



Face
Equality
Training

THEORETICAL REPORT

Designed and made by
Nichola Rumsey & Thomas Nilsen, TRISKELION NORWAY,
Martin Persson Kristianstad University
Gareth Davies, ECO



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Section 1 Introduction

Foreword: The Genesis of this Project

The imperative to develop training as part of efforts to promote Face Equality in Europe and beyond was addressed at a workshop in the European Parliament "*Inequalities in access to cleft and craniofacial care*", held in Brussels, 27 February 2018. The lack of training and resources to facilitate effective interventions by healthcare and other key community-based agencies was also highlighted by participants from 32 European countries in COST Action IS1210, 'Appearance Matters' (2014-2017; Harcourt et al, 2018) and Cost Action 16234 European Cleft and Craniofacial Initiative for Equality in Care (ECCE – 2017 – 2022). The founding of the UK-based NGO *Face Equality International (FEI)* in 2018 further emphasised the need for a change in approach to dealing with disfigurement. FEI is a social justice movement which emphasises the need for society to change so that people with a visible difference can live freely, without indignity or discrimination. Education is at the heart of this – educating healthcare professionals to better understand the challenges faced by people who look different, educating communities, educating educators. As a backdrop to the above initiatives, the EU launched the European Reference Networks for Rare Diseases in 2017. These 22 networks were primarily designed to allow exchange of clinical knowledge and skills across national borders for individuals with a rare disease. However, the importance of recognising the role of patients as partners in their care has become fundamental within the networks. Improved communication between healthcare professionals and patients is a priority. One of the authors of this report is the lead patient representative in the European Reference Network for Craniofacial Anomalies ([ERN CRANIO](#)); the voices of those with a visible difference within the network have been instrumental in shaping this project.

Why is this Project Needed?

In Europe, the estimated 10 million people who live with an appearance that sets them apart from the norm face challenges and stigma as they go about their daily lives (Harcourt et al., 2018). Research shows that significant numbers of people with visible difference

experience stigmatisation and social exclusion with negative impacts on both their mental health and life chances (Rumsey and Harcourt, 2012), however, the practical application of this research into effective support in medical and social communities is lacking. People living with a disfigurement report that the majority of the general public and many health professionals have insufficient understanding of the specific challenges they face (Kornhaber et al., 2014, Dahl et al., 2012, Moi and Gjengedal, 2008) and health care staff report having insufficient time and little confidence in meeting these patients' information and support needs (Konradsen et al., 2009, Persson et al., 2008, Clarke and Cooper, 2001). Although a small number of specialist health care teams now have the ability to facilitate access to psychosocial specialists, in the vast majority of European teams working with people with a disfiguring condition, psychosocial care provision is either inadequately developed or non-existent (Harcourt et al., 2018).

In the absence of appropriate training for health care professionals and other key agencies, people with an unusual facial appearance spend the majority of their lives unable to access optimal support and intervention. Furthermore, distress related to appearance can be exacerbated in people belonging to disadvantaged groups. A visible difference can be a cause or be a consequence of social disadvantage (Banerjee and Dittmar, 2008). People from lower socio-economic and otherwise disadvantaged groups are likely to be disproportionately affected by the pressures exerted by social norms as they try to access to new or existing groups. The consequences for the person's self-esteem, sense of belonging and sense of identity are particularly acute (Widdows, 2018) as people from disadvantaged groups do not have access to resources to prevent damaging effects on subjective well-being and self-worth.

A Word About Language

An appearance set apart from current norms and ideals is usually described using language associated with negative connotations of fault or blame. Common descriptors include words such as 'disfigurement', 'abnormality' 'flaw' and 'deviation'. Researchers and charities in this sector have long debated the most appropriate terminology to use and the term 'visible difference' has been in common parlance in these communities over the past decade.

However, a recent survey by Changing Faces (2023) of more than 1500 people highlighted that 67% of respondents didn't recognise the use of the term 'visible difference' to describe people with an unusual appearance. The Non-Governmental Organisation 'Face Equality International' uses 'disfigurement' in its campaigning, as this term is widely understood and is used in legislation. In this report, the terms 'visible difference' and 'disfigurement' are used interchangeably (www.changingfaces.org).

Defining 'visible difference'

A 'visible difference' (disfigurement) can result from a wide variety of cases. It may be congenital and therefore, present from birth (for example, a cleft of the lip; a birthmark), acquired at some stage of life (for example, a burn injury), the result of disease (for example, a skin condition such as eczema or psoriasis), or the result of medical or surgical intervention (for example, the removal of a tumour, or a side effect of medication). The visible difference can be permanent, progressive or transitory in nature. Estimates of the overall incidence of visible differences in the general population vary, but may be as many as 1:5 (Partridge, 2020).

Background: Why are efforts to promote Face Equality needed?

The societal context

Interest in appearance is a universal social phenomenon and evidence for the current heavy emphasis on physical appearance in society is plentiful. Millions of Euros are spent each year on cosmetic products and diet foods as people struggle to match up to images communicated through social and broadcast media. Advertising continually endorses the importance and benefits of physical attractiveness, promotes unrealistic ideals and is replete with explicit or implicit messages that our bodies are malleable – we should be striving to bring ourselves more closely in line with ideals. To a greater or lesser degree, we all internalise the imperative to reduce the gap between our own appearance and these ideals,

often motivated by the belief that this will enhance our relationships, social lives and occupational prospects. The value placed on outward appearance is becoming greater and more disproportionate to other aspects of self-esteem and self-worth.

Good-looking people are perceived to be more intelligent, popular, honest and socially desirable. Children from as young as 5 years of age stereotype on the basis of physical appearance, choosing more attractive children as potential friends, expecting them to be more popular and intelligent than their less attractive peers (Masnari et al., 2013). Despite lobbying in recent years type-casting in films and on television on the basis of appearance remain rife. Characters with unprepossessing personalities and anti-social behaviour are frequently portrayed as being ugly or in some way disfigured. Language is used that reflects negative attitudes towards those who deviate from perceived norms, implying that there is something inherently 'wrong' about the way the person looks (Partridge, 2020).

The message that young people & adults need to change their bodies has overwhelmed a generation (see for example, www.bodyimagemovement.com). Technological advances and the widespread availability of aesthetic surgery are now widely advertised in magazines and other forms of the media. People have surgery and less invasive cosmetic 'tweakments' in the belief that an appearance more closely aligned with current ideals will improve their chances of employment, of securing a relationship, of appearing more youthful and of reducing defining signs of their heritage (for example, skin lightening; rhinoplasty; eye shaping). The shortcomings and risks of aesthetic procedures are often downplayed in the media. This may contribute to unrealistic expectations of the likely outcomes of surgery and other treatments designed to enhance appearance (Widdows, 2018). The perception of cosmetic surgery and less invasive aesthetic procedures as a 'normal' intervention to address appearance concerns may increase the pressure on people with visible differences by promoting the notion that visible anomalies are 'unacceptable' and should be removed through surgical intervention.

Frameworks of disability have also been used to explain the public's response to visible difference. The *moral model* of disability revolves around the notion that an affected person in some way deserved their fate. Disfigurements are viewed as a mark of sin or a curse.

Children may be prevented from attending school and adults from seeking employment or entering into relationships in the belief that they might scare others or bring shame on their families. The *evolutionary model* explains negative responses to disability and disfigurement through a mechanism of instinctive rejection of the 'less than perfect' in which stigma is a natural reaction to something that is different or potentially threatening. Researchers exploring this possibility have typically employed an experimental paradigm based on the Implicit Attitude Test (IAT). The IAT assesses the reaction times of respondents when they are asked to associate positive and negative words with images of people depicted with or without visible differences. The results of these studies have been contradictory. Some have supported the existence of an instinctive rejection of people with an unusual appearance and have been used to inform the content of attitude campaigns (see below). Others (most recently, (Roberts et al., 2017) have shown no evidence of the existence of instinctive negative reactions, instead attributing any differences in reaction times to the additional time taken to process an unfamiliar facial difference.

The *medical model* frames disability as the direct result of pathogens in the body or mind and focuses on signs and symptoms of disease and functional impairment. Medicine aims to cure these. Within this framework, the onus lies with the affected individual to get the 'problem' treated. The care and treatment of people with visible differences reinforces this notion by seeking to 'normalise' appearance, reinforcing the assumption that aesthetic improvement will enhance a person's quality of life (Rumsey and Harcourt, 2004). The *social model* is widely discussed by disability activists & scholars. In this framework, society is the primary cause of disability. and the problem lies with society rather than the individual. *Ableism* is the stereotyping, discrimination or oppression of people with disabilities and/or disfigurements. Through a process of social conditioning (for example, through messages in social and broadcast media and in advertising) people with disabilities and visible differences are viewed as second-class citizens who need to be 'fixed' - and who experience abuse, discrimination & inequality as a result (Bogart and Dunn, 2019).

There are differences in the extent to which the beliefs of each of these models predominate in different countries and sub-cultures (see, for example, Face Equality International's

reports on stigma in India & Nepal and in Mexico – available from www.faceequalityinternational.org), but whatever the root causes, each works to the detriment of people set apart by an unusual appearance. Although popular culture is changing to be more inclusive across the globe, damaging negative stereotypes of people with an unusual appearance persist. Public understanding of the causes and consequences of visible differences has a long way to go. Rarely are people with disfigurements portrayed in positions of power or authority (or as a hero) in the media and all too often, still appear in the role of villain or victim, or someone whose mental health is compromised. In their 2014 survey, Changing Faces reported that 64% of their sample of people with disfigurements didn't feel represented in advertisements and that 27% felt ignored by shop assistants or report receiving poor service (Partridge, 2020).

