Exposing Human Rights Violations:

LIVING WITH THE STIGMA OF FACIAL DISFIGUREMENT IN AN LMIC

INDIA & NEPAL

FACE EQUALITY INTERNATIONAL

SmileTrain

ACKNOWLEDGEMENTS

Thanks goes to all those that input into this project, from academics, to organisations, and most of all to those that shared their experiences of living with facial difference or disfigurement.

"'Oh she has a scar don't call her because our children will get scared'. The high society people are educated but still they are discriminating."

Executive Summary

WHAT IS FACE EQUALITY INTERNATIONAL

Face Equality International (FEI) works to build capacity for a growing Alliance of charities, NGOs and support groups around the world to advocate for face equality. The vision of this Alliance is for people with facial differences to live freely, without discrimination or indignity.

With a strategic focus to position face equality as a human rights issue, consultation with member organisations delivering services in low- and middle-income countries (LMICs) revealed anecdotal evidence that the most extreme examples of stigmatising behaviours included human rights violations, such as abandonment, abuse, infanticide or being banned from attending school often occur in a low-income context. Our consultation revealed that these occurrences were not being spoken about publicly, let alone recorded or addressed.

AIMS & PURPOSE

There is a dearth of research to inform how best to address this issue in a culturally astute manner. Intersectionality is fundamental to understanding the needs of the FD community globally. For this project, the intersecting nature of race, ethnicity, culture, religion, caste, education and socioeconomic factors, in particular poverty, are important factors in understanding life with FD.

The majority of this project took place in a healthcare setting, given that the primary focus of most FEI member organisations is largely in healthcare, be it surgical, psychosocial or supporting persons financially to access healthcare.

This project was possible thanks to funding from Smile Train, with FEI building a project proposal to align with founder member Smile Train's strategy to reduce stigma. As a founder member of FEI, and the organisation with the most extensive global reach, with their help, we sought to better understand to what degree stigma is a driver for human rights violations in LMICs. Our aim was to reveal the most successful interventions which could be adapted and rolled out globally, whilst better informing the worldwide face equality campaign.

Heavily influenced by campaigns to reduce stigma around HIV, we wanted to scrutinise our understanding of stigma. FEI aims to act as a catalyst for the growth of a diverse and inclusive face equality movement via community-led campaigning, together with the FD community, organisations, activists and beyond. We want to get to the very source of the social construct or stigma, which cannot be achieved without turning our attention to society. This was as opposed to the more common approach which focuses on enabling those affected simply to cope with stigma, as though stigma is an inevitability, when in actual fact it can be prevented.

FEI hopes that these findings will catalyse collective responsibility across the FD sector to build in principles of reducing stigma both into delivery of care and in efforts towards equity and inclusion for people with FD in wider society. Such efforts are reliant on capacity building for communities, academics and organizations in the Global South, to prevent Eurocentric research or delivery of services in LMICs.

METHODS

Thematic analysis was conducted of semi-structured interviews with parents and adults with disfigurements to the head and neck. This information was combined with recorded conversations with healthcare professionals (HCPs), charity workers, social workers, and government officials. This was then coded according to the themes relevant to stigma reduction using NVivo which colour coded and categorised themes according to the most common themes.

Interviews were conducted with individuals and patients from both rural and urban environments in Nepal and India. Interviews in Nepal took place in Kathmandu and in both the centre and surrounding rural areas of Janakpur. Interviews in India were conducted in Delhi and Hyderabad, with patients travelling from inner city and rural areas to seek treatment. Similarly, interviews were held with HCPs, charity workers and social workers in remote and urban settings in the two countries. Though the two cultures have many similarities, and open borders mean that there is much crossover in communities, we recognise the two distinct countries and cultures. Studies from the two countries have been combined for the sake of beginning to gain a deeper insight into the shared experience of the facial difference community in South Asia, but we recognise the limited view we've gained into countries with vast and diverse populations.

Interviews were translated directly in real-time during the interview by the assisting charity worker or healthcare professional.

Our academic steering committee was made up of 15 international academics, all but one of whom had personal experience of facial difference or disability. Their input into formulating interview and project plans, along with consultation throughout the project was instrumental.

The process consciously tried to move away from conversations solely about interventions (predominantly medical) that have been developed 'on and to' the FD community, and more so about consulting with community members about their wishes for how best to reduce stigma and discrimination in their specific environment.

Building relationships with interviewees ahead of interviews enabled persons to open up both about their experiences and also their hopes for the future of society, which was helped greatly by the support of charitable organisations willing to facilitate meetings with their communities in their home environment.

KEY FINDINGS

The findings of this study demonstrate that collective responsibility to proactively reduce stigma is needed across society, particularly in fields where the FD community are seeking services such as healthcare or government support. **Unless service providers actively take measures to reduce and prevent stigma, they may be complicit in reinforcing it.**

Finding inner strength to self-advocate due to the failure of others. *1*

The need for representation of FD. *2*

Disfigurement as a disability. *5*

Victim blaming' heightens discrimination and abuse. *4*

"Health education alone does not reduce stigma." *3*

1. Finding inner strength to self-advocate due to the failure of others.

This meant being failed or disregarded by families, media, communities, HCPs or government. Resignation, and having to draw upon inner strength in the face of either being ignored, failed or persecuted, was a dominant theme across all of the interviews.

2. The need for representation of FD

Positive visibility both publicly and in a community setting, i.e. proximity to others with FD, is crucial for reducing self-stigma and public stigma. We must build supportive communities, whilst reducing barriers to societal success in order to ensure representation of FD across society.

3. "Health education alone does not reduce stigma."

HCPs are liable to reinforce stigma without proper training, which should be led by their patients. General health education for the public is poor and when it comes to understanding of disfigurements, knowledge is often prejudiced, with many myths about cause. Face equality training to reduce stigma both in the healthcare industry and for the general public, if integrated into medical priorities will guarantee the best possible patient outcomes.

4. Victim blaming' heightens discrimination and abuse

Blame is often placed upon those affected and their parents. This can be reinforced by religious or traditional beliefs, particularly affecting women. The Face Equality Movement must align with intersecting movements such as gender equality in order to reduce the disproportionate impact on women.

5. Disfigurement as a disability

People with disfigurements often do not qualify as disabled, nor are individuals likely to regard their FD as a disability in itself. But disfigurements are likely more disabling in a low-income setting without healthcare access, so recognized disability status in a low-income setting could be pivotal to reducing poverty and improving health. Partnering with disabled people's organisations (DPOs) across all interventions would lead to legal, social and economic empowerment.

KEY SOLUTIONS

Theoretical and strategic

1. Involvement of the FD community in the design, implementation and evaluation of stigma interventions is essential.
2. Our aim is to work towards a holistic framework to support the FD sector to adopt destigmatising principles into all care, incorporating relevant 'theoretical, behavioural, psychosocial and cultural models' (Mostert, 2016, p. 22).
3. Intervention mapping for social behavioural change is required in order to map, plan and test stigma interventions. This must cut across with a 'programmatic settings approach' as inspired by HIV/AIDs stigma and discrimination programmes focused on media, government, justice, healthcare, workplace, education and community (UNAIDS, 2020).
4. Align with intersecting movements and communities experiencing stigma and inequality to forge strategic alliances such as women's movements.
5. Move away from solely regarding FD from a medical model perspective.

