: arises from a differentiation on the basis of an apparently neutral criterion, which has the effect of persons with disabilities being disadvantaged compared to persons without disabilities, and no objective justification can be shown to exist for the applied criterion;
- Harassment;
- Discrimination by association: It occurs when a person (with or without disability of his/her own) is discriminated against on the ground of the disability of an “associate” (such as the person’s family members and friends); and
- Denial of reasonable accommodation: Reasonable accommodation is defined as necessary and appropriate modifications and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure for persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.^{cclxxvii}

Under Article 5 of the UNCRPD (*Equality and Non-discrimination*), State Parties must ensure that persons with disabilities are treated as equal to everyone in society and that they are not discriminated against because of their disability. In carrying out this obligation, State Parties must: (i) recognise that all persons are equal not only before the law but under the law; (ii) prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds; and (iii) take all appropriate steps to ensure that reasonable accommodation is provided. Furthermore, Article 5 encourages specific measures to encourage *de facto* equality of persons with disabilities.

The rights and protections afforded under the UNCRPD also address a number of areas in which people with facial disfigurements may encounter discrimination. For example, Article 27(a) of the UNCRPD prohibits discrimination in the workplace on the basis of disability, including in matters relating to the conditions of employment, continuance of employment and career advancement.^{cclxxviii} The UNCRPD also provides that persons with disabilities have the right to equal pay and equal opportunity in the workplace.^{cclxxix} Furthermore, there is an express obligation on State Parties to take appropriate measures to employ persons with disabilities in the public sector.^{cclxxx}

State Parties are required under the UNCRPD to ensure an “inclusive education system” at all levels with a focus on developing the individual’s potential and strengthening their sense of dignity and self-worth^{cclxxxi}. There is also an

obligation on State Parties to enable persons with disabilities to learn life and social skills and to facilitate their full and equal participation in education.

Education and the workplace are just two of the many areas in which the UNCRPD seeks to protect persons with disabilities. Other areas include, but are not limited to: access to justice^{cclxxxii}; equal protection before the law^{cclxxxiii}, protection for the integrity of the person^{cclxxxiv}; freedom from exploitation, violence and abuse^{cclxxxv}; the right to live independently and to being included in the community^{cclxxxvi}; respect for privacy^{cclxxxvii}; respect for home and the family^{cclxxxviii}; health^{cclxxxix}; participation in political and public life^{ccxc}; participation in cultural life, recreation, leisure and sport^{ccxci}.

5. What gaps exist in the UNCRPD in terms of providing protection for persons with facial disfigurement?

The UNCRPD should serve to broaden the scope of protections afforded to persons with disabilities and should play an amplifying role in ensuring that any disability-related abuse is viewed as a grave human rights issue.^{ccxcii} That, however, will depend on how it is implemented and enforced. In our opinion, these gaps exist in the implementation and enforcement of the UNCRPD in practice.

Applicability of UNCRPD depends on State Parties' ratification

The UNCRPD is an international treaty and so it requires State Parties to first ratify it and then take action to reflect its provisions in national law. If State Parties choose not to accede to the UNCRPD, citizens in those State Parties will have no access to its protections.

Insufficient enforcement mechanism for aggrieved individuals

Even for a State Party that has ratified the UNCRPD, if the State Party does not implement the UNCRPD into national law, individuals will not have any meaningful recourse to realise the rights and protections provided for under the UNCRPD. In practice, individuals have very limited means by which to take direct enforcement action under the UNCRPD against the State Party unless the State Party has also signed up to the Optional Protocol to the Convention on the Rights of Persons with Disabilities (the “**Optional Protocol**”) which establishes a separate complaint mechanism to the UN treaty body.^{ccxciii} This creates a gap between the aspirations of the UNCRPD and the reality of the protections that actually exist in law.

The implementation of the UNCRPD is monitored by the United Nations Committee on the Rights of Persons with Disabilities (the “**UN Committee**”) which comprises 18 independent experts elected from a list of persons nominated by the State Parties at the Conference of the State Parties to serve in their individual capacity.^{ccxciv} All State Parties have to submit regular reports to the Committee on how the rights enshrined in the UNCRPD are being implemented. State Parties must report initially within two years of ratifying the UNCRPD and, thereafter, every four years. The UN Committee examines each report and makes suggestions and general recommendations on the report. It forwards these recommendations, in the form of concluding observations, to the State Party concerned.^{ccxcv}

