



FACE EQUALITY
INTERNATIONAL

A photograph showing two women in a close embrace. The woman on the left has dark, curly hair and is looking down with a somber expression. The woman on the right has short dark hair, wears glasses, and has her back to the camera as she hugs the first woman. The background is blurred, suggesting an outdoor setting.

FEI is the first and only global Alliance devoted to ensuring the global facial difference community can live freely, without indignity or discrimination.



Facial disfigurement is a globally neglected human rights issue, with vital reform needed to ensure individuals are protected from abuse, discrimination and exclusion



There are many expert organisations working at national level, now is the time to bridge borders and build a global movement for change

We are a unique membership organisation, united by a shared mission to campaign for the fair and equal treatment of all, irrespective of appearance



Our collective mission is to position face equality as a social justice movement

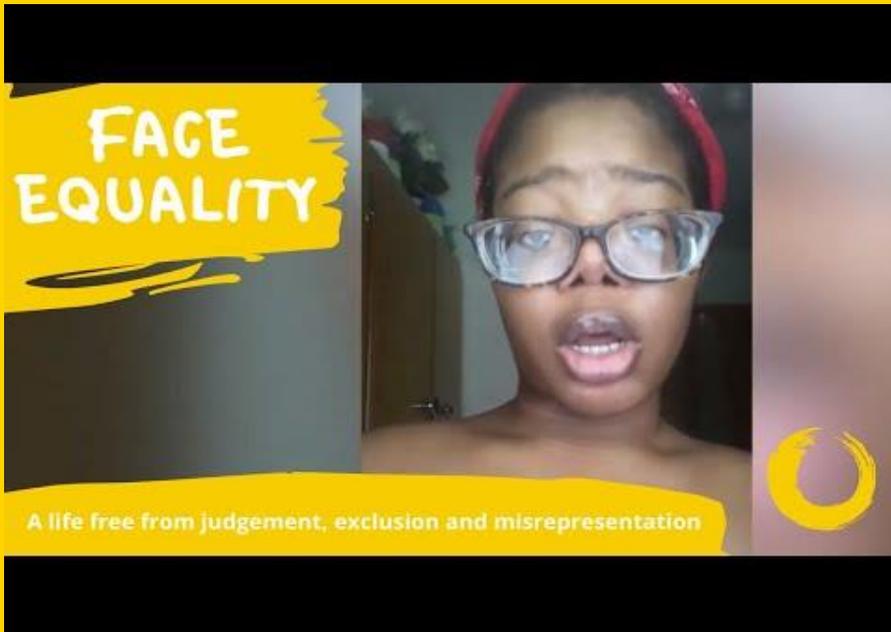


Who has forged this unique Alliance?



Our vision

Let our members tell you what face equality means to them:



[Watch here if viewing pdf version](#)

"Smile Train is so honored to play a part in this wonderful initiative. We look forward to all that is to come!"

We are the only Alliance of this kind, as the sole international network devoted to ending discrimination and life-limiting stigma for people with facial disfigurements.

Adele Lie, Member of FEI's Lived Experience Working Group,

"We need humanity to acknowledge the facial difference community as an entity that has a strong identity and a standalone voice. To know that we exist. Respect our fortitude, our insight, our indomitable spirit."

"We are so thankful for all the hard work that FEI does to support our mission for Face Equality"

President of FACES, National Craniofacial Association, USA

"Thank you for creating this international initiative - it is so needed and I am excited about the impacts it will have in the coming years."

Director of Patient Services, BC Professional Firefighters' Burn Fund,
Canada

The global challenge

- Disfigurement is a globally neglected human rights issue
- Wherever in the world they may be, people with facial differences face very similar psychological, cultural and societal barriers to living fulfilling lives
- Disfigurement inevitably goes hand in hand with poverty, prejudice and exclusion
- Legal protection for people with facial disfigurements is often flawed, ineffective or non-existent across the world
- Individuals, NGOs and support groups are all fighting hard to seek recognition of the needless exclusion of millions living with facial disfigurement.

The solution

This unique alliance was created in order to facilitate and amplify the impact of our members to influence the global human rights debate as the leading voices on disfigurement.

We make it easier for members:

- 🌀 To inspire, inform and advocate for change for their constituents
- 🌀 To access our unique peer-to-peer learning and collaboration to better understand, share and disseminate solutions
- 🌀 To connect as a specialist membership in order to harness the potential of internal and external partnerships, such as The Human Rights Watch.

2021 Achievements

1. [United Nations CRPD Recognition](#)

Reference to FEI in thematic report and engagement with the Special Rapporteur on the Rights of Persons with Disabilities.