Specific interventions to explore in the immediate future

1. Empowering, dignified photography in medical and promotional settings, accompanied by storytelling to dispel myths.
2. Given the socially disabling nature of FD, we believe that lobbying global disability non-profits to better understand and include the FD community in programming will help us to reduce inequality as well as stigma, in particular through social and economic empowerment programmes.
3. Mandatory training for any healthcare and charity staff that tackles implicit bias, discriminatory language, wider FD education beyond their specific field, managing expectations, and dispelling myths. This must focus on empowering patients and parents, and taking the child or individual's lead on their needs as priority over family.
4. Engage with UN representatives in India and Nepal in order to better understand how to facilitate meaningful exchange. United Nations CRPD ratified countries have a duty to serve the disfigurement community, and so the UN would benefit from increasing representation and seeking expert advice from the disfigurement community.
5. DEI practice and policy in the workplace that promotes opportunities and equitable hiring practice for people with lived experience to seek employment in healthcare, charity work and across societies is required to reduce all kinds of stigma. All sectors working with the FD community should adapt their hiring practices to create more opportunities.

INTERVIEWS

Nepal

Facial difference community (parents and adults): **6**
Healthcare professionals (HCPs): **6**
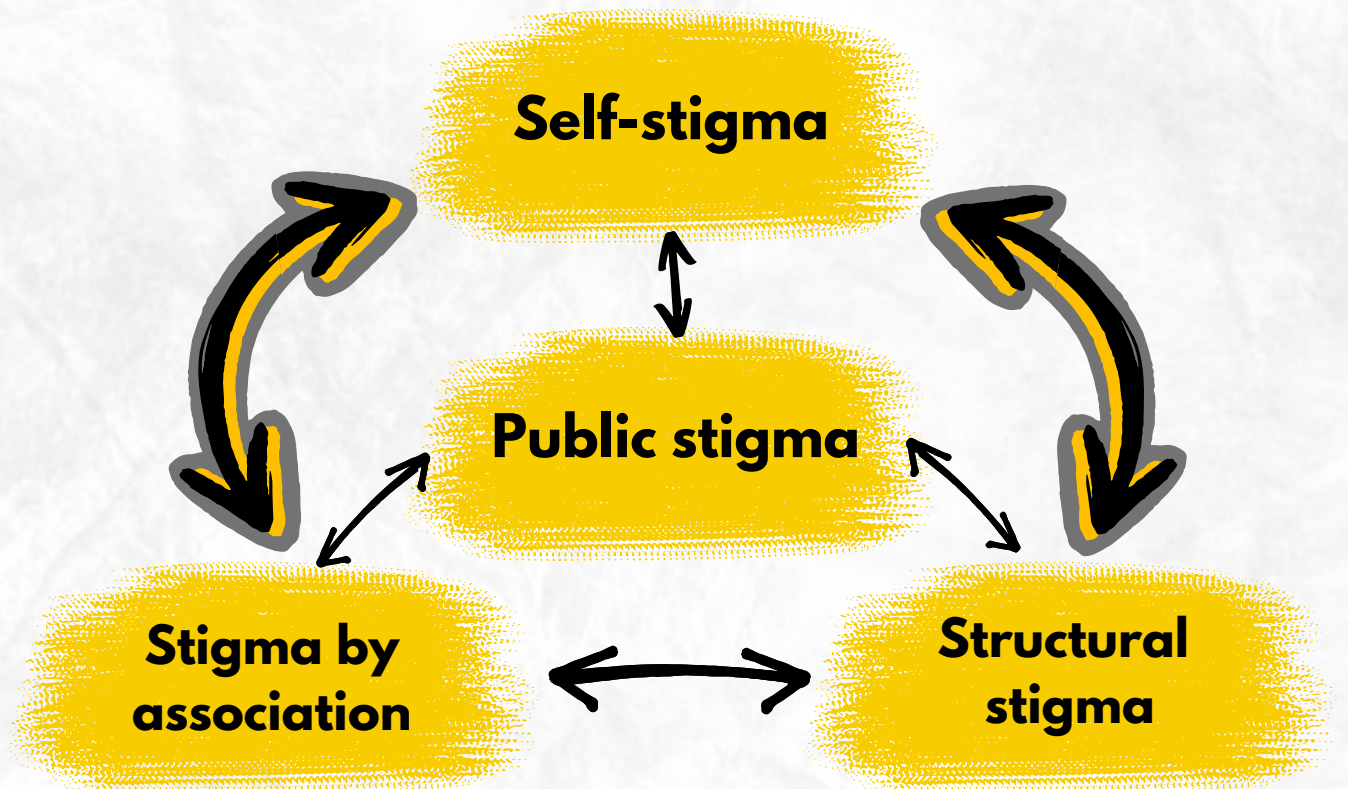Charities: **6**
Government officials: **5**

India

Facial difference community (parents and adults): **8**
Healthcare professionals (HCPs): **6**
Charities: **5**
Academics: **3**

DEFINING STIGMA

Defining stigma in a non-academic way was a challenge from the outset, especially in such a way that it could be translated into Hindi, Nepali and a variety of other local dialects. It was much easier to talk around the topic of stigma, and in particular negative or discriminatory behaviours, which could then help us to form a collective understanding of stigma through the course of interviews.

Throughout this report, we primarily use the Pryor and Reeder (2011) social stigma framework due to it being outlined effectively in the recent study relating to the social stigma of facial difference by Rasset et al. (2022), which splits stigma into the following types:

Self-stigma

Public stigma

Stigma by association

Structural stigma

(Pryor and Reeder, 2011)

People who are stigmatised			Sources of stigma	
Anticipated stigma (perceived)	Internalised stigma (self-stigma)	Experienced stigma (discrimination)	Enacted stigma (discrimination)	Negative attitudes Prejudice

**Social participation restrictions
Increased morbidity and disability
Poor quality of life and mental health
Reduced access to care
Delayed diagnosis
Poor treatment adherence**

**Counselling
Skills building
Empowerment**

**Information/education
Contact with affected person
Change agents/Popular opinion leaders**

<u>(An assessment and intervention model of health-related stigma (model modified from Weiss)</u>

Self-stigma — The internalisation of beliefs or behaviours from others that have a negative impact on a person's wellbeing.

Public stigma — Behaviours, actions or beliefs from others, inflicted upon a person with a stigmatised identity. Could manifest as 'enacted stigma' ie discrimination.

Stigma by association — The stigma felt by parents, family members and others that know the person with FD.

Structural stigma — Systems, laws and societal norms that reinforce negative treatment of someone with FD.

We also looked at several other academic frameworks such as the health and discrimination framework below, which helped us to understand the meaning of stigma and how it not only affects those living with a disfigurement, but their friends, families, communities, and how it plays a role in society and systems too.