Coining the term '*face-ism*' to refer to all types of discrimination based on facial appearance, Changing Faces responded to their survey by issuing a call to action in 2019, stating that '*we need to act now to challenge stigma & prejudice, to achieve better representation for people with visible differences across media & brand campaigns....*' (www.changingfaces.org). However, despite these calls, there is no doubt that face-ism and other forms of discrimination working to the detriment of those with an unusual appearance, remain damaging to millions of Europeans and others across the globe.

The challenges associated with living with a visible difference

Looking 'different' in a society obsessed with 'looks' and where there is pressure to emulate unrealistic appearance ideals, is tough. Being or feeling excluded from public life because of a visible difference can have negative impacts in key areas of living, including people's health and well-being, their life chances and their opportunity to live a life of their own choosing. Reports of negative emotional impacts, including enduring lowered self-esteem and self-worth, states of anxiety, depression and social anxiety as well as more transitory states of shame and embarrassment from the stigma of feeling different, negative body image, anger, guilt and self-consciousness (Rumsey and Hamlet, 2017). Quality of Life among those with skin conditions, for example, is frequently reported as lower than that in the general population, with between 25-50% of patients with skin conditions experiencing heightened

levels of psychological distress (Bundy, 2012, Schmit-Ot and Steen, 2010) reported that the impact of psoriasis on the quality of patients' lives was just as pronounced as the impact of other chronic and even life-threatening diseases, including cancer, heart attack, or chronic pulmonary diseases.

Reports of negative experiences relating to encounters with others are frequent amongst those with a visible difference. People with disfigurements experience a loss (or lack) of civil inattention that most people take for granted. In a survey in 2019 of 800 people with visible differences, Changing Faces reported that 23% of respondents felt self-conscious going out in public (because of the potential reactions of others), 36% had experienced hostile behaviour, 47% had experienced unwanted and negative attention from others (including staring and negative comments). While almost everyone experiences teasing and while physical appearance is a very obvious characteristic to choose as the focus of teasing and butt of jokes, for many people with an unusual appearance, teasing, bullying, and staring are commonplace and sources of worry and distress. These experiences can include unsolicited and unwanted attention in the form of staring, 'double-takes', unwelcome questioning, hurtful comments or outright avoidance by others. Fifty eight percent of respondents from a general public sample in Changing Face's 2023 survey reported having found themselves staring at someone with a visible difference and 60% recalled that they have quickly looked away from a person with an unusual facial appearance (www.changingfaces.org). Research indicates that social difficulties may be exacerbated at times of transition or change, for example, moving to a new neighbourhood, changing schools, college or jobs (Rumsey and Harcourt, 2012).

Although this kind of avoidance, or the lack of an appropriate response, is often underpinned by a lack of awareness of types and causes of visible differences and a resulting lack of confidence in knowing how to behave, this reaction is often unpleasant for those affected. People with visible differences who are anxious or distressed by actual or potential responses from others may avoid specific activities (such as holidays in warm climates, or swimming) where the feature might be on show may be avoided, or there may be a more general avoidance of social encounters. An unplanned revealing of the feature to others (for example, in a changing room, in certain weather conditions, being seen without camouflage

make-up) can also be stressful (Sharratt et al., 2018). If the visible difference appearances to be contagious in some way (as in some skin conditions, or in relation to neurofibromatosis), affected people are particularly sensitive to the fact that others may not wish to touch them.

Not all socialising takes place face-to-face. In line with the exponential increase in the use of social media over the past decade, there is increasing evidence of the stresses of navigating this medium for people with visible differences. Social media streams that rely heavily on visual representations (such as Facebook, Instagram/Meta & TikTok) present a particular problem. In these streams, posts are often accompanied by aspirational (rather than authentic) images. Users habitually take multiple pictures, choose the best and apply filters and editing software to enhance the image before posting online. Likes, other emojis posted by others often relate to a person's appearance, over-inflating the importance of appearance in everyday life (Rumsey and Diedrichs, 2018). While social media offers the opportunity for someone with a visible difference to connect with others living with a similar condition, many report high levels of distress when using more widely used streams. For those affected, this distress stems from a perceived dilemma relating to whether or not they should reveal their actual/authentic appearance. If a person shares depictions of their visible difference online, they risk being trolled by people expressing disgust and the view that the person shouldn't go out in public. While social media literacy training can encourage the affected person to take control of their social media streams, by muting streams that make them feel worse about themselves, focussing instead on body positive sites and supportive interchanges with other people sharing similar issues, Bogart and others (<https://www.instagram.com>Aboutfacecanada>) have called for broader action to provide an online environment in which all users believe it is acceptable to post authentic pictures – an online world where people can stop hiding and instead feel that it's acceptable to share and celebrate what makes us unique.

As they go about their daily lives, negative social experiences can lead to lowered self-esteem and self-confidence, and in detrimental impacts performance at school or in the workplace. In efforts to establish new friendships and romantic relationships, lowered self-esteem and feelings of self-worth may result in people with visible anomalies settling for less-than-ideal partners. Visible differences can impede the capacity and confidence of

some to engage in and to enjoy intimate relationships (Hamlet and Harcourt, 2015). Sharratt et al (2018) noted that the cumulative effects of negative social experiences can be disruptive to relationship development and that physical intimacy and sexual activity may be influenced by embarrassment, shame or the fear of these experiences. Some do not feel able to reveal their anomaly to a partner.

Anecdotal evidence suggests that a significant proportion of people with visible differences have trouble obtaining the kind of employment they would ideally like due to negative reactions to their appearance during the recruitment process, especially for those jobs that require customer contact. In a survey of people with the skin condition psoriasis, 67% claimed that their condition limited their job opportunities (Bundy, 2012) and the charity Changing Faces reported discrimination from potential employers in relation to front-of-house jobs from respondents to a survey in 2014 (Partridge, 2020). Thirty six percent felt they had been discriminated against in job applications, others reported being restricted to 'behind-the-scenes' roles, 34% of those in employment say their employers were not effective in preventing discrimination in the workplace. Partridge contextualised these findings in the existence of what he described as the 'soft bigotry of low expectations' relating to people with disfigurements at school (through the mechanism of teachers' assumptions & beliefs) and at work.

Differences in levels of adjustment to visible differences are considerable. Research has identified key factors and processes contributing to risk or to the protection of those affected. These include the person's susceptibility to his/her sociocultural context; demographic characteristics, such as age and gender, racial and cultural groupings; psychological factors and processes, including the person's outlook on life, their level of communication and social skills, the role of appearance in the person's self-esteem and sense of self-worth, and the extent to which a person relies on the opinions of other people for this sense of self-worth. Notably absent from contributory factors are the type, extent and visibility of a person's visible difference to others (Clarke et al., 2013).

The issue of Intersectionality

Body image dissatisfaction is now normative and has far-reaching consequences on the wellbeing of large sectors of the general population, and this distress can be compounded for those in particular social and cultural groupings. Appearance-related discrimination is more keenly experienced, for example, by older people – particularly women (whereas men 'age', women 'decay'), by disabled people, by migrants (who are not familiar with or able to conform to appearance norms and ideals) and by those from racial groups who are distanced from appearance ideals on the basis of skin colour and/or dress codes.

Intersectionality is a critical framework that examines how various forms of social stratification, such as race, gender, class, and others, overlap and intersect in individuals' lives (Cho et al., 2013).

In relation to social disadvantage, intersectionality posits that the effects of multiple forms of discrimination combine, overlap, or intersect, especially in the experiences of marginalised individuals or groups. For instance, a black woman's experience of discrimination is not just a sum of sexism and racism, but a unique combination of both that affects her in specific ways.

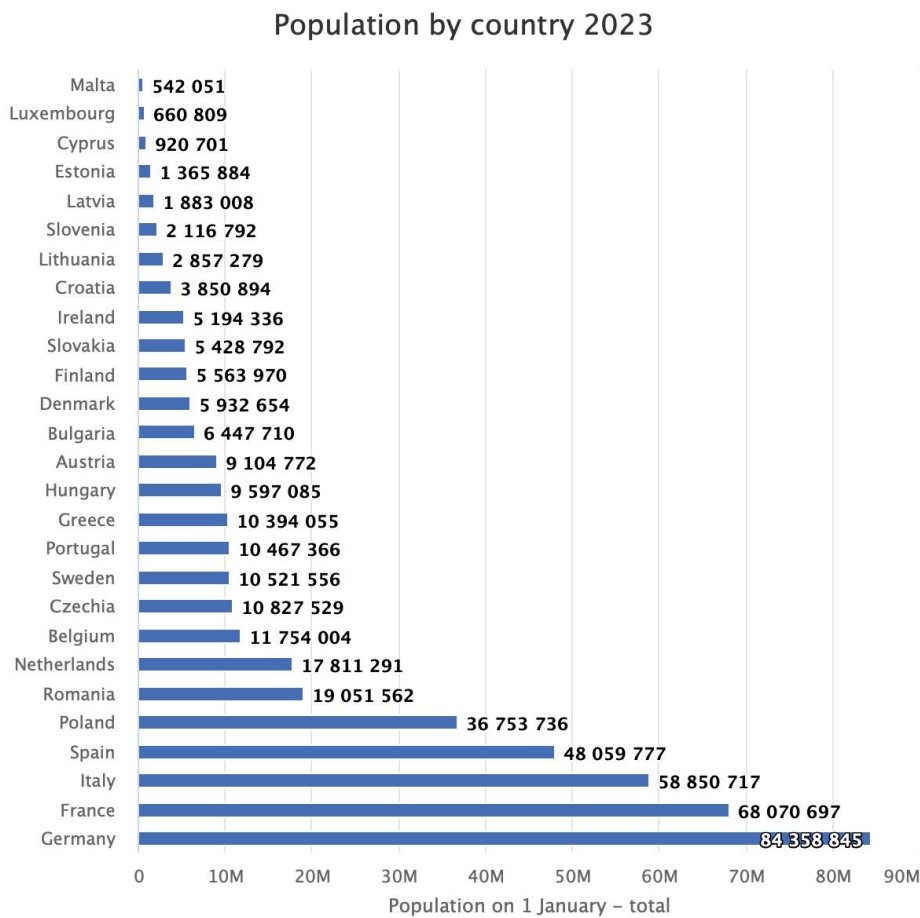
Socioeconomic status (SES) is another critical dimension that intersectionality helps to explore. SES, which encompasses income, education, and occupational status, significantly influences individuals' access to resources, opportunities, and privileges. Intersectionality reveals how SES intersects with other identities, such as race, gender, and ethnicity, to produce distinct experiences of advantage or disadvantage. For example, the experience of poverty can be vastly different for a white man compared to a woman of colour, due to the interplay of race, gender, and class.