Parties to the UNCRPD may choose whether to also ratify the Optional Protocol. If a State Party has ratified the Optional Protocol in addition to the UNCRPD, it would be possible for an individual or a group (such as a civil society organization) to complain to the UN Committee if a State Party to the Optional Protocol has violated the UNCRPD.^{ccxcvi} The Optional Protocol requires subscribing states to recognise the competence of the UN Committee to receive and hear complaints from individuals who believe their rights under the UNCRPD have been violated.^{ccxcvii}

Upon receiving the complaint (a.k.a. “communication” in UN terminology), the UN Committee examines the merits of the complaint and the observations of the State Party, formulates its views and recommendations (if any), forwards them to the State Party, and makes them public. This mechanism therefore provides individuals with recourse for alleged violations of the UNCRPD.^{ccxcviii ccxcix}

However, this procedure is not akin to ordinary enforcement at court (e.g. where a domestic law such as the Equality Act 2010 is violated by a local government) and individuals are likely to face challenges in enforcing the UN Committee’s decision in their home country. The procedures may also appear daunting to an individual especially if there is no support from a civil society organization or legal professionals conversant in international human rights law.

Where a State Party has not ratified the Optional Protocol, such mechanism is unavailable to citizens in that State Party even if the State Party has ratified the UNCRPD. Article 2 of the Optional Protocol clearly states that no communication shall be received by the Committee if it concerns a State Party to the UNCRPD that is not a party to the Optional Protocol. As of May 2021, there are 94 signatories and 98 parties to the Optional Protocol^{ccc}, as compared to 164 signatories and 182 parties to the UNCRPD. The United Kingdom has ratified both the UNCRPD and its Optional Protocol.

Poor monitoring mechanism by the United Nations and the lack of strong incentives for State Parties' compliance

The UNCRPD and its Optional Protocol contain various mechanisms to monitor State Parties' compliance with their provisions and encourage State Parties to comply, such as:

- **State Parties self-monitoring** – Article 33(2) of the UNCRPD requires State Parties to establish an independent framework for promoting, protecting and monitoring implementation of the UNCRPD. Article 33(3) of the UNCRPD envisages that civil society will participate fully in the monitoring process.
- **Reports by State Parties** – Article 35 of the UNCRPD requires State Parties to submit a comprehensive report to the UN Committee on measures taken to give effect to its obligations under the UNCRPD and its progress within 2 years after entry into force for the concerned State Party and thereafter every 4 years. Such reports should be made available to the public under Article 36(4) of the UNCRPD.
- **Inquiry by the UN Committee** – Under Article 6 of the Optional Protocol, if the UN Committee receives reliable information indicating grave or systematic violations by a State Party to the Optional Protocol of any of the provisions of the UNCRPD, the UN Committee may invite the State Party in question to respond to such information. After considering the State Party's observations and any other reliable information, the UN Committee may designate one or more of its members to conduct an inquiry and issue a report urgently. If the State Party agrees, the UN Committee may visit the country in question. After undertaking the inquiry, the UN Committee transmits its findings to the State Party, which has six months to submit further observations. The UN Committee eventually summarizes its findings, which it makes public. However, under Article 8 of the Optional Protocol, a State Party ratifying it may "opt out" of the inquiry procedure under Articles 6 and 7, which may limit the effectiveness of such process for people trying to raise awareness of a State Party's non-compliance with the UNCRPD (and the Optional Protocol).
- **Role of the UN Committee** – Article 1 of the Optional Protocol provides a procedure for individuals to complain to the UN Committee established under Article 34 of the UNCRPD.

Although there are monitoring and enforcement mechanisms, we do not consider them to be sufficiently robust. In particular, State Parties are primarily responsible for monitoring their own compliance with the UNCRPD and reporting on their progress, while the UN Committee established under the UNCRPD has limited powers to make enquires and public findings. As illustrated by the following case study on the UK's compliance with the UNCRPD, it can be seen that the overall enforcement mechanism relies heavily on cooperation of the State Party concerned and whether a State Party has ratified the Optional Protocol. The UK's approach to implementation of the UNCRPD is an example of State Parties electing to take limited action despite subscribing to the UNCRPD (and its Optional Protocol).

Case Study: United Kingdom

In the UK, the UNCRPD was given effect through policies and legislation, including the UK Equality Act.^{ccci} The UK Independent Mechanism, consisting of the Equality and Human Rights Commission^{ccci}, the Equality Commission for Northern Ireland^{ccci}, the Northern Ireland Human Rights Commission^{ccci} and the Scottish Human Rights Commission^{cccv}, was established to promote, protect and monitor the UK's implementation of the UNCRPD.^{cccv} The UK Independent Mechanism, together with the UN Committee and the Conference of State Parties, provide some

degree of oversight and accountability to ensure that the UK implements the rights and protections set out under the UNCRPD into national law and policy.