THEMES EXPLAINED

1. Finding inner strength to self-advocate due to the failure of others

Being failed or disregarded by families, media, communities, HCPs or government are all examples of public or structural stigma. Resignation, self-stigma, and having to draw upon inner strength in the face of either being ignored, failed or persecuted, was a dominant theme across all of the interviews.

Reducing inequality through advancing economic and social empowerment for people with FD involves removing barriers to self-defined success, be that in the workplace, in relationships or spiritually.

A remark made by a mother of a child with a craniofacial condition was, *"In our community, there are lots of people, but they don't have same heart. Somebody likes and somebody unlikes. So for that type of people we cannot do anything."'*

Resignation, or the acceptance of something undesirable but inevitable, is a theme spoken about a lot in the existing research in European contexts about life with a disfigurement (Changing Faces, 2017).

A mother spoke of her son with FD being attacked in the street. *"I don't know how to stop this from happening. What wrong did you do to that boy? He is a good boy. You should be happy. Why should I be angry with him?"* She then told us that there was nothing that could be done about it, that people don't listen even when you try to say something, they don't care.

An adult male with a visible skin condition living in a remote part of Nepal, had a brother living with the same condition which may have helped him to cope given he showed a great deal of strength when it came to disregarding the poor treatment from the local community. Many around him refused to touch him due to this skin condition.

"I can't fight with people, so better I just hear them and neglect their words, in one ear and out the other."

When he was small, he had just a small spot on his skin. In his community in Nepal, it's a good thing, it's lucky. If it spreads it's often called 'churuk', meaning infectious or Leprosy and then its negative. This was the word people used to refer to him instead of his name.

Several interviewees did not have any emotional support from family, peers or HCPs throughout their journey, and they had to find it within themselves.

"'I was really uncomfortable to go out of the house also, but I come through all my pain and I heal myself, and I became like more stronger, and one of my inspiration I love nature, you see, the surrounding and I comfort myself seeing all the nature. If you see the tree now it seems like no life but next year it will bloom again and make a fruit. I was just thinking life is the same. This now I'm nothing but I just try to have hope and be stronger."

"When I was growing up, I have no support, no help, no advice. My education was delayed a lot, no one was personally there to support. I struggled a lot."

A female acid survivor in Nepal, who was training to become a counselor for other burns survivors said, *"Mostly people go into depression and anxiety when they get scars"... "my everything is gone, I can't face society, I have many scars.' I want others to know that scars are nothing. Don't treat it like it's everything, and think 'I have a scar and I can do x, y, z'."*

This is paralleled with the global experience, where we're seeing more representation of people with lived experience wanting to work in healthcare and services to give back to the FD community. This could indicate that the desire to do so is to fill the gaps in the care that individuals might have hoped for, in striving for comprehensive care that is more mindful of people's holistic needs.

"I want to be financially strong. I am dreaming to have a survivor cafe so others will come and they don't have to worry for a job, because still some don't have a proper job. So my dream is to give everyone a chance because day by day there are more cases right now. Some are just burning themselves. Its not getting less even though there are lots of awareness program."

One of the final questions we asked interviewees was how can FEI help to make a better world for people with FD. There was often a sense of despondence about how to bring about change, indicating a further sense of resignation. The majority of respondents found it difficult to answer this question, even given prompts from interviewers and accompanying charity or hospital representatives. We asked what government, media or healthcare could do to make their lives easier, and many either outright said "government don't care" or that it won't make a difference, or simply couldn't find an answer. It appears the onus continues to be on the community themselves to come up with the answers to the challenges they're facing, perpetuating the model of placing the blame and responsibility on those directly affected.

"When I tell people you're not supposed to treat others that way, they sometimes act like they don't listen and they just avoid me."

Being failed by government, media, HCPs and local communities was a common reoccurring theme that indicates the presence of structural stigma, whereby systems are reinforcing prejudicial treatment of the FD community.

The inspiration for this pilot came from hearing stories from the charitable and medical community about abandonment and other human rights abuses, particularly affecting children with FD. These stories were coming from low-income settings in South Asia, Latin America and Sub-Saharan Africa. Research in Nigeria found that around a quarter of respondents wished their child with a cleft lip and/or palate (CLP) had never been born, and two of the participants even wanted to abandon their baby at the hospital (Adeyemo et al., 2016). A study in Kenya found that children with CLP may not be considered human, they may be killed, or deemed unworthy of a name (Kimotho & Macharia, 2020).

In consulting with human rights agencies or child protection organisations, there is clearly little awareness about disfigurement and specific services and protections afforded to this unique community. Yet we know many children with disfigurements are abandoned and thereby end up in orphanages, 'lots of children with Clefts end up in orphanages' was a comment from an interviewed charity worker, whilst also hearing several stories of medical centres, individuals or affiliated charities having to fund and find carers for children. 'If there is no center, there would be no (child)', was a remark made by a foster mother in an interview whose costs and accommodation were paid for by a local hospital.

A standout comment from a social and outreach worker, whose job is to find patients with Clefts and encourage them to seek treatment was when discussing infants with rare facial clefts, (meaning a Cleft that affects more than just the lip or palate and affect the cheeks, nose and eyes). His view was that the moment such a child is identified, they should be taken into care by a charity. Many infants die whilst waiting for surgery, which can be delayed if they're under weight, particularly given associated problems with feeding, and being susceptible to infection, diarrhea or anaemia. Parents need to commit time and money to travelling back and forth, sometimes great distances. We were told that this cost could be too much for parents with minimal income, or farmers needing to attend to land. This could then lead to infants being 'left to die', or even killed, recalling comments such as 'why won't she die', which may indicate a lesser value attached to young girls lives. The structural aspect of this relates to the role of healthcare providers and the World Health Organisation, in that such cases are deserving of attention in the global health space, especially given that South Asia has the highest incidence of rare facial cleft s and the high numbers of lives lost (Wang et al., 2023).

We regularly hear cases of discrimination based upon facial appearance around the world, and so we aimed to deepen our understanding of the cultural context in India and Nepal.

"After my attack, even though I had a qualification and knowledge, it was really hard to find a job. And my financial condition was really poor because my mother was also a single mother with two daughters. And my elder sister was kind of mental retarded so it was really difficult and hard to find a job because they just judged me on my external look. Even though I go with certificate they said 'no you have scar.' Even I am educated, lots of other survivors they are not even educated and they are just covering their face, and they are just struggling their life not finding a job."

"Mostly people didn't get job because of their scars"

'Colourism' was a regularly occurring theme throughout the project, although it wasn't ever defined as such. This is effectively a hierarchy or prejudice attached to the colour of someone's skin, in that the lighter someone's skin is, the higher the perception of their status, with darker skin tones being associated with lower status or caste. Charity workers told us of textbooks for schools which promoted such hierarchies, along with labelling people with scars as 'ugly'.

Similarly, the caste systems in India and Nepal played a huge role in the intersecting prejudice experiences by the FD and disability community.