Educational level is also deeply intertwined with intersectional identities. Education is often seen as a pathway to social mobility, but intersectionality highlights how access to and experiences within education systems are profoundly shaped by factors like race, gender, and class. For instance, students from lower socioeconomic backgrounds may face unique

challenges in educational settings that are not experienced by their more affluent peers, and these challenges can be further compounded for students who also belong to racial or ethnic minority groups.

In summary, intersectionality provides a nuanced and comprehensive framework for understanding the multifaceted impacts of social disadvantage, socioeconomic status, and educational level. It emphasises that these factors do not exist in isolation but are interwoven in complex ways that shape individuals' societal experiences and opportunities. Therefore, it is imperative to have a fundamental understanding of these aspects in a European context in relation to appearance-related discrimination.

The European Union Consists of 27 countries with a collective population of 448 million inhabitants.

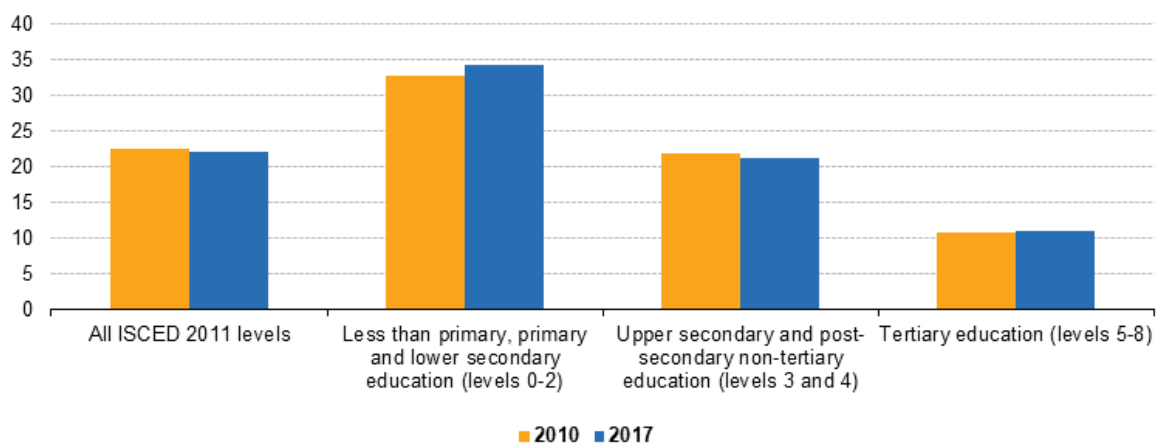


EUROPEAN UNION. 2020. EU in figures [Online]. Available: https://europa.eu/european-union/about-eu/figures/living_en [Accessed 31 August 2023].

In Europe, a range of communities face increased risks of social exclusion and poverty due to a mix of social, economic, and political influences. These socially marginalised groups include but are not limited to, individuals grappling with unemployment, those with disabilities, people experiencing mental health challenges, those with a limited educational background, as well as migrants and refugees (Sharratt et al., 2020). Migrants and refugees, especially those without legal status, encounter significant obstacles in social integration, language acquisition, and employment, heightening their poverty risk. Individuals with disabilities often find themselves with limited healthcare, education, and employment opportunities, perpetuating their exclusion and economic challenges.

People at risk of poverty or social exclusion, by educational attainment level, EU-28, 2010 and 2017

(% of population aged 18 and over)



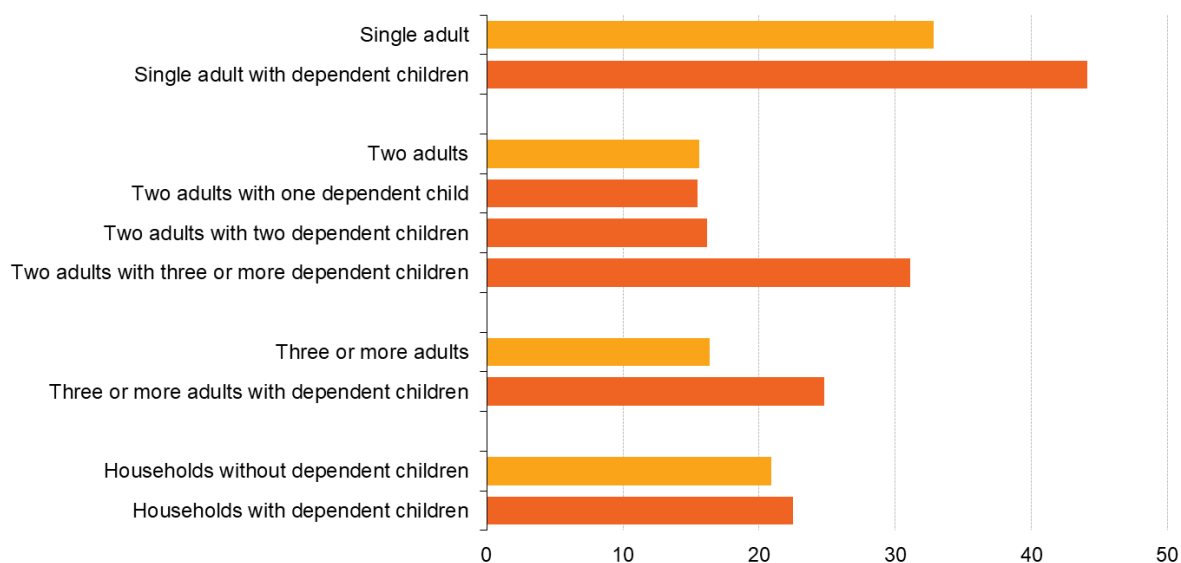
Source: Eurostat (online data code: ilc_peps04)



Single-parent families, predominantly led by women, are more vulnerable to poverty because of lower incomes and higher caregiving demands.

Share of the population at risk of poverty or social exclusion, analysed by household type, EU, 2021

(%)



Source: Eurostat (online data code: ilc_peps03n)

eurostat 

Additionally, long-term unemployed people struggle to re-enter the workforce, increasing their chances of social and economic hardship. Recognising and addressing these diverse groups' specific needs and hurdles is crucial for fostering social inclusion, economic stability, and fair opportunities throughout Europe.

Individuals with visible differences, such as physical disabilities, distinctive facial features, or skin conditions, frequently encounter a range of obstacles and challenges in their daily lives, accompanied by varying degrees of discrimination (Stone and Wright, 2013, Swift and Bogart, 2021). These challenges can manifest in multiple aspects of life, from social interactions to professional environments.

In social settings, these individuals might face stigmatisation or stereotyping based on their appearance (Jamrozik et al., 2019). This can lead to social isolation, as others may unconsciously or consciously exclude them from social groups or activities. The psychological impact of such exclusion can be significant, potentially leading to lowered self-esteem, anxiety, and depression.

In the workplace, individuals with visible differences often face biases in hiring and career progression (Jamrozik et al., 2019, Stone and Wright, 2013). Such experiences can hinder their professional development and negatively affect their job satisfaction and mental well-being.

Moreover, these individuals often face discrimination that can be both overt and subtle. This discrimination can come in the form of derogatory comments, invasive questions, or reduced opportunities in various spheres of life. Such experiences can reinforce feelings of being marginalised and misunderstood.

It is crucial for society to foster inclusivity and understanding towards individuals with visible differences. This involves implementing anti-discrimination laws and policies and promoting public awareness, education and empathy to create a more accepting and supportive environment for everyone, regardless of their physical appearance (Swift and Bogart, 2021).

The treatment context

Appearance concerns are prevalent in patients treated in a broad spectrum of surgical and medical specialties. Many factors will influence the experience and impacts of treatment on a person with visible difference. Contact with health services can happen in a number of ways, with the nature of this contact varying on the funding and configuration of services in different countries. Those born with congenital anomalies are likely to engage with healthcare professionals from birth onwards and this contact may continue either regularly or sporadically throughout life. Others will be treated following trauma and will experience healthcare on an unplanned basis. Those with visible differences resulting from disease (for example, skin conditions, tumours or neurofibromatosis) will receive specialist treatment as their condition develops. People with intermittent conditions may be managed by a family practitioner, with referral for specialist care when conditions flare up. Some will pay for elective treatment in the private sector.

