



Research Paper

A hidden community: Facial disfigurement as a globally neglected human rights issue

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ABSTRACT

Disability rights continue to lag behind other equality movements worldwide. Disfigurement rights have an even more uncertain position, sometimes included in disability rights law, but often not explicitly. This article describes the efforts of Face Equality International to end “face-ism” worldwide, and how healthcare and mental health providers, community developers, and educators can engage to move this vision forward. Beyond medical and surgical treatments, mental health needs, societal, and legal barriers must be addressed. We call for strong and explicit legal protections for disfigurement. Culturally appropriate public education to counteract stigma is crucial in shaping an inclusive and sustainable environment for people with disfigurements.

1. Introduction

The disability rights movement has been coined by many activists and critics as, ‘the last frontier’ in the equality stakes. This is due to the pervasive, systemic inequalities still experienced by 15% of the world-wide population who live with a disability.¹

Many believe that the issue is still falling behind in comparison to other equality movements, such as those to counteract sexism or racism. So where does this place facial disfigurement? Seemingly still even further buried in deep-rooted stigma, prejudice and a lack of clarity around where this issue fits within legal, social, and health development goals. One of the key questions in the minds of affected individuals, policy makers, health professionals and wider society that perpetuates this problem is, ‘are people with disfigurements considered disabled?’

This paper is also an appeal to health professionals serving people with disfigurements to consider the challenges individuals and families face beyond direct surgical intervention. By working in this field, academics, service-providers and experts will have seen first-hand how disfigurement is linked with poverty, exclusion and a poorer quality of life in comparison to an individual’s counterpart without a facial disfigurement.

The aim of this paper is to explore the concept of facial disfigurement beyond medical, surgical or cosmetic terms, and consider the wider societal and social construct. It will explore the additional barriers that are created by the fact that disfigurement doesn’t fit neatly into the

definition or concepts of any form of disability. With this article, it is the hope that readers are empowered to engage in the conversation around how the rights and opportunities of the disfigurement community can be profoundly and positively impacted by those involved in health interventions, education and development who are equipped and empowered by tools and information to better address the societal barriers these communities face.

1.1. About Face Equality International

The global movement for Face Equality builds momentum for a campaign pioneered by the late Dr James Partridge OBE, burns survivor and Founder of both Face Equality International and Changing Faces UK. At Face Equality International, which formed in 2018, we have built a unique Alliance of NGOs, support groups and charities worldwide to further the global movement for face equality by counteracting ‘face-ism’.²

Members include cleft care providers such as Smile Train USA, craniofacial support and advocacy organisations such as CCA Kids, support and information providers such as AboutFace Canada and MyFace USA. Many members are focused on capacity building and international education to provide surgical interventions, others are focused on condition-specific support. All work with individuals and families living with facial disfigurement, and so are bound by the vested interest in creating a world where people can choose the life they wish to

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live, irrespective of their facial appearance.

Each member of the Alliance provides vital care and support through direct intervention with those affected by facial disfigurement. Face Equality International has a big-picture, long-term, societal focus. Similar to organisations such as Stonewall or Human Rights Watch, we are focused on justice, equity and inclusion, all of which rests upon recognition of disfigurement as an equality issue.

This core mission intersects in particular with ableism and other 'isms'. Together all these organisations campaign as activists and allies in calling for widespread, equitable, fair representation, from the media to inside boardrooms and across businesses, whilst calling for explicit recognition of disfigurement by bodies such as the UN and the WHO. Alongside this, the membership calls for greater education and awareness amongst society about what life with a disfigurement is like in the modern world, particularly in key sectors and areas where greater advocacy is needed, such as healthcare, education and business.

The vision of Face Equality International is that all societies across the world accept, respect and value people who have facial differences and disfigurements so that they can lead the lives they wish, unaffected by prejudice, low expectations and stigma.

FEI's mission is to:

- facilitate charities working together to tackle the injustices experienced by people with facial differences — whether at work, in schools or the media, or in culture and lifestyle
- enable the sharing of best practice and be an incubator (capacity-builder) for NGOs to campaign for face equality in their own settings
- be a learning exchange and set global standards on how to challenge disfigurement discrimination (eg: at work) and promote face equality (eg: in schools)
- identify examples of facial prejudice and disfigurement discrimination and take action to eliminate them wherever they occur (eg: by lobbying agencies and companies)
- spur the collection and spread of evidence about what people with disfigurement in different countries confront in their lives and what enables their life chances
- represent its members on global bodies engaged with the UN's Convention of the Rights of People with Disabilities (CRPD) and the Sustainable Development Goals (SDGs).