GOVERNMENT

The Home Secretary of Nepal believed prevention of poverty to be the most effective way to reduce discrimination for the FD community, and that as a distinct community, they would never be a government priority. Observations from wider conversations with government officials was that human needs were not of interest, instead their motivations were focused on economic growth, with a particular interest in building hospitals, rather than taking an interest in the needs of the patients in attendance.

Recent advancements of sentencing laws in Nepal which differ in jail sentences according to whether perpetrators damage the body or the face have been long campaigned for, and are appreciated by survivors. However, *'it's my thoughts that pain is pain, whether it's face or body, we can't divide it. If anyone throw acid on my hand, it's as much of a pain'.*

A healthcare professional interviewed recalled to us a conversation with a government minister in which they remarked that they had so many people in the state to care for as it is, how could they be expected to think specifically about these kids with CLPs. Surgeons spoke of the financial case for CLP care in that the financial burden on families with untreated CLPs who would thereby struggle to speak would be far higher than if they were to have medical treatment.

Every individual should change their mind. One by one, then comes society, then city or government...It should come from the heart... Its not like a law or system so first we have to change one person to another then it should surely affect the government because first we pick out the government then it will not happen.'

The role of government will be expanded upon below in relation to the legal definition of disability in India and how this extends to the FD community. Governments in India and Nepal have a duty to conform to their ratification of the United Nations Convention on the Rights of Persons with Disabilites, and thereby protect the dignity of persons that fall within this definition of disability, which is inclusive of FD. In reality, government officials questioned were unaware of this responsibility.

Studies on CLP in Kenya recommend that governments should support nationwide policies and campaigns together with charities to reduce stigma and increase public education, but again the project revealed very little awareness of FD (Chung et al., 2019). Similarly, Noma (a tropical disease causing FD) patients and advocates, call for 'rigorous sensitisation campaigns in communities to raise awareness about the disease' (Live a Dignified Life with Treatment – Says Noma Survivor, 2023).

But awareness raising alone is well discussed in social justice spaces as an insufficient method of reducing discrimination. Instead, interventions must actively change behaviour, which is well documented in 'social behavioural change' theory as a mechanism of reducing stigma (Stutterheim et al., 2022). Leaders in the disability sector at this time are moving more towards these methods.

In attending a meeting with leprosy care workers in Nepal, along with the World Health Organisation (WHO), the WHO representative had little knowledge of the incidence and associated stigma experienced by those affected. 2021 figures from the WHO indicate 2394 cases in 2021, but the HCPs and charity workers devoted to this community know there to be many more unrecorded cases as their patient records did not correlate with this number.

A priority for South Asian communities is getting married and having a family as 'a sarosanct union' (meaning highly important). This was a challenging topic for several interviewees who may have faced rejection, which we were told was common. With arranged marriages having been called off at the point at which families discovered their potential son or daughter-in-law had a disfigurement. Some families asked for a higher payment in the form of a dowry in order to marry their child. Despite dowries being outlawed in India since 1961 and in Nepal since 2009, they're still commonplace. This meant that some interviewees were not able to afford to get married due to families being asked for high sums. Generally, many believed that South Asian respect and adherence to the law was minimal, so this would not be an effective solution.

Violence and abuse associated with dowries is widespread. In 2011, the National Crime Records Bureau in Indiaa reported 8,618 dowry harassment deaths. This resonates with what we were told by acid survivor charities in Nepal where stories of acid or burn violence being used by inlawed families if dowry payments weren't made or if their children were marrying someone from a lower caste.

An interviewee spoke of being abused by both family members and neighbours. The neighbours made complaints to the management of the building in an attempt to evict them for having a skin condition. Neighbours claimed seeing them was a bad omen and it ruined their whole day as a result. They were referred to as 'a snake' and as non-human, and neighbours had urinated on them previously. The same interviewee had been abused over a long period of time by family members, who forcibly took their home and beat them every time they tried to return. Law enforcement repeatedly disregarded them, left them to wait for long times in uncomfortable settings which exacerbated the skin condition and caused pain, and despite being given bribes, they continued to deny support in reclaiming their home. This was taken to the courts, and a high court ruling and proof of home ownership was secured, but still they were beaten when trying to return home, and law enforcement refused to enforce the law.

Many charity workers consulted with told us that governments in India and Nepal had little regard or understanding of the needs of the FD community, despite extensive media coverage of acid attacks for example. Their suggestions were to run campaigns to both reach patients, to promote services, whilst building self-esteem.

EDUCATION

We at FEI hear many anecdotal stories of children with disfigurements being hidden away due to stigma and shame, or kept out of school due to being told by teachers that the child is scaring the other children or that they can't teach someone like them (Ama Watts, 2021). This GoFundMe page relating to a child with facial tumours in Ghana represents a common method of attracting financial support for individuals in remote geographies often with minimal interaction or support from local services or charities. The prevalence of such methods of attracting support could lead to heightened stigma, mistrust and prejudices given the accompanying stories are often harrowing, and aren't always entirely truthful, whereby parents sometimes use these mechanisms to seek funding for their child's treatment, but instead keep the money themselves.

We heard of interviewees dropping out of school early due to being tormented by other children and even their teachers. A man with a rare facial cleft told us about his teachers and his community making fun of him and so he left school during 7th grade.

"My brother and sister started crying a lot when I told them I don't want to study anymore because of what they were doing. And they tried to counsel me that my future will get affected. Don't worry about what people say. But I didn't listen to them…This is my burden. I want to do something so that their tears don't get wasted."

Social workers told us of parents of children with CLPs not seeking treatment until the age of around 7, when bullying started to happen at schools, such as being teased for looking like a 'wolf'. Similarly a lot of the professionals we spoke to who worked with the FD community in Nepal and India said that 'sensitising' society, and in particular teachers to FD would be the best place to channel efforts.

Education in South Asia can come at a cost to families, and so if parents have a low-income, it's common that they will prioritise educating their sons and letting daughters go without.

MEDIA

Media such as films and TV and news outlets are big contributors to all forms of stigma, with FEI historically having lobbied Hollywood to cease using harmful depictions of FD on screen and having co-produced an International Media Standard with guidance on interviewing and storytelling for journalists (Face Equality International, n.d.; Face Equality International, 2023).

In remote parts of Nepal, social media via smartphones may be more widely used as opposed to having access to a TV, with TikTok being used a lot in Nepal, but banned in India. Health education, or proactive awareness campaigns to reduce stigma through social media could work well in India and Nepal (Winkie & Nambudiri, 2022).

Only one interviewee could recall having seen a positive role model in the public with FD, and this was on social media. Indicating that a lot of work needs to be done to influence greater representation of FD in mainstream media and advertising, and that perhaps social media is a more achievable place to start.

At FEI we often campaign for fair and positive media representation in the countries where we have the most reach right now, which is mostly North America and the UK, because we want people to be able to see themselves reflected in the world around them. This also plays into social change, in reducing barriers to fulfilment, success, and achievement.