Access to state funded healthcare provision varies considerably from country to country and in some instances, within each country, from region to region. This variation includes the professionals making up a care team, the way care is delivered and in relation to the funding of various treatments. Despite the consistent finding that psychosocial factors are more predictive of adjustment than the severity of a person's visible difference, the belief that the aetiology and severity of a visible difference predict adjustment persists. In most cases, treatment of visible differences focuses on 'fixing' any functional impairment and 'normalising' any anomaly in appearance. The training of health-care professionals may lead them to assume that 'fixing' the difference will be the best way to enhance the life experiences of their patients. The prevailing assumption is that improvements in appearance will result in decreases in psychological distress and any associated emotional and behavioural dysfunction. This well-motivated belief may lead to the perception that the visible difference is a 'defect', but, as Swift & Bogart have pointed out, what is perceived to be a 'defect' (accidents?; 'blemishes' from birth?; Downs syndrome?; small breasts?; asymmetric breasts?) and whether a person actually needs to be 'fixed', is socially and culturally constructed (Swift and Bogart, 2021). The availability of reconstructive procedures varies, influenced not only by funding policies within each country, but also by cultural ideas about what is 'normal' and perceptions of the likely benefits of aesthetic change. (Chambers, 2022) uses a quote from a woman who had undergone mastectomy to illustrate this point. *"I'm being offered many ways to keep looking normal [via various methods of breast reconstruction] to avoid offending the eye of the average man in the street, but zero ways to just be myself....a woman, like thousands in the UK, with one breast."* Surgeons, other team members and policy makers are also members of wider society and are also exposed to the same socio-cultural messages as their patients. Their beliefs may influence their dialogue with patients, inadvertently increasing the pressure to undergo treatment and influencing expectations of the likely gains in psychological wellbeing that might result from treatment (Rumsey, 2018). The process of treatment decision-making may also be affected, both in relation to whether or not treatment is likely to result in improved psychological well-being and in relation to the types of treatment the patient might undergo. Significant numbers of people with visible differences report that they have experienced pressure to have treatment from their healthcare system.

Many people with an unusual appearance report feeling uncomfortable in busy, very public, hospital waiting areas. Pre-existing worries or fears may be exacerbated by seeing others who are at various stages of treatment. Patients treated in publicly funded healthcare systems may experience pressure (either self-imposed, or conveyed by staff) to keep their consultation brief. In addition, many patients believe that doctors are primarily concerned with physical symptoms and any functional limitations associated with the visible difference. Although psychosocial concerns may be the primary motivation for seeking treatment, these frequently remain unaided. Previously prepared questions may be forgotten and sensitive issues avoided. Time pressures may also act as a barrier to practitioners and patients to allocate sufficient time for carefully considered decision-making in relation to treatment options (Rumsey and Hamlet, 2017). At larger centres, multidisciplinary teams may comprise in excess of 10 clinicians (including junior doctors, occupational and physical therapists) and other visitors. Patients can find the experience of being looked at and assessed in this type of consultation very distressing.

Coping with additional disfiguration in the immediate postoperative period (for example, as the result of swelling and bruising) may be particularly difficult for patients who have long-awaited improvements in their appearance. It may be a while before any long-term change can be detected. Following a traumatic injury, or changes to appearance as the result of treatment, there can be an acute sense of loss of identity. In some cases, people complain that they no longer recognise themselves, nor look like the 'real me'. Customary patterns of social behaviour and styles of coping may no longer work so well, leaving the person vulnerable to problems in interactions and relationships with others while they grow accustomed to the change in their appearance. (Pruzinsky, 1992) noted that during this time, patients often experience depression, anxiety and doubts about the eventual outcome of the surgical procedure. Reconstructive surgery involving complicated (and often unsightly) grafting procedures can take many years to complete. Follow-up is likely to focus on the physical aspects of post-operative recovery, with psychosocial issues taking a back seat, or ignored.

The lack of training and resources to enable healthcare professionals to appropriately support children, young people, and adults with visible differences has been highlighted

repeatedly in previous European projects (Persson et al., 2018a, Williamson et al., 2018, Persson, 2023). The desire of health care professionals to access appropriate materials is also very clear (Harcourt et al, 2018; Williamson et al, 2018).

What is the current legal situation?

Over the past decade, strides have been made across Europe and globally in the development and implementation of legislation to support the rights of people with disabilities. Cyprus, for example, revises and implements three yearly Disability Action Plans and a government Department of Social Inclusion of Persons with Disabilities promotes the social protection, social inclusion and employment of people with disabilities. Spain has a Ministry for Inclusion, Social Security & Migration and Sweden has a series of laws prohibiting discrimination in employment and educational settings. Although people with visible differences can be also considered to be the target of discrimination by virtue of societal attitudes, people living with a ‘disfigurement’ do not fit neatly into any existing categories of disability. Currently, a key dilemma for activists and legislators in the field, is whether people with disfigurements should be considered under the umbrella of ‘disability’. A substantial number of people living with visible differences are reluctant to self-identify as ‘disabled’ and the need for specific legislation to support people with visible disfigurements has been described as a globally neglected human rights issue (Swift and Bogart, 2021).

Legislation in the UK illustrates this dilemma well. Disability legislation introduced in 1995 was the first legal recognition world-wide that someone with an unusual face could be disadvantaged, not necessarily by physical barriers, but by people’s negative attitudes. The Disability Discrimination Act included people with ‘severe disfigurements’ alongside those with physical disabilities. The legislation required that people with disfigurements should be judged fairly, without prejudice or bias, and that they should be treated fairly and equally at work, in shops, in restaurants and at school, however, the majority of people with disfigurements, employers, lawyers, customer service organisations etc, remained unaware of the law or what it meant in practice. Although several cases were settled out of court, few came to the public’s attention. This Act was superseded in 2010 by The Equality Act. Although ‘severe’ disfigurements were again protected from discrimination, the definition of

'severe' remained fuzzy. Furthermore, a body of evidence had accumulated that demonstrated that discrimination and distress in people living with disfigurement are not well predicted by the objective severity of the 'difference'. The guidance accompanying the new legislation specifically mentions 'scars, birthmarks, diseases of the skin, limb or postural deformities', but an unusual appearance more generally, is not. This omission means that the UK's Act is not an effective deterrent to an employer choosing a 'better looking' job applicant over one with a visible difference and few claims have been made citing this legislation as validation of discrimination (Saunders, 2020)

It is clear that greater recognition of disfigurement and explicit legal protections are needed as part of broader human equality & rights movements and legislation. To this end, Face Equality International, About Face (Canada) and UK-based legal researcher, Dr. Hannah Saunders are currently engaged in efforts to lobby the United Nations to produce guidance & legislation to

1. Create appearance inclusive workplace environments
2. Make information about how to challenge appearance-based/visible difference discrimination more accessible
3. Increase engagement with the need for equality at individual, employer & policy levels.

At the time of writing, the outcomes of these lobbying efforts are not yet known.

Potential future challenges

Concerns have been raised by Face Equality International & Dr. Saunders that as artificial intelligence (AI) technologies (for example, in facial recognition) proliferate, discrimination may increase. For example, if face recognition software replaces human judgements in the process of shortlisting for jobs, the AI may reject faces or bodies that do not conform to expected patterns. Face Equality International has received several examples of people with facial differences who have had images of their faces classified as 'sensitive content' on Twitter (X), Instagram (Meta) or TikTok, further contributing to a sense of stigmatisation and marginalisation for those affected.

What needs to happen?

Enduring change is urgently needed at a societal level to improve the current situation. There is a need for greater understanding amongst the general public about the causes and consequences of visible differences, of the distress experienced by those set apart by their looks and of effective methods of offering support and intervention to prevent and ameliorate their distress. The challenge of unravelling current biases working in favour of people closer to physical ideals and to the detriment of those whose appearance is further from these ideals is a daunting one. Experience in other areas of attitude change (including, for example, racial prejudice; gender discrimination) suggests this is an ambitious, laborious and time-consuming task, but not one that should be shirked. 'Shoulder shrugging & the expectation that change will come from somewhere else' is not an adequate response to the current issues (Nuffield Council on Bioethics, 2017).

In addition to change at a societal level, efforts within key community agencies will also be required. Respondents to Changing Faces' survey in 2017 & 2023 (www.changingfaces.org.uk) have highlighted the need for more education about differences for children and young people (21%) and (Rumsey et al., 2013) have discussed the need to promote more inclusive environments in educational settings. Optimistically, respondents to surveys and research studies have also indicated the desire for more education about visible differences and the desire of respondents to 'help'. Young people in particular are inquisitive about the causes and consequences of visible differences and keen to know how best to behave to support peers with an unusual appearance.

There is considerable evidence that the prevailing ethos of health care provision and delivery for people with visible differences needs adaptation. Healthcare professionals operate within a wider social context and, in a similar way to the broader public, are also prone to the influences of advertising, social media and celebrity culture. Clinic staff may make assumptions about the consequences for patients of an appearance that falls short of prevailing ideals and may unwittingly convey unrealistic expectations of the likely benefits of a change in appearance. A key step in creating a more person-centred ethos of care will be

to develop awareness-raising resources and training in psychosocial aspects of living with a visible difference and its treatment.

Section 2: What do we know about effective ways to promote Face Equality

It is widely acknowledged that the goal of achieving social change is extremely challenging. Experience of efforts to eradicate sexism and racism, for example, illustrates the need for action at to take place at both macro (global, societal and community) and micro (individual and group) levels. An additional challenge is that it is notoriously difficult to evaluate the immediate and longer-term effectiveness of interventions designed to change beliefs, attitudes & behaviour. When reviewing the existing research and practise literatures, it is important to critically assess the evidence underpinning the conclusions drawn. Research studies are few and far between and evidence-based assessments of the impacts of interventions by charities and governments are hard to come by. There are, however, some parallels that can be drawn with interventions in related fields (such as campaigns intended to ameliorate racism & sexism and interventions designed to promote body image positivity. Below is a summary of examples of methods of providing support to individuals and condition-specific groups to support them in taking steps towards face equality, initiatives targeting specific professional groups and campaigns designed to reduce discrimination and prejudice at community and societal levels.