1.2. Importance of language

It is important to highlight the language used. In this paper, we speak to disfigurement beyond that experienced by people with craniofacial conditions, and will also refer to any mark, scar or condition which affects appearance, be it congenital or acquired, from scars and burns, to skin conditions like acne or vitiligo, craniofacial conditions, cleft lip and palate or neurological conditions and facial palsy.

At Face Equality International, we have made a conscious decision through consultation with our international members to use 'disfigurement' as a collective term that describes the visual effect that a mark, scar or condition has.

Society's perception of disfigurement far too often imposes disadvantage on individuals and their families and so this is a publicly-understood term that expresses this. Given that the term is also enshrined in legislation in some countries to protect people from discrimination, Face Equality International will use 'disfigurement' whenever it is arguing for the end to disadvantage and injustice. However, Face Equality International also respects the fact that some people dislike the term 'disfigurement' as a collective word, in which case 'facial difference' tends to be more widely accepted. In some instances, 'visible difference' may be used when relating to a disfigurement that affects a person's face and body.

1.3. Enabling someone with a facial disfigurement to thrive, and addressing wellbeing needs

NGOs delivering psycho-social support such as Changing Faces UK, or AboutFace Canada, and researchers³ recognise that all 'facial differences' in their diverse natures cause similar appearance-related concerns and needs for psycho-social care that reflect the looks-obsessed world we live in. Our global society attaches moral value to 'good-looks' in all of its cultural variance; none of which consider disfigurement to be of value.

Difficulties accessing surgical interventions and adequate psycho-social support are not limited to low and middle-income countries (LMICs), with several of FEI's member NGOs working to provide financial aid for healthcare needs in the USA, Latin America and South Africa. However, medical interventions are simply not enough to ensure individuals and families are able to thrive in a global and globalised society which prizes looks and attaches value to such narrow perceptions of beauty. The odds are stacked against the community across all aspects of life. We cannot expect people with disfigurements to be able to have equitable access to education, work and fulfilment in a world that does not yet adequately recognise their rights, needs, or in fact their very existence.

Research indicates that the journey to fulfilment and acceptance is not complete post-cleft correction surgery without psycho-social consideration, for example, studies "demonstrate the importance of identifying 'psychological outcome' as well as 'clinical outcome' in order to improve rehabilitation for cleft lip and palate patients."⁴ Adequate interventions for low-income countries devoted to holistic care are yet to fully encompass the extent to which culturally nuanced societal attitudes adversely impact upon an individual's wellbeing, let alone an individual's human rights which are being infringed upon due to having a disfigurement, be that through being denied a right to education, rights not to be discriminated against, or the right not to suffer degrading treatment.

People with disfigurement experience high levels of distress, including depression, anxiety, and body dissatisfaction.⁵ Much of this distress can be attributed to others' stigmatizing responses toward them and resultant internalized stigma.⁶ The majority of people with disfigurements desire a professional with specialised training in mental health issues around disfigurement.⁵ There are specific educational programs and credentials for mental health providers working with chronic illnesses⁷ and disabilities⁸ but little exists for disfigurement. Although a small number of mental health services targeting people with disfigurement exist in the UK and certain European countries, it is rare in the United States, and non-existent in developing countries, especially for adults. Standards of mental health care for many disfiguring conditions do not exist or have only recently been developed.⁹

Despite these challenges, the resilience of people with disfigurement can be supported. Cognitive Behavioural Therapy for appearance anxiety has been used and found to be effective for a variety of types of disfigurement.¹⁰ Peer support, including support groups, support conferences, and online communities is a valuable avenue for developing positive self-esteem and identity. For example, repeated attendance at a support conference for people with facial palsy was associated with improved stigma, and social support.¹¹ Perhaps the most powerful role of peer support is developing community among people with disfigurement,¹² building solidarity, and the possibility of empowering collective action for the rights of people with disfigurement.

1.4. Social and societal barriers beyond surgical intervention

These barriers are exemplified by two contrasting case studies, sought through FEI member NGO, Future Faces, whose aim is to support the training and development of all professionals involved in the management of patients with cleft lip and palate and craniofacial developmental conditions as well as other craniomaxillofacial problems.