In 2016, the House of Lords Select Committee on the Equality Act 2010 and Disability heard evidence from disability groups that the UK government had failed to implement provisions of the UNCRPD including the need to closely consult with people with disabilities when developing and implementing policy and ensuring equal access to justice, political participation and independent living.^{cccvii} The findings of the House of Lords Committee report were followed by a complaint instigated through the Optional Protocol mechanism and the UN Committee found that there had been “grave and systematic violations of the rights of persons with disabilities” in the UK.^{cccviii} In the UN Committee’s concluding observations on that report, issued in October 2017, it found that there was “insufficient and uneven implementation of the Convention across all policy areas and levels within all regions, devolved governments...” and expressed concern with “existing laws, regulations and practices that discriminate against persons with disabilities”.^{cccix} The UN Committee issued a number of recommendations both in its initial report and in its concluding observations, including a recommendation to incorporate the UNCRPD into UK legislation.^{cccx} In addition, it requested that the UK submit a report by July 2023 detailing the implementation of its recommendations.

While this case study illustrates the monitoring and oversight role played by the UN Committee, there has been little change in the approach of the UK government, and instead, it has at times expressed disagreement with the UN Committee’s findings.^{cccxi} This highlights the bureaucratic nature of seeking recourse under the UNCRPD. This is the only path available to groups acting for persons with disabilities to seek recourse for breaches of the UNCRPD; there is otherwise no effective enforcement mechanism^{cccxi} that can require the UK to take action and so there remains a gap between what the UNCRPD provides for and what protections individuals can avail themselves of under law in the UK.

Article 40 of the UNCRPD provides that the State Parties should meet regularly in a Conference of State Parties in order to consider any matter with regard to the implementation of the UNCRPD. However, the establishment of such a conference mechanism has also had limited impact with regard to the implementation of the UNCRPD and is yet to realise its potential in instigating changes in the law.^{cccxiii} Whilst it has the ability to increase the overall effectiveness of the UNCRPD, it has yet to take on the role of interpreting and developing the UNCRPD.^{cccxiv} In the absence of such action, State Parties are unlikely to take the initiative to implement change in this area.^{cccxv}

UNCRPD does not define disability to include facial disfigurement

The former Chairman of Face Equality International, the late Mr James Partridge, expressed considerable concern that the UNCRPD does not explicitly recognise that persons with facial disfigurements can be vulnerable to prejudice and discrimination.^{cccxvi} The UNCRPD defines the term “Discrimination on the basis of disability” in its Article 2 but does not define the term “disability” or “persons with disability”. Similarly, the Optional Protocol leaves “disability” undefined in its Article 12. However, Article 1 of the UNCRPD provides some guidance, stating that:

“(p)ersons 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”.

The lack of a restrictive definition of “disability” was deliberate. The Preamble to the UNCRPD recognises that “disability is an evolving concept” and that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.^{cccxvii} The United Nations has also clarified that it preferred to avoid a static definition of disability or a definition that restricted coverage to particular persons^{cccxviii} and explained that “disability is not considered as a medical condition, but rather as a result of the interaction between negative attitudes or an unwelcoming environment with the condition of particular persons.”^{cccxix}

It follows that there is no internationally agreed definition of “disability” and there is certainly no express protection for persons with facial disfigurement under the UNCRPD, although the scope of “disability” under the UNCRPD is

wide enough to cover facial disfigurements. Whilst State Parties are free to enact domestic legislation to expressly protect persons with facial disfigurements, the lack of express recognition under the UNCRPD can be considered a gap, which may lead to a divergence in the protections afforded by the UNCRPD when it is reflected in national law and policy.^{cccxx}

For example, the UK Equality Act provides that only someone with a “severe disfigurement” should be treated as meeting the definition of disability.^{cccxi} However, a lack of clear statutory guidance and case law on the meaning of “disfigurement” means that the parameters of the UK Equality Act remain uncertain. Furthermore, EU law yields no definition of disfigurement either.

The UK Equality Act Guidance merely provides a limited explanation of the concept of severe disfigurement:

‘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).’^{cccxii}

There have been relatively few reported cases under the severe disfigurement provision, but those reported have not moved much beyond the examples given in the Guidance. *Johansson*^{cccxiii} and *Hand*^{cccxiv} (both decisions of the Northern Ireland Industrial Tribunals, applying similar severe disfigurement wording) and *Griffiths*^{cccv} all concerned facial scarring. It is not clear *why* the reported case law is so limited: this is an area currently under research, but possibly the lack of a clear definition may be one factor deterring claims.