Bollywood is a cornerstone of South Asian culture, and it perpetuates beauty ideals, in particular fair skin (Mishra, 2015). Bollywood fails to positively represent the FD community, and instead it reinforces harmful tropes about people with diverse faces.

The sense from all of the acid and burn survivors we spoke to was that news and media outlets had failed to tell their stories respectfully, and that there is only interest in the immediate aftermath which is often sensationalised, whilst the media are less interested in who people, and more so their traumatic experiences.

"Its not easy to repeat all those things but we want to change the others and we are keep repeating but its just like one title headline for a day and it will disappear...The day we repeat our story in front of others the wound will refresh and we will have to deal with months more to heal again."

"One time media person came and film in our organisation. I'm ready to do anything to promote our organisation... Before my personal document came out on his channel, 'look what a pity her husband burned her when she is pregnant' I had a fight with that journalist because they are just using and trying to use the content"

2. The need for representation of FD

SELF-STIGMA

Self-Stigma represents the internalised challenges of living with an identity which can lead to being treated differently to those living without it. Self-Stigma presented itself in this project as internalised shame, guilt, and the associated wellbeing challenges as a result of traumatic experiences such as abuse, isolation or being blamed for the occurrence of FD. External factors influence experiences of different types of stigma, as referenced in the Sightsavers systematic review into 'Disability-related stigma and discrimination in sub-Saharan Africa and South Asia', the study indicated that age, poverty and severity of impairment may be associated more clearly with internalised stigma, whereas public and enacted stigma were heightened by rural residence, type/severity of impairment and lower socio-economic status (Jolley, 2021).

'Disassociation and refusing to acknowledge the Cleft' as a coping mechanism, were common experiences according to charity workers. They recalled a patient changing their name, with many patients being reluctant to admit when asked about their scar that it's due to a CLP, instead saying their scar was caused an accident.

Both in remote and urban parts of India and Nepal, access to healthcare services are inequitable and can often come at a high cost to the individual, particularly if travelling long distances.

Psychosocial support is therefore rare and surgeons are often the ones having to provide emotional support. Only a handful of well-resourced partner hospitals had integrated psychologists into the care team.

Very few Craniofacial teams have integrated psychosocial support, and so the onus is on surgeons, and speech therapists to counsel patients. This raises the need for better understanding of how to reduce stigma by HCPs in line with delivering the best patient-outcomes.

Research to analyse ways to reduce self-stigma in a low-income context are desperately needed, and this study revealed that simply building a psychologist into a medical team would leave out the vital power of community, kinship, and a sense of shared human experience.

"I always used to stay back and wouldn't attend family functions also because I had the fear that people would comment on her and judge [my daughter]. I also felt like it would have been an insult to my parents, that I would do something and they would feel bad. You know, parents worrying about me and me worrying about them."

A challenge during our interviews was the inability to signpost to additional support should persons display signs of needing it. One interview had to be terminated because the interviewee was crying and could not continue, and multiple other interviewees became emotional during their interview.

FEI's core focus is on shaping society, and so interventions for self-stigma aren't strictly within our remit, but the theme of representation was evident across all interviews, and the experiences highlighted the intrinsic link between both being seen, and seeing others that look like you as a tool for increased wellbeing.

An important observation was the perception of mental health in India. HCPs correctly stated that the correlation between living with FD and having mental health problems can sometimes lead to wrongly assuming that mental health challenges are an inherent part of facial difference. Such conversations revealed that this false assumption was perceived to be a negative outcome of the extensive research on the psychosocial needs of the FD community in European settings. Resistance also clearly came from a desire to normalise FD and eradicate prejudice, which was positive and uplifting to observe.

We cannot take for granted the increased openness and thereby reduced stigma on the topic of mental health in recent years in North America and the UK in such a way where we forget to acknowledge entirely different cultural contexts when building the global face equality movement (Pescosolido et al., 2021).

The significant stigma attached to mental health and mental disability in South Asian communities means these topics aren't raised for fear of bringing shame on a family (Kayani, 2018).

Building communities of people with FD could potentially be more effective in reducing wellbeing concerns or internalised stigma, as opposed to simply increasing access to medical model psychological support. Medical professionals in India had reservations about integrating psychologists into CLP teams. This is likely in part due to the significant stigma attached to mental health and mental disability in South Asia.

"When it comes to relatives and family occasions we don't really talk much about this topic and avoid it. It's mostly education and family they're worried about. You have to tell people directly. Just conveying though posters many not help people. We have to go and tell people that this is wrong [mistreatment]. This might happen to your children or family members at some point. It's not that difficult to just be kind."

The above experience, of not talking about stigmatised topics at home, was the impetus for Smile Train India to start running Cleft Con India conferences, to 'address the elephant in the room'. The same team are also currently piloting a quality-of-life study to better understand the holistic needs of the community, along with the challenges experienced outside of the medical setting, which so often go overlooked. Charity workers spoke of reaching CLP-affected people who didn't find the courage to talk about their experiences until they were in their 70s.

Interventions to address the stigma of mental health are often geared towards talking about it to reduce shame. The same is true of FD, where addressing 'the elephant in the room' has been found to be associated with positive mental health, job, and stigma outcomes (Bogart et al., 2022). The use of euphemisms or failing to use clear language to tackle the topic head on can actually heighten stigma rather than reducing it, creating fear from those without personal experience who could then refrain from talking about it at all for fear of saying the wrong thing, depriving them of developing practice. This is evident from conversations had where HCPs working with the FD community stumbled upon which words to use.

Observing 'The Cleft School Project' in Hyderabad, India which had nearly 100 students with CLPs studying and living under one roof was a stark reminder of the history of institutionalization of persons with disabilities in the UK and US (Walmsley, 2008). To this day human rights abuses of the disability community are present in institutions where neglect can be common. Enabling families to shed responsibility for caring for children, or continuing to hide away people with disabilities is a highly contentious issue.

With the school starting out as an orphanage for abandoned children, attached to the local hospital, there is now a tier system in place according to income, gender and other factors such as location, which thereby enables students with CLPs from low-income backgrounds to also attend the school without charge whilst continuing to have access to hospital treatment, including speech therapy.

But unlike institutions confined to UK history, students observed at the school appeared bright, high achieving, mature, polite, and seemingly very happy. Seeing their CLPs reflected back at them every day in their fellow students clearly meant that this was an environment in which FD was entirely normalised, as it should be, and those interviewed had only positive experiences to speak of since coming to the school and gaining the education, support, and healthcare they needed to thrive. Those running the school had hopes for a student to one day take leadership.

"It's like an extended family here and my mom and dad are very happy I am putting myself out there unlike how it was back home. I also want to help people who are having these same kinds of issues."

A sense of gratitude to the school, hospital and foundation providing their care was evident. Granted, those receiving the kindness of these institutions would be unlikely to speak ill of their benefactors, especially in a culture with entrenched senses of hierarchy and authority.

This was an experience that challenged beliefs held about the importance of integration into mainstream schooling as opposed to what could be perceived as segregation. Especially given that without this orphanage and school, it's likely children would either have been abandoned or gone without an education.