Operating from a UK base, in Nepal and Hyderabad, India, both individuals have had access to services through the charity's outreach health programmes and speak to positive surgical outcomes and social outcomes, but the long-term emotional impact of disfigurement-associated stigma is evident.

1.4.1. Case study 1 – Raj

"I was born with bilateral cleft lip in Andhra Pradesh, India and I lived 16 years of my life with the defect until I got my cleft lip operated in 2001 when I was 16 years old. I come from a poor family based in India. I was operated for palate in 2002. I had surgery for my nose in 2005. Today I look like any other person. I have speech difficulty as I got my palate operated very late in life. I got all my surgeries done by Dr. GSR sir in Hyderabad.

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. I've yearned for my father's attention and love all my life.

My entire school life I had the cleft defect and so was the discrimination. My classmates used to beat me, abuse me verbally & 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."

When asked, outside of direct medical interventions, what his experience of the societal inequalities faced by someone with a facial disfigurement were? Raj said:

"The preference in anything is always given to people without any facial difference. In my case I was denied of various jobs which I deserve many times as I have difficulty in speech and also because of the scars on my face from multiple surgeries.

Even though I am very determined to ignore all the negative comments, sometimes they get the better of me.

I completed my schooling & graduation successfully. I am a graduate in Accounts from SKU university. I am an accountant now in GSR Hospital, Hyderabad. I can take care of myself and my family. I have a beautiful wife & daughter now."

1.4.2. Case study 2 – Punita

"My name is Punita. I come from an economically backward family based in India. My father abandoned my mother and me once he knew I was born with a facial defect. We were forced into poverty. My mother was not able to fend for both of us. We were taken care of by my maternal grandparents till a period of time. I have always felt the lacunae of not having a father in my life.

Through one of the doctors whom we visited for my defect referred me to Dr. GSR Sir in Hyderabad, India. My first surgery was held when I was 4 years old in 2002 I studied in my native place till 5th grade until a point when my grandparents were not able to take care of me and left me under the care of Dr. GSR Sir.

Even though my defect was corrected, the facial scars on my face has an impact on others and draws their attention. Some good-hearted people try to ignore it. Some try to point out the flaws. I ignore most of the times, but sometimes I fall into the trap. It takes a lot of effort to come out of it.

The teachers in the school I studied in before I got my surgery done always treated me differently from the rest of my classmates. Even in

my own family I had discrimination from the rest of my cousins. I was never given the best of clothes & toys.

I was one of the first students of the boarding school initiated by Dr. GSR Sir. Here I started my education in English medium which would have been still a dream if I had stayed in my village. As I continued my education in the school, my confidence to interact with other people elevated drastically. I was becoming an individual of my own.

I was admitted in the 9th grade in New York sponsored by a Professor of Surgery and three other people from Switzerland. I completed my 9th to 12th grade from the USA, after the graduation I returned back to India. I joined Bachelor of Science degree in Audiology and speech language pathology (BASLP) in Sreekar academy of rehabilitation sciences.

I will soon be a speech pathologist and help the people born with cleft defect to speak better. The aim of my life is to give back what I got. I will put all my effort in uplifting others lives especially the ones who have cleft disability."

By no means is the second example likely to be common, nor is it something that could easily be replicated in the world as we know it right now. Reading these examples should encourage clinicians, academics and potential advocates for the facial difference community to consider the potential of the ever-growing educational infrastructure, already embedded within the innovations of the global development sector. This is a neglected community, and a neglected equality issue that provides opportunity for exponential growth in terms of addressing the holistic needs beyond direct surgical intervention. One can only hope to ignite interest in measures which consider the environment in which an individual exists, and so the environment in which an individual may or may not be bolstered to thrive given the best possible reasonable adjustment, best possible care, and above all else, the best possible attitude from care-givers, whose attitudes can make or break an individual's potential, depending on how susceptible someone is to the disproportionate bias that limits our expectations of those with disfigurements.¹³

Face Equality International set out to be a capacity builder, bringing together experts in the field to share expertise, preventing silos and reinventing wheel. Engaging with and activating the existing networks providing vital care for the disfigurement community will be integral to securing the success of this global movement, as will empowering disfigured people to advocate for their rights.