A campaign for disfigurement equality



We are calling for the rights of persons with disfigurements to be explicitly recognized. Although the Convention on the Rights of Persons with Disabilities, and the human rights model of disability, embraces people with disfigurements, 'disfigurement inequality' remains invisible. The discrimination and abuses endured by persons with disfigurements are neither seen, understood nor challenged.

The lived experience of disfigurement

At least 1.3 million people in the UK are estimated to have a significant disfigurement. A quarter of them have experienced a hate crime and over half have experienced hostile behaviour. Many suffer psychologically as a result.¹

Disfigurement inequalities can extend to all areas of life, including work, healthcare, and social inclusion.

Stereotypes about appearance extend far beyond ideals of beauty into assumptions about character and ability. A study in America found that photographs of faces with disfigurements were rated as significantly less honest, less employable, less trustworthy, less optimistic, less effective, less capable, less intelligent, less popular and less attractive than photographs of the same faces with the disfigurements digitally removed.²

The lack of international data on this issue means that we don't know the numbers of people affected globally, but our membership of 36 worldwide NGOs tells us that in many countries the situation is far worse.

The experience of **Tina**, a young girl from Ghana with NF1 (a genetic condition causing visible facial tumours) was one of ostracization and denial of education due to her appearance.

Raj, who lives in India, recounted years of being beaten, pelted with stones and verbally abused due to his cleft lip. Raj's father, too, refused to acknowledge him.

As a consequence of stigma, abuse and discrimination, many people with disfigurements across the world are quite literally being hidden away from society.³

¹ Changing Faces. <https://www.changingfaces.org.uk/for-the-media/facts-figures/>
² Rankin and Booth, 2003, doi:10.1097/01.PHS.0000090106.63333.9C
³ Swift and Bogart, 2021, doi:10.1016/j.jobor.2021.09.011

Priorities for change

Priority 1: People with disfigurements need to be expressly recognized as rights holders under the UN CRPD. **Disfigurement needs express inclusion** by the CRPD Committee because it can so easily be excluded by the medical model of disability principles prevalent in so many countries.

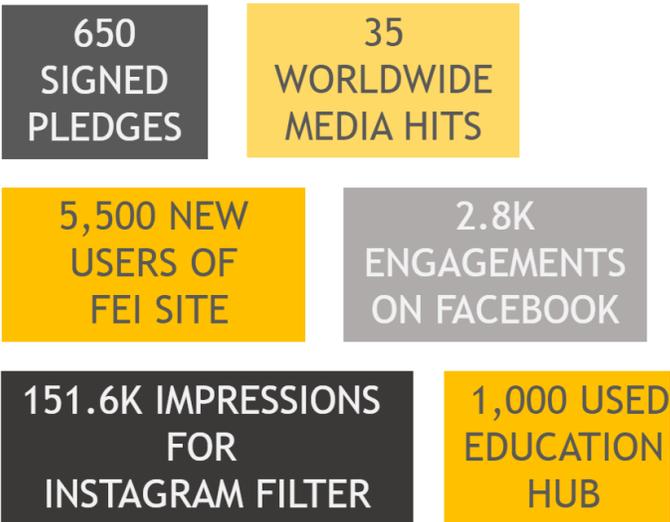
Priority 2: The CRPD country reports system should include consideration of the rights of people with disfigurements. This will improve visibility of the problem internationally, increase accountability of state parties and provide a roadmap for change.

FACE EQUALITY INTERNATIONAL
T: +447841908852 www.FaceEqualityInternational.org

Registered address: Moulière, La Blanquette, Albecq, Guernsey GY5 7EQ
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2. Face Equality Week

This was the biggest international campaign yet!



LIFESTYLE FEATURES

Is it time to talk about face equality?