The power of community to reduce self-stigma was observed in interviews conducted with acid survivors seeking wellbeing and economic empowerment support via Astitwa Nepal. Survivors had a great sense of self-esteem, and were able to brush off comments from others,

Seeing peers in the immediate community and having role models with lived experience in day to day life goes a long way towards reducing not only self-stigma, with several people talking about how powerful it was to have hospital visitors who also had scars or other health conditions,

'Later I see people with Leprosy in Pokhara for my surgery. I went there and I was inspired by all the patients there because they don't have a hand, they lost their hand, some have lost their limb but still they are happy and making and they do handicraft so I was inspired.'

Having positive, successful role models to look up to in the public eye, then dovetails into structural, enacted, public and stigma by association too in the sense that the general public are also exposed to difference in a positive light.

"After I got discharged I google 'scar face girls' I found Dana Vulin and she inspire me a lot, when I suffered a lot she motivate me by her story. I very respectful to her, I follow her on instagram... Awareness in remote areas is important."

PUBLIC STIGMA

Public stigma is effectively another term for discrimination. When a person or institution treats a stigmatised person negatively due to them living with a stigmatised identity. In this case, we set out on this pilot project having heard stories of abandonment, infanticide or hiding children with FD away both across the medical and charitable communities. It's now evident that poverty is as big a driver to such human rights violations as stigma, and both poverty and disfigurement go hand in hand in a low-income environment.

An adult male spoke of growing up with a CLP,

"My grandparents took care of me my whole life, not my parents. They took care of me because my father left me because I was born with this condition. They were not happy that I was born this way. At 15 I got my first surgery. Without any surgery with this face I stayed in the hostel until I was 15 years. I was not able to go to the hospital. In the village I was the only child born this way. So not just my father, but along with the entire village they were insulting me. I was very scared.

"They discriminate because we don't look as attractive as them. We don't have sharp noses. But people with Clefts have better IQs, usually we don't forget things."

The man above now works in a craniofacial hospital, and has witnessed the positive impact of a well-known, respected community surrounding the hospital,

"We need to prevent more children from ending up in hostels because their parents don't want to take care of them. So there's a lot happening these days. They don't get the child aborted, so they are tending to leave them after they are born. So there is usually something wrong, they abandon them post-delivery. That's what I have seen."

Challenges in adult life remain, for instance, another male with a rare facial cleft told us:

"In my daily life I face challenges. When I go to buy a few things people tell me on on purpose they don't have it, even though they do, and ask me to leave. Probably because they have a problem of their customers are scared. Because of all this, mostly my brother and sister do these things."

Existing disability stigma research in developing countries supports observations that a person's ability to contribute financially to their family and their ability to work plays into stigma, and if someone can work, this stigma can be reduced (Rohwerder, 2018). Similarly socio-economic status contributes. Misconceptions about the abilities of someone with FD lead to stigmatising behaviours and being treated as less than by families and surrounding communities.

Workplace discrimination came up several times in interviews, with one interviewee having applied for 20 government jobs but always being rejected after interview. Another interviewee consistently faced bullying and belittling from managers and peers in the workplace due to having a physical skin condition and being told this made them 'look so old'.

Acid survivors in Nepal spoke of when inquisitiveness from their immediate or online communities turned into hurtful and intrusive behaviours:

"Most of my neigbourhood came to visit me to see what my face looked like. They were curious about whether my face had changed. It didn't feel good at the time but after days and days passed I made some connections with other burns survivors from the charity and I realised it's OK to have scars on your face. 'Even if your appearance does not look the same, the way you used to be, first you have to accept yourself. You have to let it go, all things will be good"

"There is one person who is quite elder person who has been working in that village for a very long time with this condition and got operated. So many people look up to him. So they don't disrespect each other and all because they see him grow up and come to a stage. so they all feel like any one of them because he is working like them and talking like them."

STIGMA BY ASSOCIATION

People with disfigurements are hidden away, shunned, or cast away. Often kept away from homes or villages for fear of contagion, whether their condition is contagious or not. We were told of cases where Leprosy patients were cast out by families and communities, sometimes left by their partners. Similarly we were told by a skin condition support group lead that members of her group were forced to live outside in chains, whilst also being abused by family members.

The parents, families and surrounding communities of someone with FD can also face associated prejudices. This presented itself in the project both as parents experiencing abuse or discrimination themselves, or as parents then adopting stigmatising behaviours towards their children.

The interpreter explained one experience:

"Her dream is to have a family. She has this burden that whoever has insulted her family members, she wants to support her parents financially because they are very poor. And see them in a better place so that everyone who has made fun of them don't talk anymore. Because they face the insult not only individually, she has the burden that her parents also got insulted."

Several parents of children with craniofacial conditions were interviewed, many of whom experienced abuse, abandonment and psychosocial challenges themselves. Charity workers in India and Nepal told us, with community consultations conducted by FEI also verifying this in the Global North, that parents can be a big driver of stigma, for instance with family members suggesting someone's scars should be covered up, or encouraging their children to have more surgeries than they might have wanted for aesthetic reasons.

"I am a school teacher. There is good awareness in the village, so people are not abandoning over there. They are, you know, assuming that they have no other option but to take care of their child and they are doing that."

A CLP-affected hospital worker in India who ran the phoneline for the hospital told us that parents would often ring up crying saying 'why has God given me a child like this'.

"I was very sad when I saw him for the first time. I already had the first baby. The baby was healthy. I didn't understand why the baby was like this. Many people don't take good care of their babies... Everyone was telling you didn't take enough food during pregnancy."

When a family and surrounding community know and support a child or adult, and are invested in their future, having seen them go through successful treatment, they will be treated well and embraced into a community, particularly when they have a protective family fending off any negativity. This also can reduce stigma (Rohwerder, 2018). Sadly this is not always the case, but there were several positive examples:

"Everybody in this community knows her [infant with rare facial cleft meaning her cheeks, eyes and mouth were not fully formed]. They know she belongs to this centre that are taking care of her. I don't want anyone to point at her. Everybody knows that I am taking care of her, and so they want to play with and hug her."

"Day by day, she gets better and as she has more treatment she will get better. Maybe one day I would like her to become a doctor and help people with craniofacial deformities just like her."

She was abandoned and found covered in flies in a critical condition. Thanks to being taken in by a hospital, she was then fostered by someone from the local community and her care is paid for by financial supporters of the clinic.

Her foster mother and surrounding family have high expectations for the child, with many Indian and Nepali families prizing the potential of having a doctor in the family, which is seen to be the ideal aspiration for a child. It is well recorded that having high expectations for any child or adult with facial difference or disability supports a child to thrive.

"I built up my confidence whilst I was with my friends. They will always support me...They don't judge about me and my old past things. There was a time when I just preferred to be staying alone in my room. In that time they didn't want to make me feel alone. They were always with me and give me good company."