Promoting Face Equality at an individual level

There are several aspects to consider when considering the perspective of the individual in efforts to achieve face equality. Individual differences in support needs amongst people affected by a visible difference are considerable and needs vary over time, however, increased awareness of effective resources and greater ease of access to these resources will be helpful in encouraging individuals to take steps to reduce any prejudice and discrimination s/he may be experiencing.

Research indicates that the behaviour of the affected person is powerful in contributing to the quality of social encounters with others. While it may not be possible for the person with an unusual appearance to control all the challenges that come their way, it *is* possible to exert a considerable degree of control over their social interactions. There is evidence to indicate that the majority of negative experiences occur when meeting other people for the first time. If the interaction continues beyond the first impression stage of an encounter (estimated as 7-10 seconds), then the experience for both parties is likely to be enhanced (Rumsey, 2018). To this end, researchers have recommended supporting the affected person to equip themselves with:

- an enhanced level of communication and social skills
- the ability to exert a level of control over interactions with other people (for example, by being able to describe their condition, reassure others that the encounter will be positive and having the confidence to divert the conversation to other topics should they wish).
- techniques to promote a positive mindset by accepting and feeling comfortable with 'who they are'.
- social media literacy techniques designed to maximise the positives of their social media use and to minimise negative impacts. Potential techniques include the avoidance of negative comparisons with influencers and celebrities; the confidence to be authentic online.

Existing evidence-based online interventions designed to ameliorate distress and to provide practical skills for dealing with common challenges include:

- Facelt (for adults living with visible difference) (Bessell et al., 2012)
- YPFacelt (for young people aged 11-19
 - YPFacelt has also been adapted for young people in Norway (Zelihić et al., 2023)
- ACTNow (using the principles of Acceptance & Commitment Therapy to facilitate adjustment to visible difference in adults). (www.actnow-erasmusproject.eu)
- ACT it Out: Look different; live well (Zucchelli et al., 2023)
- Health Talk Online – Burns. 180 video clips of young people and adults talking about different elements of their experiences of being burned.

<https://www.healthtalkonline-burn-injuries> (the impact on consumers is currently being evaluated).

Resources available to support individuals living with visible difference in dealing with everyday challenges, including those resulting from Face *Inequality*, are available on the websites of many charities and organisations working in this sector. In excess of 80 podcasts on a broad range of topics related to the psychology of appearance are available from the webpages of The Centre for Appearance Research. Examples of these resources and access details are provided in Appendix 1. It should be noted that the majority of these resources are in English and there is clearly an imperative to develop resources more easily accessible to speakers of other European languages.

Individuals living with an unusual appearance are themselves powerful advocates for change. Those who are willing to tell their stories (why they look like they do and what it's like) can leave a powerful impression on their audiences. They or their carers can also volunteer (with appropriate training) to offer support to other people living with, or caring for someone with, the same condition. (Heath, 2020) reported that a large majority of a sample of parents of children affected by burns wanted support offered by other parents of children with burns).

Individuals either living with or personally unaffected by disfigurement, can also be encouraged to advocate for change by challenging everyday acts of discrimination, by calling-out stereotypic depictions (or the lack of representation) of people with an unusual appearance in films, video games and advertising, or by publicly applauding examples of when the current status quo is challenged. Individual members of the public can also take steps to understand how best to engage with someone who does have an unusual appearance.

Examples of this include the British born Greek, [Christian Hadjipatera](#) – an active campaigner for Face Equality who draws on his own experience to advocate for acceptance, compassion and visibility of people with an unusual appearance. The New York-based face equality activist [Sora J Kasuga](#), founder of [CirqOvation](#), is a performance artist who is trying

to break down societal barriers and bring awareness to the human rights issues at stake for those with facial differences. As a performer in the entertainment industry, she has experienced firsthand a system that erases and denigrates people with visible differences, starting with the lack of positive representation for facially different people on stage, on screen, in print, and throughout the media stratosphere. In a society built on shutting certain people out, Sora reaches for an inclusive world that emerges stronger because of our differences, not despite them. Sora is currently working on a project with inspirational speaker [David Roche](#) looking at ways of better educating health professionals to communicate with people with a disfigurement in a manner that extends beyond the 'medical model' of care. To this end she has taken an active interest in this Face Equality Training project.

Promoting Face Equality in health care settings

The wisdom of equipping healthcare professionals with appropriate knowledge and skills has been highlighted in a series of previous EU funded projects. Open access resources resulting from these projects are available to all. For example,

- Cutting Edge Training www.cuttingedgetraining.nu includes resources and modules to enhance knowledge and skills for healthcare professionals working with patients undergoing appearance-altering procedures, with the overall aim of improving patient outcomes
- Speech, Communication & Resilience for Cleft (SCR4Cleft) www.scr4cleft.org offers modules designed to enable healthcare professionals to support parents in promoting positive outcomes in children with craniofacial conditions.

However, funding rarely extends to the broad dissemination of the outputs of these and other similar projects beyond project partners and their own networks and the routine incorporation of this material into the training and continuing professional development programs for HCPs is yet to be achieved. There remains a clear imperative to provide HCPs across Europe and beyond, with a broader knowledge base, skills and confidence to:

- 1) Understand the challenges faced by people with visible differences (including pressures created by the societal context; psychological risk and protective factors at the level of the individual patient)
- 2) Incorporate effective ways of ameliorating these challenges into the routine delivery of health care; incorporating methods of assessing and managing the patient's psychosocial needs throughout the treatment pathway; promoting patient involvement in treatment decision making and in the process of achieving informed consent for treatment (Nuffield Council on Bioethics, 2017).
- 3) Support parents and families to contribute to the likelihood of positive psychosocial outcomes for their family member. Parents are key agents in the process of optimising psychosocial outcomes for children with visible differences. The challenges are many. (Thornton et al., 2021) amongst others, have highlighted the challenges faced by parents caring for children with an appearance-affecting condition or injury. The majority are keen to arm themselves with the resources to manage the challenges they and their children face, but lack clarity about how to access the necessary resources. Parents and family members typically turn to their care team for help and advice, but if staff feel unsure about how to respond to their concerns, these key opportunities to support the affected person are lost.

A new EU-funded project to encourage open and positive communication between healthcare providers and individuals with a visible difference was launched a meeting of the European Reference Network for Craniofacial Anomalies ([ERN CRANIO](https://www.ern-cranio.eu)) in Dublin in November 2023. With the help of artists, the Face Me project aims to look at the mutual understanding between care professionals and patients/caretakers. As a pilot project they invited three patients and a mother, two neurosurgeons and one plastic surgeon to be part of a unique and once in a lifetime experience. As a team, they worked together to reorganise every moveable object in the home of one of the surgeons, literally turning the house upside down. The message was 'exchanging places' - facing each other, really seeing each other and being more than the role of doctor or patient. <https://www.ern-cranio.eu/faceme>

Promoting Face Equality for Guidance Counsellors and Vocational Trainers

Psychosocial well-being plays a crucial role in enhancing students' capability and willingness to excel academically. Particularly, issues related to body image and appearance concerns are pivotal in the psychosocial health and development of adolescents. Studies indicate that 40-70% of students are dissatisfied with some aspect of their appearance (McCabe et al., 2012, McCabe and Ricciardelli, 2004, Soares Filho et al., 2020).

Research has conclusively shown that preoccupations with appearance can harm educational outcomes (Gupta, 2013, Halliwell et al., 2014, Tallat et al., 2017). Students who are overly concerned about how they look often experience increased anxiety and stress, which can divert their attention and energy away from academic pursuits. This heightened focus on appearance can lead to a decrease in classroom participation, lower engagement with coursework, and impaired concentration during studies.

The psychological effects of appearance-related worries, such as diminished self-esteem and heightened self-consciousness, can further exacerbate these challenges. These factors can create an environment where students are more vulnerable to social pressures, potentially leading to isolation or avoidance of peer interactions, which are vital for a wholesome educational experience.

Moreover, the impact of appearance concerns is not limited to emotional and psychological effects; it can also manifest in risky health behaviours (Bornioli et al., 2019). This physical toll can further reduce a student's ability to focus and perform academically.

The correlation between appearance anxieties and educational performance highlights the need for supportive school environments that promote body positivity and mental well-being. Schools and educators play a crucial role in fostering a culture where students feel valued and accepted regardless of their appearance, thus enabling them to concentrate more fully on their academic achievements.

Adolescents with visible differences often face unique and complex challenges that can significantly impact their psychosocial development and overall well-being. During adolescence, a period marked by heightened self-awareness and peer evaluation, having a visible difference can intensify feelings of appearance-related distress (Paganini et al., 2021). These individuals may become the targets of bullying (Hunt et al., 2006, Dumont et al., 2023) or social exclusion, leading to isolation and a sense of being misunderstood or marginalised (Rasset et al., 2022). The emotional toll of dealing with a disfigurement or facial scar during these formative years can be profound, affecting self-esteem, confidence, and social interactions.

Moreover, the impact of living with a visible difference can extend to academic performance (Persson et al., 2018b, Persson et al., 2012a) and participation in extracurricular activities, where adolescents might feel hesitant to engage due to fear of negative attention or judgment. Such experiences can hinder their opportunities for social learning and peer engagement, which are critical for developing interpersonal skills and building a supportive social network.

The need for empathetic support from educators is crucial in helping these adolescents navigate their experiences positively (Stock and Ridley, 2018, Stock et al., 2019). Creating inclusive and understanding environments in educational settings is essential to ensure that these young individuals feel valued and empowered, despite the challenges posed by their physical appearance.

