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International  
Face Equality Week

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# FACE EQUALITY IS A HUMAN RIGHT

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FACE EQUALITY  
INTERNATIONAL

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## Background

Facial difference is a cultural identity, a characteristic, and the term represents a community of people to be celebrated.

But the global experience of disfigurement and facial difference is also one of inequality, marginalisation, being hidden away or abused, and human rights violations.

A study in Nigeria found that around a quarter of respondents wished their child with a cleft lip and/or palate had never been born, and two the participants even wanted to abandon their baby at the hospital. Studies in the 'Global North' repeatedly report discrimination and mental health problems experienced by people with facial differences.

FEI's 36 member NGOs provide vital medical and psychosocial support to the facial difference community, recognising the unique challenges that come from looking different in global society. FEI strives to create a world where the facial difference community can live freely, without indignity or discrimination, with a view to reducing these challenges in the future.

Wherever in the world someone with a facial difference might be, the impact of stigma and prejudice towards facial difference can have a profound impact upon mental health and wellbeing.

FEI's Ambassador, Jono said the following about the pressing need to achieve face equality:



**"It's still clear to see that hate crime and inequality for those living with a facial difference is happening on a DAILY basis across all aspects of life, from school playgrounds to social media, it's happening and it's near impossible to escape. Depression, self-harm, self-hate and suicide, are all things that have followed on from these kinds of situations.**

**So, I will continue to fight, fuelled by this, fuelled by the love from others and fuelled by the epic self-love that I have for myself."**

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This Face Equality Week, we are carving out space for this unique community to be seen, heard, and protected from harm as we shift our focus as an Alliance towards positioning face equality as a social justice issue.

Our new strategic vision can be found [here](#) which seeks to unify individuals and organisations around the world to make face equality a reality.

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**“The stereotypical image of an individual with facial scarring is ugly, evil, a fault in personality. Society on the whole is unaware of the emotional pain and embarrassment of a life lived with facial disfigurement. You’re never fully accepted as being a whole person with worth.”** Ellen, respondent to FEI’s consultation.

### **What is face equality?**

‘Face equality’ is a term originally coined by the UK charity, Changing Faces UK. The late founder, Dr James Partridge OBE, also founded Face Equality International. As the pioneer behind the face equality movement, James was instrumental in lobbying for the protection of those with facial disfigurements in current UK law.

Of his vision for the movement, James said:

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

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The history of the face equality movement has been documented in his second book, ‘Face It’ which is available [here](#).

### **Who does this affect?**

The exact number of people who have facial differences worldwide is still unclear. But with over half a million people in the UK identifying as having a facial disfigurement, we can estimate that there are over 100 million people worldwide. As violent conflict continues around the world, the prevalence of acquired disfigurements will only continue to increase.

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## The language we use

Facial difference (FD) describes a facially-diverse or non-normative appearance of the neck and above. This indicates conditions or marks that an individual is born with, as well as changes of facial appearance that are acquired either permanently or temporarily.

Medical and legal settings have historically used the term disfigurement. Facial difference or FD can be more universal and inclusive terms to strive towards in the future. Self-identification and freedom of choice are always paramount.

As the language we use will continue to evolve and adapt according to culture and context, we aim to reduce shame, fear or awkwardness around the 'right word' to use. Instead of challenging language, we will harness our collective energies to challenge inequality.

FEI's Ambassador, Carly Findlay explains the context of self-identification:

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**“People can identify how they wish. But I also think it's important to acknowledge the human rights and disability activists who have come before us, and to recognise that people with facial differences should be protected by human rights policies and laws.”**

## Why are we repositioning disfigurement as an independent equality and human rights issue?

**“I realise it may take a while for the world to recognise this, as it has with various other human rights issues. Still, we have to start somewhere, and the more we speak, the louder its echo will reach everybody.”** Crystal

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Historically, legal recognition of disfigurement has been limited to disability laws and spaces. But is facial difference always classed as a disability? While it is true that there is often an overlap between the two characteristics, many members of the facial difference community indicate that facial difference is an identity in itself.

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**“I identify as a disabled woman with a facial difference. These are integral parts of my identity - that I am now very open about. Years ago I denied my facial difference - and certainly didn’t see myself as disabled.” Carly**

**Only about one-third of adults with a facial difference identify as having a disability, according to the most recent community surveys conducted by AboutFace, Canada's facial difference charity.**

**Research indicates that existing disability-focused laws are failing the facial and visible difference community on several levels, and do not provide sufficient protections against the specific attitudinal prejudices and discriminations experienced by the facial difference community.**

**‘Quoting from a Florida case, the court held that “To show that a disability affects the major life activity of working, a plaintiff must demonstrate that the disability precluded him or her from working in a "class of jobs" or a "broad range of jobs." Because the plaintiff was unable to demonstrate that his facial deformity precluded him from performing a broad range of jobs, the court held that he did not have a disability substantially limiting his major life activity of working, and therefore was not entitled to any accommodation.’ Reed Smith & Bank of America Report on Interpreting disability Legislation to assist people with Facial Disfigurements.**