Similarly, in remote villages in Nepal, multiple parents of children born with treated CLPs did not speak of receiving any negativity from the surrounding community, particularly after receiving surgery. Children were embraced and protected by their community. This may indicate that in remote communities where access to external prejudices via the likes of media/social media may make life with a visible difference easier than in parts of the world that promote 'flawless' appearance through media.

That said, 'covering up' was both observed and noted in conversations with charity workers, in that adult women from a lower caste, or with a facial difference or disability will often use their sari or scarf to hide their face. Social workers running economic empowerment programmes for remote communities in Nepal spoke of all women covering up at first, but over time, they no longer felt the need to hide.

A mother of a girl with a CLP proudly told us of her daughter who 'never stops talking, even when she was in the ICU'. Despite her CLP causing speech problems, 'she is always talking and she now created videos online... She is the positive role model.' Her biggest concern for her daughter is her frustration when having to repeat herself to her peers in school. Ensuring speech was clear appeared as a common priority for parents, placed above aesthetics.

"She doesn't get scared of anything. Even if she doesn't say anything, she can say, I love you, we don't have any concerns or fears regarding her because she is very good. She is out there. She is not feeling bad even if they are not understanding. She can repeat it 10 times and make them understand. But she will not give up. So we don't have any specific concern, but we just wish that the speech would become much clearer so that it becomes easy for them."

An observation from the interviews was when a remote community became aware of surgical intervention due to another community member having FD.

"Ever since this happened I've informed one more person in the village who was born this way and got them the treatment from this place. I have given out pamphlets to nurses in the hospital in the village and whenever I travel I doesn't waste time and I keep on passing this information to people so that it might be useful to anyone."

The individual or parent then became an informal advocate for the programmes available to them through the likes of Smile Train. We were told by CLP care workers that, "In rural areas - when a child goes back to a remote community with a fixed CLP - will hear 10 villages away - everyone comes to see that child."

Throughout the interviews with social workers and HCPs, we would often hear stories of families either covering up or not coming forward for support. When we attempted to understand the potential reasons for this, we were told that money is the number one factor, be it having to pay for services themselves, or the travel required to seek treatment. Stigma was a secondary factor, where some families would be too ashamed to come forward.

Lack of exposure to others with FD is at the heart of the issue when it comes to stigma, as is the same when it comes to reducing barriers to accessing treatment in that unless someone has seen someone with a treated CLP, they are unlikely to know about treatment options.

Observations were made of poor quality, stigmatising promotion of services, which would likely be seen as degrading in a Eurocentric context. For instance, dated, overly medical posters of patients photographed close up, looking very serious and sad were observed. A very obvious, easily adopted intervention to reduce stigma, which has been positively measured in the US would be to use empowering photography. The work of non-profits such as Positive Exposure to transform medical photography and showcase the true nature of the FD community have gone a long way to promoting dignity, respect and empowerment to the FD community both in a medical setting, but also via imagery available to the general public.

By working with FD-affected communities to provide tools not only to raise awareness of treatment options, but also to tell their stories in a positive, empowering, myth-busting way, charities delivering these services will not only be able to promote their services, but they will be able to concurrently reduce stigma, and potentially attract more patients who otherwise might not come forward for treatment due to shame or fear of judgement from others.

"Things at his village where I am from are much better than what it was before because there is little awareness. A family members' daughter just 2 years younger was born with this kind of defect and she was operated in the same hospital."

In promoting healthcare services to the FD community, committing to hiring in an inclusive and diverse way, where opportunities can be promoted for people with lived experience to have roles across the hospital is important. One hospital visited had a mandate for a certain percentage of staff to have a disfigurement or disability; thereby ensuring that visibility of disfigurement is the norm, leading to a sense of comfort created for patients and families who otherwise might not have been exposed to seeing people with disfigurements thriving in terms of health, financial security and wellbeing. This sounds like an excellent solution that aligns with current DEI movements progressing in North America and Europe which not only promote representation and thereby positive role models for future generations, equitable economic empowerment is achieved, which can then help to reduce public and structural stigma.

Such solutions are dependent on stepping outside of the 'drama triangle' and creating a levelled environment in which no party is either the victim, rescuer, or persecutor (Lac & Donaldson, 2022). This is dependent on those with lived experiences driving the solutions. Again, aligning with community or patient-led solutions in global development, which acknowledge cultural power structures such as the surgeon and patient dynamic, or the surgeon and wider medical team. Such dynamics appear entrenched in India and Nepal, with patriarchal structures dictating the way in which power is distributed.

HCPs must engage in continuing education, and ethical standards should require all HCPs to undertake training that scrutinises any biases that might have an impact on their patient outcomes.

There is a cohort of HCPs that are leading the way on holistic care that acknowledges their responsibility to shift societal attitudes, with surgeons recognising their role in preventing psychosocial challenges, but this is often the exception, not the rule.

"Unless someone is there in their family who has underwent or someone in their past in their family has undergone that problem only then people tend to understand."

3. "Health education alone does not reduce stigma

Community based rehabilitation, and face equality training both in healthcare and for the general public, should be integrated into medical priorities in order to guarantee the best possible patient outcomes.

General health education for the public about disfigurements is poor and filled with bias, myths and overly medicalised or sensationalised information. The above quote 'health education alone does not reduce bias' is a direct quote from a social worker running community-based rehabilitation programmes with Leprosy patients and their surrounding communities. This same care worker stated that 'when the disfigurement comes, the stigma comes', indicating that the visual nature of disfigurement is what causes stigmatising attitudes and behaviours.

This all came from their own observations amongst the medical community, within which stigma and aversion to Leprosy patients was common. The same observation came out of interviews with the FD community in Nepal.

Community-based rehabilitation when observed via Nepal Leprosy Trust highlighted the importance of reintegrating a patient into their community after immediate medical care at the hospital (Sermrittirong et al., 2014). This would involve support groups which initially started solely for people with leprosy, but then extended to wider neglected tropical diseases, people with disabilities or those marginalised through poverty or gender. The same programme involved preventative health education programmes in schools and communities, along with advocacy training tailored to women who were encouraged to advocate for sanitation measures to their district warden.

The programme also involved economic empowerment programmes, again targeted to women who might be susceptible to Leprosy. They were given a small loan to enable them to pay medical fees or support their own small businesses, which would then be monitored and repaid. Self-efficacy was significantly improved through these programmes, and such empowerment had a knock-on impact on reduction in self, public and structural stigma.

FEI, would like to collaborate more closely with organisations like Nepal Leprosy Trust that consider the entire person, and not just their medical needs. The research conducted to evaluate such programmes is also some of the most impactful and holistic we've seen, and the FD sector has a lot to learn from this approach.

Awareness around treatment options for craniofacial conditions like CLPs is often limited, particularly in remote areas, and there are beliefs that CLPs are caused by a mother using a knife during an eclipse. The Hindi word for eclipse 'Grahan' or 'kaatana' (cut) is the word used by social workers conducting outreach throughout Delhi and the surrounding areas. In finding patients, they will refer to the eclipse, because words like 'Cleft" aren't known.