The awareness of guidance counsellors, vocational trainers, and teachers about the unique challenges faced by adolescents with visible differences is paramount for several reasons (Persson et al., 2012b). First, these professionals are often the primary sources of support and guidance within educational settings. Their understanding and sensitivity can significantly affect how these adolescents navigate their school experiences. Educators who are aware of the potential for bullying and social exclusion can proactively create an inclusive classroom environment, promote acceptance among students, and intervene effectively when issues arise.

Secondly, guidance counsellors and vocational trainers are in a unique position to provide tailored career advice and support that considers the potential challenges and barriers these adolescents face. They can help students explore careers that align with their strengths and interests, while also considering any additional support or accommodations that might be needed due to their appearance. This guidance is crucial in helping these young individuals build confidence in their abilities and in making informed decisions about their future careers.

Furthermore, educators and trainers who are aware of these issues can also advocate for necessary resources and support services within the school, such as counselling or peer support groups. They can lead efforts to educate the wider school community about diversity and inclusion, fostering a culture of empathy and understanding.

In essence, when guidance counsellors, vocational trainers, and teachers are aware of and responsive to the needs of adolescents with disfigurements or facial scars, they play a critical role in ensuring these students have equitable opportunities to succeed academically, socially, and in their future careers. Their support can help mitigate the challenges these adolescents face, empowering them to thrive despite the hurdles posed by their physical appearance.

Promoting Face Equality at Community & Societal Levels

The need to foster more inclusive behaviours and empathy for people with an unusual appearance is incontrovertible. Despite campaigning over the past two decades, negative reactions (and avoidant reactions – often interpreted by affected people as negative) persist, and are often underpinned by a lack of understanding, knowledge and contact. Renewed efforts are needed to boost the progress of change.

To date, there have been two main foci for public campaigns:

- 1) Raising awareness of the causes and consequences of visible difference
- 2) Changing beliefs, attitudes and behaviour that work to the disadvantage of those living with an unusual appearance

These imperatives were endorsed by responses to a recent survey conducted by Changing Faces (2023), in which respondents favoured new campaigns explaining the impact of staring and making comments (29%), seeing role models in popular culture (28%), and more education for children and young people about visible differences (21%). However, the impact of previous campaigns designed along these lines is unclear. It is widely accepted that meaningful evaluation of the effectiveness and impact of public campaigns is complex and challenging. Campaigns contain many elements operating in parallel and the relative impact of these different elements is difficult to unravel. The overall approach may be driven by theories of behaviour change derived from health psychology (for example, campaigns for body positivity designed to induce cognitive dissonance in the target audience in the hope that this dissonance will drive change in beliefs and actions), public health, or the world of social activism. Campaign goals (for example, to improve the reach of the key messages of a campaign; to give voice to people with visible differences) are often vague and not precisely articulated. The planned and actual outcomes are often diffuse and difficult to capture. In addition, although successful campaigns may impact the intentions of consumers, the 'intention-behaviour' gap is well recognised as difficult to bridge, and changes in actual behaviours may not be achieved.

Campaigns to *raise awareness* may be targeted at the general public, education in schools or workplace education. In Cyprus, the Medicleft Centre for Clefts and Facial Deformities has partnered with a local restaurant to raise awareness of craniofacial conditions and to fundraise for the Centre via a levy on every bill. In Spain, the [Microsomiahemifacial organisation](#) stages a range of awareness raising events on public holidays. Campaigns designed to engender empathy and understanding in consumers are most likely to promote acceptance are those featuring compelling personal stories about the issues and experiences of those affected. These stories can be conveyed in various ways, for example, through film format, in book format or via the public display of posters. An early poster campaign staged by Changing Faces was designed to encourage people to approach and talk to people with a facial difference. The 2000-2001 campaign depicted close-ups of the smiling face of a person with a facial difference, together with the strap line "*Hello. Nice to meet you. How are you?.....Now YOU try!*". This campaign was judged to be well received, but little is

known about the effectiveness of the campaign in raising awareness about the causes and consequences of visible difference.

Other methods of increasing the familiarity of the public with people with unusual faces have included story books for children, novels, photographic and painted portraits and exhibitions and public engagement events such as interactive workshops at Science Cafes and panel discussions at Science Festivals. The book (and subsequent film) *Wonder* by R Palacio (2012) told the story of August, a 10 year old with an unusual craniofacial condition. The book became the New York Times Bestseller in 2013. The Nina Burman's photographic portrait of American veteran Ty Ziegler's wedding following his recovery from severe facial burns sustained in active combat (image available from google search "Ty Ziegler wedding". Subsequently winning the 2007 World Press Photo Competition, this portrait was widely distributed in the global press, increasing awareness of extensive disfiguration caused by burns.

Examples of photographic exhibitions include *Perspectives* an exhibition staged in by the Centre for Appearance Research in collaboration with professional photographer Joanne Nobriga, in 2012; *Faces of Equality* published by Changing Faces in 2017; *How Do You See Me Now?* an exhibition of professional photographs of 30 young people with congenital melanocytic nevi – CMN - at the Oxo Tower, London, 2019 (images of a selection of the portraits can be accessed at www.caringmattersnow). A study evaluated the impact of the CMN exhibition on 464 members of the general public (Zolkwer et al., 2023). Respondents overwhelmingly reported the exhibition in positive terms. Their understanding and acceptance of skin conditions such as CMN and other forms of birthmark increased significantly. Interestingly, they also reported improvements to their own body image following the exhibition. ALL the people who posed as models for the exhibition rated the experience of being photographed, choosing the image they wanted displayed and the public scrutiny of the exhibition in positive terms. They found the experience valuable and helpful in relation to their confidence and their acceptance of their difference.

Other charities have compiled photobooks (see for example, the Changing Faces Equality portrait book, Scars for Life photobook depicting people scarred by cancer treatment –

available from www.wegetit.org.uk) or staged exhibitions of portraits (for example, the Royal College of Surgeons of England exhibition of World War 2 surgeon Henry Tonk's pastels of patients before and after surgery to reconstruct extensive facial war wounds; the charity 'Saving Faces' exhibition of Mark Gilbert's portraits of patients undergoing treatment for head and neck cancer.

Whether or not formal evaluations of the impact of photobooks and exhibitions are undertaken, audience feedback is consistently positive. Why is this? One theory is based on the innate response to an unusual visual stimulus (such as a visible disfigurement), which is to want to look and examine the difference more closely. Photographs, portraits and posters offer this opportunity, allowing the viewer to gaze without the fear of social disapprobation or anxiety about making the person who is the object of their attention uncomfortable. As long ago as 1976, Langer et al coined the term the 'novel-stimulus hypothesis' to describe this process. They reported that the viewing of photographs of someone with an unusual appearance prior to an opportunity for face-to-face contact can reduce levels of avoidance. The hypothesis predicts that as a new experience (viewing someone with an unusual appearance) creates discomfort and uncertainty in the viewer, providing prior exposure reduces discomfort and compensates for the lack of experience in this particular situation, reducing stigma.

Some of the photobooks and exhibition have included a brief personal narrative alongside the image of the person (Faces of Equality, for example, uses a quick-fire question format to convey personal information about the 'model'). Anecdotal evidence relating to the impact of this technique in relation to disfigurement is positive. Depicting the person engaging in 'normal' and unremarkable activities can challenge negative stereotypes, emphasising the similarities (rather than the differences) between the viewer and the depicted person and (hopefully) increasing the potential for attitude change. Furthermore, if the portraits and accompanying brief biographies are co-produced, this allows the 'sitter' to have a degree of control in the communication of their own story. Furthermore, a brief commentary (or accompanying booklet) offering an explanation of the cause of the disfigurement can serve as an educational tool as well as increasing the viewer's familiarity with that particular condition. Although clearly engaging, sponsorship to produce professional publications or to

stage exhibitions such as these is hard to come by. As a consequence, few of these activities have been subject to robust evaluation and the extent, nature and durability of their impact remains unclear.

Educational interventions have also included the development resources for schools and individual teachers (see for example resources offered by Changing Faces & About Face (Canada). An interactive game 'Who's Who', was displayed as a permanent exhibit in a hands-on Science Museum in Bristol and a board game aimed at children of 9-11 years was also developed by researchers at The Centre for Appearance, UWE Bristol, UK. An evaluation of the impact of a board game indicated that 74% of the 267 respondents had absorbed key messages about people with a range of disfigurements (Guest et al, 2021).

Open-access resources designed as awareness raising resources for individuals, key agencies and the general public. Examples include ACCORD – a project undertaken by the charity Headlines and researchers from CAR, UWE Bristol (www.headlines.org/uk/for-adults) Driven by participant voices, the materials aim to educate people about common challenges resulting from craniofacial conditions (including, for example, issues of intersectionality such as being a member of a minority racial group and living with craniosynostosis) and to offer solutions successfully adopted by the people to overcome these challenges. In addition to evaluating the impact of the online resources on viewers, the effects of associated blogs & newsletters are also currently being assessed. Interestingly, positive impacts for the people who have shared their experiences for these videos are already apparent, mirroring the experience of others who have taken part in photoshoots and videos (see below).

Several organisations, including FEI, AboutFace(York) & AboutFace(Canada) compile and edit blogs and podcasts as a medium to educate members of the public about visible difference. Although the impacts on participants and listeners are unknown, these are a rich source of information for people wishing to learn more. The *Appearance Matters* podcasts currently comprise in excess of 80 podcasts on a wide range of topics, including social activism & appearance; parenting children with visible differences; coping with specific conditions; men with visible difference; being a teen with a visible difference; fostering positive body image;

visible differences and romantic relationships (links available via www.uwe.ac.uk/research/centres-and-groups/appearance).

Campaigns to *change beliefs, attitudes and behaviour* have included pledges for employers, pledges for advertisers and marketeers to include people with visible differences in their campaigns, diversity training in the workplace, and campaigns to develop and implement legislation.