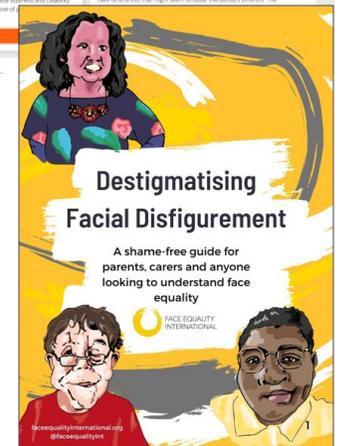
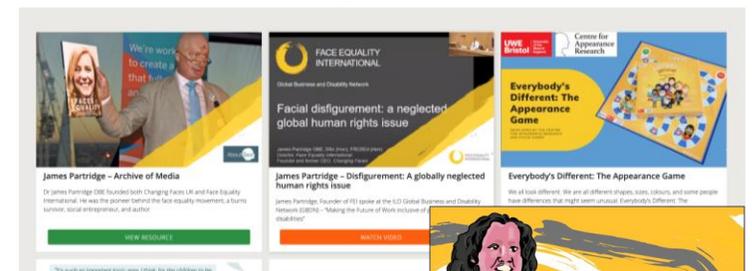
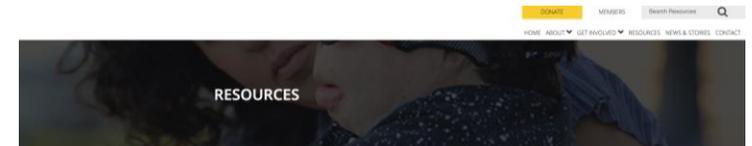
Although facial disfigurement affects almost 600,000 people in the UK, many of us don't know how to react when we meet someone who has a visible facial difference. **Saman Javed** speaks to charities on how to best normalise it



Friday 21 May 2021 17:33 | comments

3. [Education Hub Launch](#)

The education hub pulls together research, videos, school and business resources, guidance for media professionals, personal blogs



Our current priorities

Positioning disfigurement as an equality and human rights issue

The problem:

- Equality laws exist on the grounds that marginalised groups require legal protection from discrimination, or "the practice of unfairly treating a person or group of people differently from other people or groups of people". This definition should undeniably extend to the pervasive staring, comments, exclusion, discrimination and marginalization of the facial difference community. But in the eyes of the law, this community's unique experiences are largely invalidated, given that disfigurement is never mentioned alongside other equality issues such as race, sexuality or gender identity.
- Medical treatment is often the focus of efforts to help people with disfigurement, and so psychosocial and human rights issues are neglected due to limited resources for organisations and groups devoted to the needs of people with facial differences.
- People with disfigurement are targets of human rights violations worldwide, including being denied the opportunity for education and employment, and being hidden away from public life.
- Disfigurement protections are often folded into disability rights laws, yet cases involving disfigurement often do not meet the threshold of being considered a disability via medical/legal models and so cases are regularly dismissed, and so remain invisible and unaddressed. Clear, explicit, and inclusive legal protections that name disfigurement are required in order to empower individuals to assert such protections.

How we will create change:

- Together with our members, and the facial difference community we will build collective pressure on policymakers, businesses, and the general public and build momentum for the movement both nationally and internationally
- We will target policymakers, feed into consultations such as UN thematic reports and conferences, and work with businesses to ensure disfigurement is understood and recognised as an equality and human rights issue.



Empowering and amplifying the voices of people with disfigurements

The problem:

- There are millions of people worldwide that are currently unaware of the face equality movement and how the strength of the community could help them.

How we will create change:

- We will place the power back in the hands of our communities by engaging them in the mission of face equality international through community building activities, resources and campaigns
- We will counteract the shame and stigma experienced by the facial difference community by co-producing materials and campaigns with the community which address the challenges of living in today's society, similarly to our recent ['Parents and Carers Guide'](#) which has been incredibly successful.
- By steering working groups of people living with disfigurement, we will work together on creative projects, face equality week, digital communications and campaigns to lobby government, the media and to shape public perception.
- We will work closely with ambassadors and activists to amplify the voices of the diverse facial difference community, inspiring and empowering more community members to come forward and take a stance against disfigurement discrimination
- International Face Equality Week 2022 will focus on putting the community first, briefing our constituents and bringing them in to the fight for face equality. Together, we will plan our annual campaign to reach more community members than ever.



Global research to understand the injustice, human rights violations and life-limiting stigma experienced by people with facial disfigurements, particularly in low-income countries

The problem:

- In majority world countries where the [moral model of disability and disfigurement](#) prevails, people with clefts and other facial differences are abandoned at birth, shunned by their families, or hidden from society.
- Beyond the UK, there is a stark lack of data to reflect the severity of harms the disfigurement community faces on a daily basis
- A third of people with disfigurements in the UK have been victims of hate crime. Whilst children in low-income countries are hidden away and banned from attending school due to their facial difference. Worldwide, people with disfigurements are abused, neglected and marginalised.