**“Although the Equality Act in the UK grants some rights to people with severe disfigurements which meet certain criteria, it fails to recognise the discrimination suffered by people with mild and moderate facial differences, despite evidence that they, too, can be disadvantaged by society for looking different.” Dr Hannah Saunders, QMUL**

**“And this isn’t the only weakness in UK equality law concerning people with facial differences; research has identified various other flaws, including a lack of clarity about who might be covered by the ‘severe disfigurement’ provision in the Equality Act 2010, and a lack of practical guidance about how the law should be applied.” Dr Hannah Saunders, QMUL**

**In terms of the European Charter of Fundamental Rights, ‘As of yet, there is no case law stating that the definition of disability covers facial disfigurement. The EU’s administrative system leaves the implementation of EU laws to the Member States. Thus, the protection of persons with facial disfigurements also depends on the implementation of EU law into national law by the respective Member State.’ Reed Smith & Bank of America Report on Interpreting disability Legislation to assist people with Facial Disfigurements.**



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FEI has received cases directly involving individuals who have experienced discrimination in Europe, and have found that they have not been successful in having their claim recognised. This is why we as an Alliance we are repositioning facial difference, both legally and socially, in an effort to validate and increase understanding of the unique experiences of this particular community.

### **What do we mean by recognising this community socially?**

Facial difference is a cultural identity. It is important that we achieve social recognition of facial difference in order to celebrate this unique community and validate their experiences.



**“For the first time in what felt like forever I saw my face, I stared at it, I noticed all my features and I was still smiling, not just a small smile though, but the biggest smile my face could possibly create.**

**In that moment I thought to myself – I love my face!**

**When you start to show your true authentic self – the world magically opens up and starts to feel very real and beautiful.” Jono**

Some living with a facial difference will also qualify and identify as disabled, along with any other marginalised characteristics. We believe all of these aspects are worthy of recognition and protection that acknowledges the specific experiences associated with marginalised identities and how they can intersect.

### **Why we must continue to unite with the disabled community and align with disability justice movements, whilst carving out our own space too?**

It is our long-term ambition to create a space for facial difference to be recognised as an independent equality and human rights issue. We will do so whilst maintaining our efforts to utilise, strengthen, and raise awareness of any existing laws that might offer protection to the facial difference community which might fall under disability law.

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There is strength and solidarity to be found in banding together with organisations and activists fighting for disability rights and inclusion. With many parallels in the human experience of facial difference and disability, such as healthcare inequalities, trauma and stigma, it's important to forge alliances that can bring about change for our shared communities.



**"We are all beautifully flawed human beings, so judging people on their appearances shouldn't be a thing because we are all the same under it all. Human beings, regardless of our differences." Crystal**

### **What if someone has a facial difference and a disability?**

Many members of our community also identify as disabled - particularly under the social model of disability which focuses on societal, attitudinal barriers rather than physical barriers. We do not wish to invalidate this sense of identity.

**"I discovered the social model of disability around 10 years ago - it means society puts up disabling barriers that can be removed, and that our bodies are not broken and not to blame for encountering disabling barriers." Carly**



We also do not wish to limit or prevent the protections and accommodations afforded to anyone with a disability, or importantly to any other marginalised, intersecting identity. We want to recognise how facial difference can lead to additional, specific barriers in global society, by recognising the cultural bias and prejudices that exist specifically around looking different.

We do not yet live in a world where laws are based on the social model of disability, where disfigurement is universally recognised and protected as a disability, or where the route of the extensive discrimination experienced by the facial difference community has been adequately addressed.

A facial difference is not just a social disability - it is so much more.

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## Why is educating on face equality important?

Stigma and bias have profoundly negative impacts upon the FD community. Implicit bias research consistently finds that people with facial disfigurements are deemed less trustworthy, attractive, and perceived to have lower intelligence. This leads to inequities in healthcare, employment and education, as well as negative experiences throughout day-to-day life.

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“Most think it's (a cleft) corrected with a surgery or a few, and that's kind of it. However, there's a higher likelihood of discrimination based on looks, medical needs and time off, speech issues, and mental health.” Community survey respondent.

“Because we are hidden, most of society does not know about facial differences and does not see it as an issue. Bullying a person who looks different on the internet because of their visible differences vs seeing a billion of us together as one as a community gives it weight. It shows that we are a group of people that are not going anywhere, and even though we may have been pushed into the shadows before, we won't let them today.” Crystal

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“I get judged before I open my mouth to speak. People stop what they are doing to look at me, whispering and giggling. I am asked intrusive questions about my medical history, and I am prayed for and preyed upon by snake oil sales people...

My photo has been misused and ridiculed online - shared on forums that are the bottom of the internet; and I've even had hate art made and distributed on Twitter. I've been discriminated against by more taxi drivers than I can remember - they've been scared of my face. I've also been told that they are allowed to refuse my fare if my face makes them feel scared. This devastates me...