1.5. Attitudes towards facial disfigurement

Disfigurement holds a variety of culturally-specific meanings, almost all of which are negative. In countries where the medical model of disability is predominant, including North America and much of Europe, disfigurement is a defect to be fixed through medical and surgical interventions.¹⁴ In these cultures, a person with a disfigurement is seen as responsible for seeking such treatment to remove the disfigurement and is blamed if the disfigurement is apparent, even after attempted medical intervention. In cultures dominated by the moral model of disability, the most common way of thinking about disability worldwide, disfigurement is viewed as a punishment or mark as a result of evil, sin, or karma. A disfigured child may be viewed as a sign of a curse on the family, and is hidden away to avoid shame or shunning of the entire family. The case studies above speak to some of these harms. In most cultures, regardless of disability model, parents of a disfigured child experience guilt and shame for having brought on the disfigurement, either for perceived poor medical decision-making, neglect, or moral wrongs. All of these factors inhibit the ability of a person with disfigurement and their families to seek healthcare, mental health support, education, and opportunities to meet basic needs and earn an income.

There is currently a study taking place at the Centre for Appearance

Research at the University of the West of England which explores how stigma leads to health inequalities in the Somali community. Campaigner Nura Aabe said in media coverage of the study, “There is nothing in between being normal and not normal in the Somali community. Difference means you don’t want the rest of your community to be aware of it, because of that you are left with hiding and being ashamed and therefore not coming forward to access services. The whole concept of understanding, from a community perspective, is something that health professionals need to take into account.”¹⁵

The previous models place the onus of disability on the individual and their families, failing to account for the role of society in constructing disability. In response, disability activists and scholars offer the social model of disability, which states that the primary cause of disability is social values, power structures, and the built environment. According to this model, people with disability or disfigurement are “disabled” by discrimination, a failure to accommodate their needs. This model places disability and disfigurement as a social justice issue, which will be discussed below.¹⁶

1.6. Disfigurement as a hidden human rights and social justice issue

Disfigurement is a community that is very much still neglected in the anti-discrimination and human rights conversation, and a community which is still buried and hidden in inadequate policies and protections.

Hidden is quite literally the case in some areas of the world where children with disfigurements are not allowed to leave the house or go to school, particularly in communities where the moral models of disability and disfigurement are upheld,¹⁷ and therefore individuals are considered a burden on family, carers, communities and the state. The Childhood Tumour Trust for example is currently supporting a young girl in Ghana, who is not allowed to attend school because she has been told that she will scare the other children.¹⁸

At the time of writing this, there is a case before the Supreme Court in Canada in which a joke was made about a public figure with Treacher Collins syndrome, “He’s called ugly. The stand-up comic pokes fun at his hearing aid. The “he” in question was a 13-year-old boy named Jérémy Gabriel who has a disability. The comedian Mike Ward says that when he found out the child wasn’t dying, he tried to kill him.”¹⁹ It’s encouraging to see a case reach the highest court in Canada that involves the sort of hateful and degrading behaviour that we know is experienced by people with facial differences around the world every day. In the UK, over 40% of people with a visible difference have had negative experiences online, and 1 in 10 people with a disfigurement say they are repeatedly harassed on social media.²⁰ It is even more encouraging to understand that the case has progressed to this stage in spite of conflicting with the right to free speech, which is often a successful rebuttal for similar instances of offensive remarks towards the community both on and offline. It is incredibly rare, if not unheard of to see cases like this progressing to this point in the criminal justice system.

To frame the non-legal context, another way in which the disfigurement community often falls through the gaps in systems of protections due to lack of awareness and understanding, is in the regular occurrence for people to have their reports of online abuse denied due to incidents being deemed ‘not to breach community guidelines’.²¹ This is likely because derogatory terminology used to degrade people with disfigurements is less recognisable or understood by moderators. It also an example of people with disfigurements not meeting the arbitrary threshold of qualifying as disabled in the eyes of social media providers given that reports of hateful content are able to be reported under certain protected characteristics, of which disability is a feature, but not disfigurement.