How we will create change:

- Work closely with our members and partners to collect quantitative and qualitative data to reflect the true extent of human rights violations, injustices and the impact of life-limiting stigma for the facial difference community.
- Work with legal advisers and experts such as Reed Smith and the UN to consult on how data can effectively help us to lobby for policy change.
- Gathering human stories, conducting interviews, workshops and discussions to gather experiences of life-limiting stigma
- Exploring existing interventions delivered by our member organisations that could be enhanced by additional measures to counteract stigma, such as positive, inspiring stories, lesson plans and education resources, and conversation guides to reduce shame around facial disfigurement



Our Founder

"There can be no doubt that face-ism is a scourge of our age. To challenge it, we must be prepared to dig out the roots of those stigmas, expose them to public disapproval and then eliminate them from our culture."

James Partridge was the Founder of Changing Faces, the UK's leading charity supporting people with disfigurements. In 2017, whilst still CEO he was asked to take the mission global via Face Equality International. James died in 2020, but the future of the face equality mission is bright and hopeful.



"Every human face should carry the same value, because each and every one is fascinating and beautifully made and is owned by a person worthy of equal respect"

How we serve our members

Our members, as thought leaders and standard setters, seek to maximise their collective impact by positioning facial disfigurement as a human rights priority worldwide.

They do this by jointly funding FEI as a central resource, enabling members to cost-effectively achieve more together than they can working in isolation.

- We exist to bridge the gap between NGOs, big and small, across the world by facilitating the exchange of knowledge to capacity build
- Each year FEI leads the co-production of International Face Equality Week, a moment to create the critical mass and solidarity needed to gain global attention for face equality
- Our annual Members Forum brings together sector expertise from within the membership and beyond to run training, workshops, strategic planning and community building for FEI members
- By amplifying the voices of our member organisations, we bring them to the global stage to attract vital attention to how they serve people with facial differences
- By leveraging allies in business, government, education and across society, we elevate the impact of each member organisation in bringing about change for its constituents

The value for our members

Amplifying your voice and campaigning to scale

- The collective voice of the membership creates a greater global impact across the health and charitable sector, the media, and government, ultimately reaching more individuals with life-changing work from across the membership
- Facilitating high-level, strategic conversations on a global scale with government and non-government bodies like the UN, corporate companies and philanthropists, by positioning face equality as an issue of critical importance to sustainable development, human rights, diversity and inclusion, and beyond

Raising your profile

- The membership base is made up of leading authority organisations and experts in the field of disfigurement.
- By working with the best minds across borders to pursue the campaign in culturally-astute ways, members are not just relying on their own ideas or reinventing wheels
- With disfigurement being an often-overlooked equality issue, combining forces and being part of a movement and a conversation larger than one single organisation has greater impact
- Raising the profile of disfigurement as a human rights priority by raising the profile of our members

Sharing knowledge and building capacity

- FEI facilitates a shared pool of resources, information and expertise
- FEI provides a platform to collaborate with experts working across the facial difference space
- We plan training opportunities to draw upon expertise within the community and externally, according to the needs and priorities of members

How we're run

Membership: We welcome as members all organisations actively working to improve the life chances of people with facial disfigurements.

All members make an annual subscription to joint-fund the platform which facilitates the work of the Alliance. Membership fees are kept as low as possible and scaled according to the size of the organisation. In addition, members are asked to contribute in-kind resources, time and expertise so that we can continue to keep fees as low as possible.

Founding members agreed that our mission is too important to rely solely upon the unpredictability of charitable fundraising to secure the sustainability of the global movement. Our founding members played a crucial role in enabling our start-up by making an initial investment to cover FEI's first year.

The Council: An advisory body to the CEO and Board which helps us to understand the needs of individual members while maximising our impact as an Alliance. The Council consists of the Chair of FEI, plus representatives of the members. **The Council is currently composed of an FEI trustee plus representatives of the founding NGOs, after which election for Council members will be considered.**

The Board: Face Equality International is managed by a Board of Trustees, chaired by Jill Clark. **Find out who sits on our Board [here](#).**

The FEI Secretariat: FEI is currently run by the CEO, Phyllida Swift, who took the lead after the loss of our Founder James Partridge. **The team also consists of a Comms lead, Finance & Admin Assistant and a network of volunteers and freelancers according to current projects and priorities.**

For more information

Phyllida Swift, CEO of FEI, would be more than happy to answer any questions you might have and can be contacted via phyllida.swift@faceequalityinternational.org



Thank you on behalf of Face Equality International and its members.

<https://faceequalityinternational.org/>

Face Equality International is a UK registered charity. No. 1198641

Phyllida Swift, CEO of FEI, *“Together, we can create a world where anyone with a facial difference is free to be unapologetically themselves.*”

In order to celebrate what makes us ‘different’, first we must recognise that it is society that must change, not us. It is the limiting perceptions placed on faces and bodies that do not conform to the ‘norm’ that we must change.”