Often those of us with facial differences are seen to be overreacting or imagining things when we speak about or report microaggressions and discrimination experienced; or raise the issue of facial difference mimicry in film.” Carly



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## **What does the law say about disfigurement?**

In theory, the ADA, and the UK Equality Act already protects those with disfigurements from discrimination, but in practice these laws are failing people who look different.

Legal protection for the facial difference community is vital to achieving face equality. A series of factsheets which can help the facial difference community to understand current laws that can protect from discrimination can be found [here](#).

A full report into the UK Equality Act 2010, Americans with Disabilities Act 1990, European Charter of Fundamental Rights 2000 and the United Nations Convention on the Rights of Persons with Disabilities 2007 can be found [here](#).

## **The problem with disfigurement getting lost in disability law**

We know that millions more stories are out there of discrimination and injustice that are going unrecorded, unnoticed, or simply brushed off as part of day-to-day life for people with facial differences. Those that are reported, are often dismissed or are unsuccessful at tribunal.

Case law and our research indicates this could be because not all disfigurements are seen to meet the 'severity' or medical-model-focused thresholds of disability. There are also cases where individuals are told not to rely on their facial difference in court proceedings.



**"My disability status was dismissed, I couldn't rely on my facial disfigurement as I hadn't been bullied owing to my face and I didn't disclose my facial disfigurement as a problem.**

**Not many women would inform an employer about scarring that they have tried to hide/ignore all their life. Not being aware of the vagaries of the legal system I was forced to rely only on my eye sight and the fact that it was corrected – I was not Disabled or protected. My facial disfigurement was disregarded even though it was the underlying cause of my difficulties." Ellen**

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## How are we going to address all of this?

Over the next two years, as part of our new strategy, we are committed to working closely with our members to collect research into the extent of the stigma and injustice experienced by the global facial difference community.

This community also deserves better access to quality legal advice which can help to prevent further discrimination, and help to empower those with facial differences to understand and assert their rights.

We will not stop until the real-life experiences of those with facial differences are heard, respected and valued.

## Why does this impact upon us all?

Advocating for face equality in society can prove hard, particularly when trying to reach anyone without direct personal experience. But personal experience is far more common – and broader in nature – than one might think, with many of us managing skin conditions or possessing scars and birthmarks.

And of course, we are also all subject to global societal pressures to look a certain way, and to conform to an extremely narrow perception of 'beauty'. Much like the well-documented impact of body image demands on mental wellbeing, the pressure for our faces to 'fit' is widespread and highly damaging.

All of us have the power to make face equality a reality. Tools to do so can be found [here](#).

**“Face Equality is a human right. And so discrimination against people with facial differences needs to be supported by a human rights framework. We need to be able to report discrimination and hate speech and for it be taken seriously – worldwide.”** Carly

## Outcomes and recommendations

- Individuals must acknowledge and utilise the power each of us holds to champion respect and inclusion for the facial difference community. Aside from supporting the movement via our various channels, individuals can access our [education hub](#) for tools that can be used to advocate in their own communities.

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- **Policymakers, regulators and public bodies have a duty to implement, test and improve policies so that the facial difference community is explicitly and adequately protected from harm, marginalisation or injustice.**
  - **Data to reflect the numbers of those living with facial differences worldwide is extremely limited. Healthcare providers must support NGOs in capturing data to reflect the prevalence of facial difference, be it congenital, acquired or episodic.**
  - **Healthcare providers must adopt adequate training and practices which understand and address the complex mental and physical needs of patients with facial differences.**
  - **With legal protection of people with disfigurements falling into disability laws, incidence of disfigurement-specific injustice remains hidden, unclear and not a true reflection of the extent of that experienced by those with facial differences. Reporting systems must explicitly capture cases of discrimination, crime and human rights abuses where disfigurement is the aggravating factor.**
  - **Media and creative outlets have a duty to positively represent and include those with facial differences, to eradicate harmful tropes, and to remove barriers for talent with personal experience of facial difference to thrive within the creative industries.**
  - **Social media platforms must include explicit mention of facial and visible difference as a protected characteristic in their community guidelines. Their systems and policies should be built in such a way that people with facial differences have freedom of expression, without censorship, and to detect hateful and abusive content by adopting a proactive zero- tolerance policy.**
  - **Businesses of any size should adopt policies and practices to ensure that employees with facial differences have equal opportunities in access to employment, with disfigurement included as an identity captured in equal opportunities monitoring. They should also support employees with facial differences to reach their full potential by fostering meaningful equity and belonging in the workplace.**
  - **Educators both inside and outside of formal education settings have a duty to create inclusive environments where all students respect and understand difference. We must reduce shame and stigma, and educate future generations about facial difference.**
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FACE EQUALITY  
A REALITY?**

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you can make to fund our vital work.**

**[Find out more, and donate here.](#)**



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