1.7. Lost in the legal context

In the UK, ‘severe disfigurement’ is protected via the Equality Act 2010, UK under disability as a protected characteristic. Our founder, Dr

James Partridge OBE was instrumental in securing this provision. But as identified by Hannah Saunders, “The parameters of the severe disfigurement provision remain uncertain. These parameters are under particular tension from the related concepts of appearance and disability, which partially overlap with disfigurement.”²²

In regards to legislation outside of the UK, further research by Saunders is important to frame the international context. “The variation is perhaps best encapsulated by the position in the United States, where federal law includes ‘cosmetic disfigurement’ as in impairment under the Americans with Disabilities Act of 1990, but various state and municipal codes also prohibit discrimination on grounds including personal appearance, height and weight and physical characteristics.”²²

In Europe, the EU Charter of Fundamental Rights does not offer a definition of disability and instead a definition has developed via case law which does in fact consider social and environmental factors rather than mention of ‘physical or mental impairment’ as in other jurisdictions. However this does not make protection for people with disfigurements any more explicit. Seemingly, the ability to carry out functions revolving around employment are indicative of disability status under the EU Charter. So it remains undetermined whether the prevalence of discrimination in seeking employment experienced by people with disfigurements would warrant them then being perceived as disabled under the EU Charter. Without case law to reflect the extent of the problem, the issue remains once again buried.

There is some recognition in Western countries with little to no protection for the likes of the Indian sub-continent. But does society, the criminal justice system, or even the medical community class those with disfigurements as disabled? And more importantly, are they classed as disabled enough to seek protections, given that the medical model of disability prevails in legal terms in order to be given adequate protections and support; be them financial, medical or societal. Organisations such as The Many Faces of Moebius Syndrome in the USA report that many people with the neurological conditions struggle to receive benefits unless they can prove some form of serious underlying medical condition beyond the appearance-affecting elements of the condition. Similarly, organisations providing support to burns survivors find that their community members often struggle to receive the benefits permitted to those with disabilities unless they can prove chronic health implications of living with the after-effects of burn injuries.

Case law indicates the importance of persons with facial disfigurements proving “disability” properly under the UK Equality Act in order to exercise their rights. This was highlighted in a recent UK court case in which an employee claiming protection under the UK Equality Act had their case dismissed on appeal, due to failure to prove “disability” pursuant to section 6 of the UK Equality Act.²³

Recommendations have been made that the requirement that only “severe” disfigurements can gain protection under the UK Equality Act should be removed. Baroness Hollis of Heigham said: “[s]mall wounds can be very disfiguring, whereas a large burn carried by an airman may be worn with pride as a sign of war. Alternatively, mild facial palsy is, for example, very isolating. Therefore, it is not size, it is not seriousness and it is not the conspicuousness of disfigurement which affects the person’s ability to cope: it is another person’s perception of it.”²⁴

As an organisation seeking global solidarity for face equality as a neglected human rights issue, reliance on the UN Convention on the Rights of Persons with Disabilities (CRPD)²⁵ to better protect the rights and freedoms of this marginalised group seems paramount. To seek recognition from the CRPD for disfigurement has been a key strategic priority for Face Equality International ever since its conception. Face Equality International has recently commissioned further research to consider international legal protections which explores potential protections via the CRPD. Early findings tell us that the definition of disability therein is intentionally broad, and that there is no need for a person to describe themselves as “disabled” to enjoy the protection therein.

Paragraph 2 of Article 1 of the CRPD provides that “persons with

disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". This is an "open description or non-definition of disabilities". Paragraph (e) of the Preamble to the CRPD recognises that "disability is an evolving concept" and that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

Seemingly this is the most inclusive of all definitions, given that the convention is based on what is more widely considered to be the social model of disability. But without explicit mention of disfigurement, or other terminology denoting disfigurement, it seems provisions aren't yet adequately serving the disfigurement community in imposing the obligations on countries that have ratified the Convention to implement measures to protect the rights of the disfigurement community. So is the broad definition serving people with disfigurements, or the systems and services in place to protect them, in that this does not answer the question of whether they are 'disabled' or not? Is the arbitrary nature of the definition, coupled with the lack of accountability measures in place for UN ratified countries leading to further systemic inequalities?

With a third of people with disfigurement in the UK having been victims of a hate crime, and less than a third of them reporting it²¹ even in Western societies with legal protections, the injustices this community faces are widespread, and the problem goes beyond legislation in itself.

1.8. So Where Does Someone Fit When They Do Not Identify as Disabled?

Many people with disfigurements worldwide do not currently, nor ever wish to identify as disabled in order to seek legal protection and this leads to further issues.