A campaign for Face Equality was launched in 2008 by the UK based charity Changing Faces. Coining the term 'face-ism' to refer to prejudices that promote the differential and equal treatment of people because of their not perfect faces, Changing Faces made the case that people with disfigurements were the target of discrimination. The aims of the campaign were to

- Promote fair and equal treatment of people with disfigurements
- Raise awareness, levels of knowledge, skills and confidence in schools, workplaces and the general public in relation to causes of facial differences and in relation to encounters with people with an unusual appearance
- Change negative attitudes towards people with facial differences

Eye-catching posters were displayed in bus stops and other transport hubs with the slogan 'Stand Up for Face Equality'.

A third Changing Faces poster campaign was mounted in 2010 directing at busting low expectations of children with facial differences. With life-size portraits of children & young people with a variety of disfigurements engaged in a range of activities, accompanied by slogans such as "*If you don't think children like me can do this*", the poster campaign was a talking point, however, no formal evaluation of the impact on knowledge, understanding, attitudes and beliefs was undertaken.

The first Face Equality Day was staged in the UK in 2017. To coincide with this event, Changing Faces solicited individual and corporate pledges of support, together with pledges from influential politicians and celebrities. A second day was held in 2018 focused on the lack of representation of people with facial differences, with a campaign *#Pledge to be Seen*

in which beauty brands were challenged to position people with disfigurements in their branding and advertising. Aware that UK-centric initiatives were limited in scope, in 2017, the then out-going CEO of Changing Faces, James Partridge initiated an international alliance of NGOs and charities. By 2020 *Face Equality International* had a membership of more than 30 organisations. Current initiatives are outlined on the FEI website, most notably efforts to influence the United Nation's Commission on the Rights of Persons with Disabilities (see below). The first Face Equality week was held in 2019 and with leadership from FEI, has been repeated in subsequent years. In 2023, activity focused on increasing representations in the Arts, coalescing around the hashtag *We Will not Hide* (see position paper Visible Difference & Disfigurement in the Arts, available in the resources section of the FEI website).

Other campaigns have also tackled the lack of representation and depiction of people with visible differences in film, broadcast media, advertising and the beauty industry. In 2009, a content analysis of TV programming in the UK highlighted the dearth of people with less than normal faces in broadcast media (reported in Garrisi et al 2018; Partridge, 2020). Lobbying by Changing Faces led to James Partridge (who had major facial burn scarring) reading the daily news for a week on one of the UK's main TV channels.

In film, there is a long history of popular film culture relying on the tired trope of attractive heroes and beautiful heroines and scarring or deformity to denote villainy. (Examples include the 'villains' in the Star Wars films; the majority of Bond films; the lion 'Scar' in the Lion King who is evil and kills his brother; Captain Hook from Peter Pan; Freddy Kruger) (Croley et al., 2017, Partridge, 2020). The outward appearance of villains implies stormy lives filled with pain and violence. In many cases, it is implied that the 'villain' brought their appearance upon themselves. Changing Faces decided to challenge this unhelpful trope in 2018 through their *#I'm am not your villain* campaign revolving around a one minute film shown regularly on TV and in the cinema. The British film industry (BFI) made the decision not to fund films in which the villain has scars, marks or burns in 2018. They also funded 'Dirty God' a film about a woman trying to reclaim her life after an acid attack. Face Equality International has continued this campaign and FEI's Global Media Standard was published in 2020 together with resources designed to support media professionals in achieving this aim.

The organisation Models of Diversity (<https://modelsofdiversity.org>) was established to campaign for greater diversity of appearance in models used by the fashion, beauty, media and social networking industries. This campaign stages workshops and panel discussions focusing on promoting diversity in race, shape, age, disability and disfigurement and has had considerable traction through its presence at a large range of fashion events. Examples have included models with facial differences, hair loss, limb loss and Downs syndrome appearing in a bridal shoot and the fashion brands, Primark & Marks & Spencer using children and young people with vitiligo in their advertising campaigns.

Legislation is clearly a powerful tool in the quest for attitude change, however, involvement in campaigns to develop and implement legislation – especially on an international scale - is not for the faint-hearted! The challenges include navigating the differing legal contexts of each country and identifying champions with an inside track in government and policy development to support the cause and stay the (often lengthy) course. Eloquent ‘ambassadors’ with personal experience who are willing to (repeatedly) tell their own stories are also an advantage in efforts to muster support in prioritising new legislation over other pressing political and policy concerns. Finance to fund a campaign leader and project manager are all needed.

Face Equality International is currently working hard to campaign at United Nations level for the express inclusion of people with ‘disfigurement’ in the remit and legislation associated with the Convention on the Rights of Persons with Disabilities (CRPD). Obstacles to progress include the thorny issue of whether or not visible difference is a ‘disability’ and whether existing disability legislation can be adapted and extended to include the full range of conditions resulting in disfigurement. Furthermore, although legislation is a powerful step, other weapons are also needed to change the status quo. The rights of people with visible differences are rarely at the forefront of debates when disability rights are being discussed, and even in contexts in which existing legislation is fit for purpose, discrimination and inequalities for people with disfigurement persist. Saunders (2020) has highlighted gaps in existing legislation in the UK and is working to plug some of these gaps. Initiatives include:

- 1) Making good-quality information widely available. New guidance is being made available on hubs provided by Changing Faces (www.changingfaces.org.uk), Face

Equality International (www.faceequalityinternational.org) and AboutFace (Canada) (www.aboutface.ca).

- 2) Guidance for good-practice for employers with a focus on creating an appearance-inclusive workplace for people with visible differences has been drafted and points readers to the desirability of:
 - a. Carrying out an audit of current employment practices in relation to employees with visible differences
 - b. Checking branding materials (for example, the representativeness of pictures used on the company website and other corporate materials)
 - c. Checking the company's employment strategy is inclusive
 - d. Checking the wording of job advertisement
 - e. Reviewing job application forms (How are any questions about disability phrased and how are people likely to respond?) and the interview process
 - f. Consider the impact of any plans to use artificial intelligence as part of the selection process (for example, will the use of AI discriminate on the basis of an unusual appearance?)
- 3). Guidance for lawyers includes the development of a legal practice leaflet summarising everything currently known about existing legislation and how to use it and a consideration of ways of raising awareness of the legal process and the potential to use the law in disputes involving people with visible differences.
- 4) Guidance for people with acquired visible differences (resulting, for example, from trauma or treatment) on returning to work.

Despite the challenges of evaluation and the resulting dearth of understanding about the most effective approaches, the accumulation of different initiatives gives cause for optimism. Small actions and campaigns accumulate until it becomes apparent that the sum of all these messages has had sufficient impact for the ideas to become the new norm – the accepted thing to do. In addition, there are learnings to be had from other effective campaigns and recommendations made in related fields. These include campaigns to promote positive body image in children, young people and adults who are anxious or distressed by their appearance and initiatives to encourage positivity towards diversity in

appearance in the broader public. Although these campaigns have not been rigorously evaluated, each are noteworthy in achieving significant changes in legislation or policy.

In 2018, a sustained campaign of lobbying together with a petition signed by more than 150,000 people, were organised by several chapters of the organisation '*Endangered Bodies*' (now known as *AnyBody Global* – an international movement bringing together body image activists from around the world, all working to promote body positivity, body acceptance and to challenge industries that turn people against their own bodies – see www.anybodyuk.org/global) The campaign *#surgery is not a game* was successful in bringing about bans by Google, Apple and Amazon app stores of plastic surgery games & apps aimed at children and young people.

Representation was made by UK researchers to Transport for London (TfL), in the form of evidence from published studies demonstrating the detrimental impacts of negative body image on young people and adults. This resulted in an invitation from TfL for the academic lead (Dr. Phillippa Diedrichs) to join a TfL advertising policy-making committee in 2016 as an expert advisor. Later that year, TfL issued a ban on all advertisements on London transport that “could reasonably be seen as likely to cause pressure to conform to an unrealistic body shape, or as likely to cause body confidence issues, particularly among young people.” TfL further undertook to look at ways it could encourage brands to feature diverse appearances, more representative of the range of the millions of people that use transport services in London on a daily basis.

The '*End the Awkward*' campaign by the disability equality charity SCOPE & UK TVs Channel 4 spoke out about negative attitudes faced by people with disabilities and highlighted the many challenges people with disabilities face. With content edited and produced by media experts from the TV station, the engaging campaign challenged and dismantled unhelpful stereotypes and aimed to help viewers feel more comfortable about disability. Viewed by millions, the initiative was an excellent illustration of how the reach of a campaign can be amplified through partnership with a large media channel. This reach was further extended by the use of social media to share impactful stories from the campaign, encouraging

influencers and other users to amplify key messages by sharing their own stories and using campaign hashtags.

Launched in 2017 and still current, the charity The Samaritans partnered with British Transport Police & the UK's Rail Network) to conduct a campaign titled '*Small Talk Saves Lives*' aimed at reducing the incidence of suicides on railways lines and in other everyday settings. Focussing on the potential role of individual bystanders in prevention, the campaign encourages people to use 'small-talk' (for example, striking up a conversation about the weather) to engage with people who are the focus of concern and who might be experiencing negative or suicidal thoughts. The key message of the campaign is that *everyone* has the power to help someone in need and potentially to save a life - just by engaging in conversation. This simple and sensitive campaign has resonated widely with the media and the general public. Once again, strategic partnerships with national corporations have been key in achieving reach and amplification in this campaign. Relatable language and the relevance to all consumers of the message are key features of the campaign – responsibility for action cannot easily be passed on to someone else.

SECTION 3. CONCLUSION

"We all look different. A world where people all look the same would be boring. Without diversity, we are nothing" (adapted from Benjamin Zephaniah's Foreword to Face Equality photobook, published by Changing Faces 2017).

