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A position paper  
on the path to  
equality for  
people with  
facial and visible  
differences

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**DISFIGUREMENT**  
**&**  
**THE UN CONVENTION**  
**ON THE RIGHTS OF**  
**PERSONS WITH**  
**DISABILITIES**



FACE EQUALITY  
INTERNATIONAL



People with visible differences have remained largely invisible in global human rights efforts.

Their status and rights as disabled people under the UN Convention ('CRPD') are crucial to changing this. This paper:

- Outlines the challenging reality of living with a visible difference (part 1);
- Affirms that people with impairments affecting appearance are rights holders under the UN CRPD (part 2);
- Calls on you to recognise and protect this marginalised community by signing to affirm their rights as disabled people
- (part 3).



Photo by Rick Guidotti

## Part 1: Living with a visible difference

### The scale of the harm:

Official statistics about the numbers of people with disfigurements are sadly lacking, but we estimate that 1 in 111 people globally have a disfigurement. Sometimes these are congenital (from birth) – as in the case of craniofacial conditions and birthmarks. At other times they are acquired – often through war, accident, illness or violence. People with facial disfigurements often face layers of stigma, exclusion and abuse across the globe.

Negative attitudes and fear about disfigurements often prevail.

Disfigurement is sometimes viewed as a punishment (i) or the mark of evil spirits. In some communities, children with disfigurements may be given away, removed from their parents after birth or locked up to avoid bringing shame on the family (ii).

A culture of guilt and blame can exist and families with a child who looks different may be treated as outcasts (i). In places, this is a particular issue for mothers of children with disfigurements, who are sometimes abandoned or ostracized by their family and spouse due to a perception that the child's condition is solely the responsibility of the mother (i).

**“My neighbours refuse to carry my child and make jest of him. My mother-in-law refused to carry my baby the last time we went home for Ramadan, claiming I was the cause of the defect because of my way of life. My father-in-law has refused to visit me since they heard about the birth of my child.” (Mother, Ethiopia)**

Reports of enacted hatred towards this community are common (iii). We often hear reports of people with disfigurements being verbally abused or physically attacked in the street or, in western societies, refused entry to public places such as restaurants because of their appearance. [You can read about one such recent event here.](#)

**“For the most part of my life, I had to deal with the people who was either scared to look at my face or who would ill treat me by beating me, throwing stones at me or abusing me in foul language including my own father. My father always thought I was a disgrace to him, he refused to acknowledge me as his own [...] My classmates used to beat me, abuse me verbally and physically, just because I did not look like them. I had a defect and the people around me was not able to accept me for who I was”.**

**Raj, India**

Studies even suggest that the bias against people with disfigurements might sometimes extend to the justice system too. Early research suggests that people with disfigurements who are accused of crimes may be more likely to be sentenced more harshly by the courts than others (iv). Yet laws and processes often do not enable negative behaviour towards this community to be challenged effectively.

***Tina lives in India and runs a support group for people with ichthyosis. She has been spat on, harassed by neighbours and had her home occupied by others, yet her plea for help has been ignored by law enforcement.***

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## Education

Children with visible differences are sometimes denied the right to attend school due to misguided fears about contagion. Even where schooling is permitted, the experience can be marred by bullying, lowered expectations and physical and mental abuse. Some families choose not to send children with disfigurements to school for this reason. This often has a corresponding impact on the parents' ability to work and provide for the family.



## Work

The ability to support oneself financially can also be compromised by pay and job discrimination within the labour market. By way of example, research from India noted a stallholder with a visible burn injury who was regularly coerced into moving her business away from other stallholders due to anticipated customer reactions to her appearance (v). And research from the UK has found that disclosing a disfigurement when applying for a job significantly reduces someone's chance of even being shortlisted for interview (vi).



**While working in the UK, Sora (pictured above at UN Conference of State Parties in 2023) was asked to cover her face if she wanted to keep her job.**

## Psychosocial impact

Given all of this, it is perhaps not surprising that many people with visible differences experience high levels of distress, including depression, anxiety and social phobia (vii).



Photo by Rick Guidotti

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## Part 2: Disfigurement as a disability

The CRPD does not define disability but includes ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (Art 1). The UN CRPD embraces the human rights model of disability under which ‘the challenge facing a person with a disability is measured in terms of the existing barriers and not on the category or percentage of the impairment.’ (viii)

So, how does this apply to people with disfigurements? Impairment is not defined in the CRPD in order to avoid narrowing the Convention’s intentionally inclusive scope. Many impairments impact individual functioning – such as seeing, interacting with others, or moving around. This is true for many people with disfigurements; for example a cleft lip and palate may sometimes impact the person’s ability to eat, breathe and hear as well as their facial appearance, and skin conditions such as psoriasis or ichthyosis can cause pain, bleeding and blistering as well as being very visible to other people. But some impairments impact the person’s appearance - creating disabling social barriers and adversely affecting their quality of life - without impacting how their body functions. This may be the case for someone with a large facial birthmark, healed burn scarring or multiple benign skin tumours resulting from neurofibromatosis type 1.