Recent anecdotal conversations through the work of FEI suggested many people see 'facial difference', seemingly the more widely accepted and internationally relevant term, and disability, as two very separate identities. Many wish not to associate with something that might further stigmatise or ostracise when they already suffer at the hands of prejudice on a daily basis. This is coupled with general awareness of protection being low, and the prevalence of resignation due to the daily occurrence of harmful behaviours and attitudes received from strangers, but also from loved ones, and well-intentioned healthcare professionals.

Concerns around identifying with a heavily stigmatised label or identity are often in part due to society's perception of disability being primarily functional. So it's unsurprising that individuals with facial disfigurements do not wish to associate with something that might further stigmatise or ostracise given that these are already common feelings and experiences for the disfigurement community. There may well be fears of taking up space, making a fuss, or being permitted finite resources dedicated for those with more conventionally recognised disabilities, so they do not feel entitled to such accommodations such as reasonable adjustments in the workplace or protection from hate crime. All of this serves to place the onus back on the individual to prove that both them as an individual, and their experiences of discrimination are worthy of consideration and protection.

The odds are very much stacked against victims of discrimination and abuse, be it in proving they meet the threshold of 'disability', being aware of such protections, or in turn lawmakers or even the police being aware of such protections. Sadly, even new statistics exposing other areas of the criminal justice system such as those around rape convictions in the UK, in the year to March 2020, just 1.4% of rape cases recorded by police resulted in a suspect being charged (or receiving a summons).²⁶ The system is disproportionately stacked against 'victims' having to prove themselves to be worthy of what protections they might be afforded throughout every step of the traumatic proceedings, so it's unsurprising that harms and discrimination towards people with disfigurements remains a hidden issue within public consciousness, within

legal case law, in the eyes of employers, and in turn the general public.

From a practical stand-point, a legal professional perspective, the law, and legal protections must prevail in terms of progression for social justice causes, but it is clear that legal definitions and legislations as a stand-alone will not adequately protect the community they intend to legislate for. Legal barriers must be removed and violations must be prosecuted.

Face Equality International recognises the duty we have to gather adequate evidence to build the case for better human rights protections worldwide as we continue to grow as a movement and as an NGO serving the disfigurement community. We can only hope that in building further coalitions with service providers who are working on the ground we are able to collect further research in order to effect change and to protect people with facial disfigurements from harm and injustice wherever possible.

1.9. The importance of considering the pandemic

The COVID-19 pandemic has served to highlight the odds being further stacked against the disfigurement and disability community. Policies are deeming them to be less valuable to society via inequitable access to ventilators^{27,28} but also perhaps by the government endorsement of 'hiding away', with shielding and wider regulations acting as encouragement for individuals to further isolate themselves away from society.²⁹ This isolation may be paired with the relief brought on by mask wearing, allowing many people with disfigurement to escape the prying eyes, stares, comments and harassment from strangers.³⁰

It's unsurprising that many people with disfigurements have found recent times to be marginally easier to cope with,³¹ but what will be the long-term repercussions of hiding away be, as a method that temporarily made life easier for people with facial differences? This is a community that suffers insidious resignation at the hands of harmful attitudes, system failure and being told that their 'face does not fit'. So has the pandemic halted growth towards a society which is inclusive and accepting of facial differences due to the issue being less exposed in public life, as a result of mask-wearing and shielding? The anxieties of the community in respect of returning to public life perhaps prove that expectations are set low. Perhaps the pandemic-related experiences of the western facial difference community can shed light on the realities of living in low-income countries where the societal pressures to hide away are deep-rooted in cultural norms as opposed to temporary protective measures.

2. In conclusion: what is the future of the face equality movement?

There are some key areas for development that are relevant to providers of craniofacial care that one would hope they would give serious consideration. In doing so they would be able to support the global efforts of Face Equality International and its members moving forward:

- Surgical intervention must be paired with mental health services for patients and families
- Culturally appropriate public education to counteract stigma and bias is vital for shaping an inclusive environment for persons to thrive within. This is all the more challenging in low resource LMICs where access to all these facilities and opportunities is often difficult
- Stronger legal protections that name "disfigurement" will be required in the future, and FEI will need support in building the case to bring this about
- Research is needed for an accurate understanding of the prevalence of disfigurement and discrimination across the globe and FEI will be reliant on organisations providing services on the ground in order to understand the real need of global communities

- Education, community-building and development that is focused not only on healthcare, but also mental healthcare and human rights is needed on the ground to build culturally appropriate sustainability.

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