The lack of a clear definition has also meant that courts have failed to recognise facial movement impairments as disabilities. In *Vatcher*^{cccvi}, the Claimant suffered from involuntary facial tics as a result of Tourette’s syndrome, which did not meet the standard definition of disability. The Employment Appeal Tribunal 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.

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 the *Johansson* case, for example, the fact that the Claimant’s facial expressions were found to be “normal and appropriate”^{cccvii} contributed to a finding by the Northern Ireland Industrial Tribunal that the Claimant’s disfigurement was not severe. Second, 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.^{cccviii}

One could argue that the lack of a clear definition in the UNCRPD has had a knock-on effect on national decision-making as national laws themselves fail to clearly define facial disfigurement.

UNCRPD is ambiguous and lacks detailed protection

Another criticism of the UNCRPD is that it is ambiguous and lacking in detail.^{cccix} Much of the language is aspirational and it is ultimately left to individual State Parties to translate those aspirations into definitive and actionable law. However, many State Parties have instead elected to take little or no action and retain existing law despite subscribing to the UNCRPD.^{cccxx} Some examples of how the vaguely worded obligations may be insufficient to protect persons with facial disfigurement include:

- **Article 8 – Awareness-raising:** Article 8(1) of the UNCRPD obliges State Parties to raise awareness throughout society regarding persons with disabilities and to adopt measures to foster respect for the rights and dignity of persons with disabilities, to combat stereotypes, prejudices and harmful practices relating to persons with disabilities and to promote awareness of the capabilities and contributions of persons with

disabilities. Article 8(2) of the UNCRPD sets out measures to implement such obligations in very broad terms (e.g. effective public awareness campaigns, encourage all organs of the media to portray persons with disabilities in a manner consistent with the UNCRPD, etc.). However, this broad language arguably does little to combat specific and complex problems faced by persons with facial disfigurements, including abuse and trolling suffered by them on social media platforms and their almost complete ‘invisibility’ on television and news broadcasting.^{cccxxxi}

- **Article 24 – Education:** Article 24(1) of the UNCRPD recognises the right of persons with disabilities to receive education and requires State Parties to ensure an inclusive education system. Article 24(2) of the UNCRPD requires State Parties to ensure, amongst other things, that persons with disabilities “*receive the support required, within the general education system, to facilitate their effective education*”. Otherwise, the only specific protections under Article 24 of the UNCRPD are found in Articles 24(3) and 24(4) of the UNCRPD, concerning educational support for deaf and blind children. The UNCRPD therefore fails to address a major problem for children with facial disfigurement, namely, bullying that targets their appearance suffered in schools.^{cccxxxi} Whilst the broad language in Article 24(2) of the UNCRPD could include support against bullying of students with disabilities, State Parties are offered no guidance by the UNCRPD texts on the specific type of support required.
- **Article 27 – Work and employment:** Similar to how the UNCRPD deals with education, Article 27(1) of the UNCRPD recognises the basic right of persons with disabilities to work, on an equal basis with others and State Parties are required to, amongst other things, take appropriate steps to prohibit discrimination on the basis of disability concerning all forms of employment and protect the right of persons with disabilities to just and favourable conditions of work, including “*safe and healthy working conditions and protection from harassment*”.^{cccxxxi} Article 27 of the UNCRPD certainly provides some protection for persons with a facial disfigurement (provided they come within a State Party’s definition of disability). However, a major barrier for persons with facial disfigurement is unconscious bias and implicit attitudes, which lead to unfair treatment.^{cccxxxi} The UNCRPD offers no guidance to State Parties about how to combat this (e.g. through training of human resource functions and staff).

UNCRPD does not protect particular risk groups for facial disfigurements

Article 6 of the UNCRPD recognises that women and girls with disabilities may be subject to multiple types of discrimination, while Article 7 of the UNCRPD recognises that children with disabilities should be treated equally to children without disabilities. These are important protections, and will extend to women and children with facial disfigurements, provided the definition of disability adopted by State Parties is sufficiently broad to capture facial disfigurements. However, the UNCRPD does not recognise any other more specific groups, including groups who may have suffered facial disfigurement (e.g. war veterans, civilians injured by war, vehicle accident survivors, cancer survivors, persons with congenital conditions, victims of violent crime, etc). This could be considered a gap in protection, with State Parties left without sufficient guidance on particular groups at risk of facial inequality issues and discriminatory treatment.