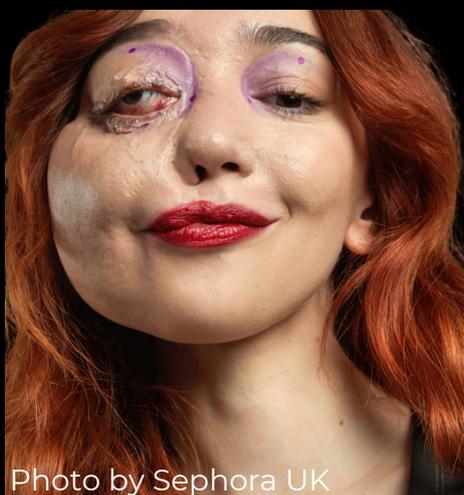


Photo by Sephora UK

Although the CRPD contains no definition of impairment, the CRPD Committee have affirmed, in General Comment No.3, that:

**'the diversity of women with disabilities also includes all types of impairments, in other words physical, psychosocial, intellectual or sensory conditions that may or may not come with functional limitations.'**

**CRPD Committee**



Photo: Phoenix Society

The CRPD also embraces perceived, as well as actual, impairments. This is important because facial disfigurements often give rise to erroneous negative assumptions by others (ix).

Many other influential policies, definitions and laws embrace the inclusion of disfigurements without functional impact too. For example:

- the Equality Act 2010 in Britain includes 'an impairment which consists of a severe disfigurement'.
- the Americans with Disabilities Act defines impairment as '[a]ny physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more body systems'.
- the Disability Discrimination Act 1992 in Australia includes 'disfigurement of a part of the person's body'.
- WHO guidance under the International Classification of Function, Disability and Health expressly lists facial disfigurement resulting from vitiligo as an impairment capable of restricting participation due to fears of contagion (x).

Disability activists themselves constructed a proposed definition of impairment under the human rights model as a 'characteristic, feature or attribute within an individual which is long term and may, or may not, be the result of disease, genetics or injury'. This community definition specifically includes facial disfigurements as something which may 'affect that individual's appearance in a way which is not acceptable to society [...]' (xi).

Accordingly, under Art 1 of the CRPD, a disfigurement is a physical impairment which, in interaction with attitudinal and societal barriers, may hinder the person's full and effective participation in society on an equal basis with others.

## **Part 3: Ending the invisibility of people with visible differences within the human rights community**

Despite the CRPD's commitment to the inclusion of people with disfigurements as disabled people, this issue has remained invisible. We have found no complaints or investigations under the CRPD, no public comments by the CRPD committee and no references under the UN Periodic Review framework relating to disfigurement specifically. This invisibility is compounded by the laws and policies of many signatory state parties which are based on the medical model of disability, which the CRPD was intended to challenge.

This means that people with disfigurements – who are disabled by the interaction between their (actual or perceived) impairment and societal barriers and may or may not also experience functional limitations – are often excluded, forgotten or ignored within these laws and policies. 'Disability status' - which is needed to access medicines in some countries - is often denied to this community. Without medicines (including skin creams and essential SPF for some conditions), people may be unable to work, go to school, or participate in wider society. This results in persistent breaches of human rights.

We ask you to recognise that people with disfigurements are disabled people under the CRPD, irrespective whether their disfigurement is accompanied by functional limitation.