There is widespread acknowledgement that people living with an unusual appearance are subject to discrimination and prejudice as they go about their daily lives. At their most extreme, Face Equality International has highlighted that these can comprise human rights violations. The evidence that this discrimination results in discomfort and distress is incontrovertible. Action is urgently needed to create a world where people are not judged on the basis of their outward appearance and the effort needed to achieve this change is the

responsibility of everyone. This action should involve the visible difference community and key stakeholders in the design, implementation and evaluation of interventions.

As part of these efforts, partners in this project are committed to producing educational and training materials for a broad range of health care professionals and for members of the wider public so they can:

- a. better understand the social challenges & psychological impacts of visible difference &
- b. acquire the skills and confidence necessary to approach, engage with and support people with visible differences to enable them to thrive
- c. contribute to efforts to bring about social change

The importance of training for health professionals and NGOs is discussed in this report and has been raised in previous studies. Even those directly working with individuals with a visible difference are not aware what resources are available to support this group. It has also been noted that while some training resources generated in the course of previous projects, have not reached important wider audiences. There is a need for a far broader approach to promoting appearance diversity, condemning stereotyping and countering discrimination. This must include engagement with politicians, employers, media, teachers, community workers as well health workers and NGOs. Two important key aspects of the Face Equality Training project are that it will include elements of social activism and also a "train the trainer" tool; those trained will also be equipped to go out and run workshops for key workers in the community which will include teachers, social workers, youth workers and policy makers thus maximising reach and impact.

"...the way a person looks does not affect their worth, The way a person looks does not raise or lower their importance. In fact, the way a person looks, is just, the way a person looks. Everyone is important and everyone matters". (Benjamin Zephaniah, poet)

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EXISTING RESOURCES

Most charities and organisations active in this sector host their own websites, many of which offer condition-specific advice, information and guidance. A minority focus their efforts on a broader range of conditions resulting in visible difference and offer a wider range of resources – examples of these are outlined below. Some of these resources are shared on more than one website and Face Equality International (FEI) acts as a hub for the resources of several charities worldwide. When considering whether or not to use these resources, it's important to check the source, evidence-base and/or credibility of the content.

About Face (Canada) (www.aboutface.ca) have an extensive array of resources available to download from its website. (In some instances, the source of the advice and materials and the extent to which the content is evidence-based is not clearly indicated).

Available in English or French, these resources include

- Personal stories (in written or video form) about living with an unusual appearance
- Educational Materials, including a school program '*Frankie & Pearl*' comprising a video & lesson plans.
- Information on visible difference and promoting diversity in appearance for Teachers
- Information for Health Care Professionals highlighting the importance of language and effective communication
- Advice for children and young people on answering questions about their appearance
- Information on Bullying (for children; youth; parents)
- Information on Building Self-Esteem (for children; parents)
- Information on dealing with treatment for young patients
- Employment advocacy (in the form of webinars for adults)
- Tips for young people on finding temporary work
- Self-care tips for children and young people
- Books about inclusion and diversity (for children & young people)

Be Real Body Confidence Campaign (www.berealcampaign.co.uk)

- Toolkit for Schools developed with input from experts in the field of body image & education
-

Body Confident Sport (www.bodyconfidentsport.com)

- A collaborative venture between Nike, Dove & The Centre for Appearance Research, designed by girls & coaches & underpinned by scientific research
 - Web-based training programmes designed to help users to recognise and tackle negative body image and to promote body confidence.
- Separate resources for
 - sports coaches and
 - young people participating in sport.

Body Image Movement (www.bodyimagemovement.com)

Australian based, this website offers a variety of resources to support body positivity, including:

- *Embrace* the Documentary (2016) A film about the journey of an Australian Woman (Tarryn Brumfitt) who has become a campaigner for body positivity in young people and adults. She was nominated Australian of the Year, 2023).
- *Embrace Kids* (2020) A documentary targeting young people and focusing on turning around the current epidemic of body hate and negativity amongst teenagers
- An evidence-based 4 week, online intervention on body positivity for young people
- An evidence-based study guide for teachers with lesson plans, worksheets and classroom activities designed to promote body positivity. These resources are available internationally. There is a fee of AUS\$89.

Centre for Appearance Research, UWE Bristol, UK (www.uwe.ac.uk/research/centres-and-groups/appearance).

- Comprehensive list of sources of support (including organisations & online support forums)
- Appearance diversity guide for teachers (in collaboration with Face Equality International). This guidance offers evidence-based advice on:
 - Discussing diversity in appearance
 - Responding to questions about a particular pupil's appearance
 - A series of 'Dos' and 'Don'ts' for Teachers (for example, avoid Body Talk; clamp down on all appearance-related teasing and bullying in the classroom and playground).
- Evidence-based self-management guidance for young people & adults with visible differences
 - Expand Your Horizons: More Than My Appearance
 - Healthtalk Burns (180 video clips showcasing real life stories of 36 people affected by burns as a child, young person or in adulthood, capturing the challenges and triumphs through the medium of diverse narratives)
 - Guide for Serving Personnel & Veterans with Appearance-altering Injuries (includes tips on how to handle staring, questions, social encounters)
 - Guide for health care professionals working with serving personnel and veterans
- More than 80 podcasts on a wide range of topics, including social activism & appearance; parenting children with visible differences; coping with specific conditions; men with visible difference; being a teen with a visible difference; fostering positive body image; visible differences and romantic relationships

Changing Faces (www.changingfaces.org.uk)

This UK based charity provide down-loadable resources for people affected by visible differences, for professionals in education and health care and for employers.

- Advice and guidance for people with visible difference focuses on common challenges including:
 - Confidence & self-esteem
 - Mental health & wellbeing
 - Coping with people's reactions
 - Relationships & social life
 - Working when you have a visible difference
- Advice and guidance for health care professionals includes:
 - Appropriate language to use with patients and the importance of good communication
 - Myth-busting for HCPs (prepared with researchers from CAR)

- Advice and guidance for educators includes resources of teachers of children aged 3-7 years; 7-11 years and 11-16 years. Materials include:
 - *A World of Difference*. A series of resources published online in 2021 at <https://www.changingfaces.org.uk/for.professionals/teachers-youth-workers-classroom-resources> with the UK Government curriculum approval. Evaluated materials include lesson plans for 9-13 year olds together with activities for school assemblies
 - Activities include discussions about stereotypes in the media and the impacts on people with an unusual facial appearance; watching the video clip 'I am Not Your Villain' and asking children to generate alternative representations of people with an unusual appearance.
- Guidance for employers on UK law (prepared by Dr. H Saunders; also available from FEI and AboutFace Canada) covers:
 - Your legal protection from discrimination at work as someone with a visible difference (Queen Mary University of London, April, 2022)
 - I have a visible difference. Am I protected from discrimination at work?
 - What is a severe disfigurement? What rights do I have?
 - If I have been discriminated against, what should I do?
 - I've been discriminated against, what should I do?
 - I don't have any proof. What if it's my word against theirs?
 - I've been badly treated because someone close to me has a severe disfigurement. What can I do?
 - What is the duty to make reasonable adjustments?
 - What kind of adjustments might be appropriate for someone with a severe disfigurement?
 - If I apply for a new job, do I need to disclose my disfigurement on my application?
 - Sometimes customers or suppliers from outside my company verbally abuse me because of my visible difference. What can I do?
 - Why is severe disfigurement a disability?
 - Where can I get legal advice?
 - Is there any help with the cost of getting advice?
 - I am an employer. How should I support one of my workforce who has a disfigurement?
 - Returning to work after acquiring a visible difference (Queen Mary University of London, April 2022)
 - I am unsure how colleagues will react to how my appearance has changed
 - How can I get my employer to understand my condition properly?
 - Can I get some changes made to my role or uniform to help me return?
 - Part time & flexible working
 - Am I entitled to take time off work to attend medical appointments?
 - What other kinds of reasonable adjustment might be relevant for a disabled person with a visible difference?
 - My doctor says I am not ready to return but I need the money. Can I come back early?
 - My visible difference resulted from an injury at work. I'm worried about returning in case it happens again.
 - How can I ensure my injury doesn't stop my career progression?

- What is the best way to deal with customers who don't know me or what happened?
- Where can I get legal advice?
- I am an employer. How should I support one of my workforce who has a visible difference?

Dove (www.dove.com/uk/dove-self-esteem-project)

Downloadable resources include:

- *Dove Confident Me* Evidence-based materials for teachers, parents, families, friends, youth workers & mentors. These include ideas for activities on which to base workshops, tutor time, assemblies, student-led campaigns, teaching body confidence across the curriculum, posters for public display, and ideas for engaging parents
- *Super U Story* – a gaming app for girls designed to promote body confidence and promote appreciation of appearance diversity
- Evidence-based materials developed for (& widely used by) the World Association of Girl Guides & Girl Scouts (WAGGS) designed to promote body confidence & self-esteem and to enable girls across the world to be free of worries about their appearance.
- An evidence-based toolkit for Doctors & Dermatologists working with young patients with skin conditions and body image concerns “*Addressing Appearance Anxiety in Dermatology*”

Face Equality International (www.faceequalityinternational.org)

This website offers a range of downloadable resources in English, French & Spanish, originating from partner organisations including AboutFace Canada, Transforming Faces, Changing Faces and CAR, UWE Bristol, or developed by FEI in collaboration with experts in the field and/or its own ambassadors, including

- Guidance on common questions about facial disfigurement & equality in the workplace
- Guidance on employment advocacy
- Guidance for people with visible differences on speaking in public, sharing your story and dealing with the media
- Guidance re dealing with patients for dentistry & oral healthcare professionals
- Books for kids & teens