UNCRPD does not offer sufficient protection to victims of violent crimes and deterrence to perpetrators of crimes causing facial disfigurement

Article 16(1) of the UNCRPD provides that State Parties shall take all appropriate legislative, administrative, social educational and other measures to protect persons with disabilities from all forms of exploitation, violence and abuse. Article 16(5) of the UNCRPD requires State Parties to put in place effective legislation and policies, including women and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated, and where appropriate, prosecuted. The obligation is placed on the State Parties, rather than individuals.

Facial disfigurement caused by violent crimes, including acid attacks, are particularly prevalent against women in India, Bangladesh, Pakistan and Cambodia, and the commission of such crimes typically causes permanent facial disfigurement.^{cccxxxv} The UNCRPD, placing the obligation on State Parties to prevent and investigate such crimes, does not offer sufficient protection to victims suffering from violent crimes because they have no recourse under the UNCRPD to seek direct remedy against the perpetrators.

Lack of consultations with and involvement of persons with disabilities

There continues to be an important gap between the goals and the spirit of Articles 4(3) and 33(3) of the UNCRPD (consulting and actively involving people with disabilities through representative organisations in the decision-making processes concerning issues relating to persons with disabilities) and the degree to which those Articles have been implemented. As the UK case study above reveals, countries have so far failed to adequately include those members of the public in the development and implementation of policies and programmes that it is trying to protect under the UNCRPD.^{cccxxxvi}

6. What legal/regulatory reforms are needed if people are to seek protection (either on the grounds that facial disfigurement is a disability, or on other grounds)?

Given the deliberately broad and aspirational nature of the UNCRPD, it is unlikely that the UNCRPD itself could be amended/reformed to increase protection for persons with disabilities, including persons with facial disfigurements – whether defined as a disability or not. However, in light of the “gaps” identified, potential measures to enhance protection under the UNCRPD for people with facial disfigurements include:

- **United Nations Guidance on the definition of disability:** Clarifying or confirming (either through a working paper or other guidance material such as the General Comment^{cccxxvii}) that facial disfigurement is considered as falling within the definition of “disability” or “persons with a disability” under the UNCRPD. This would enhance protection for persons with facial disfigurement under the UNCRPD.
- **United Nations Guidance on consulting with people with disabilities:** To ensure the goal of consulting and actively involving people with disabilities through representative organisations in the decision-making processes concerning issues relating to persons with disabilities no longer remains a mere aspiration, the UN Committee should outline clear examples via guidance material as to how such inclusion and consultations could effectively be implemented by State Parties. It should further offer concrete guidance in the development and implementation of such national policies and programmes. We note that the UN Committee has already attempted to do so by issuing the General Comment No. 7 (2018)^{cccxxviii} on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the UNCRPD. It is noteworthy that the UN Committee has explained in this General Comment that full and effective participation entails the inclusion of persons with disabilities in different decision-making bodies, both at local, regional, national and international levels, and in national human rights institutions, ad hoc committees, councils and regional or municipality organizations. State Parties should recognise in their legislation and practice that all persons with disabilities can be nominated or elected to any representative bodies: for example, ensuring the nomination of persons with disabilities to disability councils at the municipal level, or as specific disability-rights office-holders in the composition of national human rights institutions.^{cccxxix} The UN Committee should ensure that the relevant requirements set out in this General Comment would be implemented by State Parties through national law and policies.
- **Increase enforcement and monitoring of the UNCRPD:**As it currently stands, the UNCRPD relies heavily on State Parties’ compliance and monitoring. Reforms need to recognise that current enforcement mechanisms are insufficient to ensure an adequate level of adherence to the goals and aspirations of the UNCRPD and are therefore insufficiently robust to provide meaningful protection to the people the UNCRPD aims to protect.
- **UNCRPD to recognise other affected groups:** The UNCRPD should officially recognise other more specific groups, including groups who may have suffered facial disfigurement (e.g. war veterans, civilians injured by war, vehicle accident survivors, cancer survivors, persons with congenital conditions, victims of violent crime, etc). It is essential to provide detailed guidance on specific considerations for any such groups at risk of facial inequality issues and discriminatory treatment.

In addition, renewed effort should be made to encourage ratification of the UNCRPD by Non-State Parties and to encourage ratification of the Optional Protocol among signatories to the UNCRPD who have not yet done so.

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- “1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.”
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