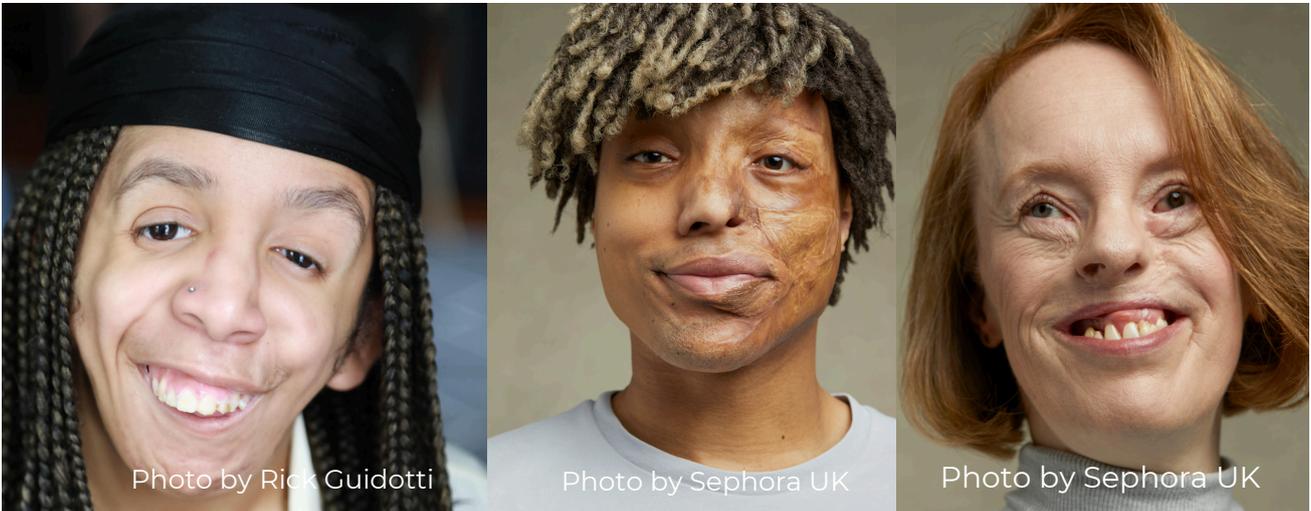
Please stand with us by signing our public FACE EQUALITY affirmation here. Your name and title will be added to the growing list of affirmations on our website.

**I recognise that people with disfigurements may face disabling attitudes and social barriers because of the way they look, which can prevent full participation in society. I affirm their status as disabled people and rights holders under the UN CRPD.**

**Signed by (name and job title):**

# Thank you for you signing!

## Why not turn your affirmation into a **commitment** for the 2025 Global Disability Summit?



This campaign is organised by Face Equality International, an alliance of NGOs working to secure greater recognition of the rights of people with disfigurements/visible differences.



Together we amplify the voices of individuals and organisations working with and for this community.

Face Equality International is a UK registered charity no. 1198641 with consultative status to the CRPD

To see who has made the affirmation so far, please visit:  
[www.faceequalityinternational.org](http://www.faceequalityinternational.org)

## References

- i See, for example, Project Harar: Stigma for Mothers (<https://www.projectharar.org/stigma-for-mothers>).
- ii Exposing human rights violations: living with the stigma of a facial disfigurement in LMICs, Smiletrain and FEI (<https://faceequalityinternational.org/exposing-human-rights-violations/>).
- iii Changing Faces, Disfigurement in the UK, 2017, p36.
- iv See, for example, Hartung, F. & Ferrier, H. (2022, April 5) Bias against facial anomalies in criminal sentencing. Retrieved from [osf.io/9fn83](https://osf.io/9fn83). On a related note, see also Bonnie Berry, Appearance bias and crime (Cambridge: Cambridge University Press 2019) 7.
- v L. Allen Furr, 'Facial Disfigurement Stigma: A study of victims of domestic assaults with fire in India' (2014) 20(7) 783-798, p790.
- vi A. Stone and T. Wright, 'When your face doesn't fit: employment discrimination against people with facial disfigurements' (2013) 43 Journal of Applied Social Psychology 515; S. Stevenage & Y. McKay, 'Model applicants: The effect of facial appearance on recruitment decisions' (1990) 90 British Journal of Psychology 221.
- vii For a summary, see Emma Robinson, 'Psychological research on visible differences in adults' in Lansdown and others (eds), Visibly different (Butterworth-Heinemann 1997) 103; Rumsey and Harcourt, 'Body Image and disfigurement: issues and interventions' Body Image I (2004) 83-97.
- viii UN Training Guide No 19, The Convention on the Rights of Persons with Disabilities, p26.
- ix See e.g., Rankin M & Borah G, 'Perceived Functional Impact of Abnormal Facial Appearance' (2002) 111 Plastic and Reconstructive Surgery 2140; Saunders H, PhD Thesis (2019) 'Does the law provide effective equality rights for people with a visible difference in the workplace?' p200 accessed at: <https://etheses.dur.ac.uk/13707/>; Hartung F & others, 'Behavioural and neural responses to facial disfigurements' (2018) PsyArXiv 1, p10.
- x WHO, Towards a common language for functioning, disability and health (2002) Geneva p17.
- xi Thomas, Gradwell and Markham, Defining impairment within the social model of disability (1997) (<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/thomas-pam-Defining-Impairment-within-the-Social-Model-of-Disability.pdf>).



children's craniofacial association





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