"We didn't know about the surgery and we didn't have money for it but as soon as we found out we brought him immediately and by God's grace they finished both surgeries"

Other beliefs surrounding craniofacial conditions are that it can be caused by having a child with a family member, "Many people here believe that marrying someone in your closer community like relatives might cause this."

"I used to the do the face painting, some will understand like ok give her a chance because she has a talent come to our birthday parties and do the face painting. Some understand, but some, like high society will say 'oh she has a scar don't call her because our children will get scared'. The high society people are educated but still they are discriminating."

This rings true with more widely recorded cases of stigma and discrimination in Europe and North America, where general health education is more widespread, and yet abuse and prejudice towards the FD community is still rife.

HCPs hold bias, misconceptions, and all have a responsibility to dispel myths and reduce stigma as opposed to feeding it. Training for all healthcare and charity teams on their responsibility to adopt destigmatising principles into delivery of care is essential to eliminating disfigurement stigma, and intersecting stigmas related to race, religion, caste and economic status for example, in order to improve patient outcomes. This intersects with other marginalised identities like race and religion as outlined below.

"High society people... They haven't seen the real world. Just like a fantasy, a fairy world they only have the good things in their life and that people will never understand. And discrimination will never end. It also depends on the education.In the school from early years they should teach the child life is not always good."

The intersecting nature of caste system, race, religion and how communities are perceived presented itself in the stories told to us by HCPs throughout the project. Many HCPs and charity workers in India had much to say about the occurrence of CLP in Muslim communities, whilst burns survivors spoke of rudeness and negative language from their care team such as reductive comments like 'it's not a big deal'.

Surgeons told us that Muslim parents would be less likely to bring their infants for surgery, instead siblings would do so against their parent's wishes which were to let 'God's will' be. Surgeons told us that Muslim families would just have more children, and so disregard existing children with CLPs. This stressed the need for awareness programmes that collaborate with faith leaders whilst considering religious context in the promotion of services. In speaking to faith leaders in Nepal at a Hindu temple, they too believed in the widespread disadvantage experienced by the FD community, and despite the charity offered to people with disabilities through free food served at the temple, little was done to address the psychosocial needs of the community.

Similarly, academics consulted talked about the importance of proactively engaging with traditional healers too, as opposed to trying to avoid the topic, given that many patients will also visit traditional healers.

An adult male living in a remote area with a skin condition previously mentioned had a non-infectious skin condition which is well understood in Europe and North America. Yet his community were refusing to 'take water from him', touch him, and they would use the word for Leprosy or 'infectious disease' to refer to him. The impact of living with visible skin conditions in India is one of 'ostracism, social restriction, dietary restrictions, difficulty in getting jobs, and a significant barrier to getting married' (Pahwa et al., 2013, p. 679). HCPs also wrongly assumed and accused this person as being drunk, simply because he was in a public area near a pharmacy.

The same HCPs also made the comment that 'negroes' didn't get CLPs because they didn't have sex with family members in the way the Muslims do. Such language may have different connotations outside of Europe and North America, but the sweeping statement was shocking all the same.

Throughout the interviews many healthcare and charity workers were observed poking, pointing and prodding at the mouths of patients without consent in order to identify them and their type of CLP to us as visitors. This was a jarring experience, and one that felt undignified for patients. Cultural norms may well be at play, but this still felt unnecessary, especially given it often occurred in a public setting such as a waiting room.

The same man assumed to be drunk was intent on finding a cure for his skin condition, and was given a lot of misinformation about a potential diagnosis in the past, some believing he had Leprosy, which could have increased stigma due to more widespread knowledge about the contagious nature of Leprosy.

There was a missed opportunity to inform and empower this man, along with his community, with some basic health education about his condition, which would have helped to reduce any internalised stigma, or enacted stigma from his community which came in the form of refusing to touch him.

Similar scenarios were observed throughout the project, where individuals in remote communities were in search of basic information, or some form of diagnosis for a variety of symptoms, but HCPs were solely focused on their one discipline or area, and their knowledge of wider care or hospitals available in the local area was limited, so signposting was seemingly non-existent.

For instance, a father with a CLP lip was interviewed and spoke about his 20 year old son who has Downs Syndrome. It was likely that his son had tongue tie, which was causing an evident speech impediment. When they visited the hospital, 'we weren't given good treatment, and we were told it will just pass as time passes.' Despite attending hospital throughout the child's early years with regular bouts of pneumonia, his speech and any physical contributors weren't addressed, and any care received throughout his life clearly failed to holistically approach him.

As a result the father of this man was sceptical of medics. "*I have money, I have land, so the people here tell me why not spend it on having my child treated, but I need assurance that if I spend my money then he will be cured.*"

As a result, he had never received treatment for the presumed tongue tie, and only his family could understand him when speaking. Bullying and taunting from others was common, who would shout the word, 'boka, boka' at him, the Nepali word for dumb.

Due to his age, his father was now in the process of seeking a wife for his son. "*I don't want anything in return. I have money and land'*, (ie he doesn't need a dowry). 'When they see he can't speak, they don't give any answer, they just leave'.

"*This community, they love to comment, dig up all the matters, all the negativity about other houses.*"

An acid survivor in Nepal recalled, **"One day I was carrying a puppy and I was walking on the street and a school student came by. And say 'what cute puppy and what a horrible bad person that is carrying a cute puppy' 'Other students said 'the one who is carrying is so horrible they were just comparing me with the dog'. ' I didn't say anything I just come home and I cry a lot."**

In remote areas, where access to healthcare is difficult, and health education levels are low, fear of contagious diseases must feed into stigma relating to health issues or disability. Disability, facial difference or visible difference act as visual indicators of potential pain or difficulty to function; importantly, impacting ones ability to work or marry. With these being the two primary concerns or priorities for communities in Nepal and India, any visible difference could impact the way someone is treated.

When visiting a Leprosy hospital in Nepal, witnessing community-based rehabilitation, which includes societal focused interventions, this appeared to be the gold standard of care. This is likely to provide the best possible patient outcomes long into the future by requiring the integration of psychosocial and community-based education through support groups, advocacy training and prevention programmes.

This approach focuses not solely on patient care, but instead on reintegrating patients into their communities post treatment through 'community counselling', which in some cases was simply awareness raising and prevention education, but in other cases, it called for a hospital staff member to attend a home or village where someone was being abused or refused return due to stigma and fear of contagion.

Prevention programmes in schools and communities surrounding overall burn prevention, and acid prevention do exist across South Asia. With academic achievement prized in Nepal and India, education is largely focused on grades, so charities have attempted to reach young people through rotary and social groups instead.

From midwives, to pharmacists, through to surgeons, a collective responsibility to patient centred care demands education that does not reinforce bias, stigma or discrimination. There's a sense across surgical care regularly observed in FEI's work, that beyond the surgeries needed for function, aesthetic surgeries are necessary to 'prevent bullying or discrimination'. This is a perception held both in the Global North and in South Asia, where surgeons interviewed stated that 'my job is just to give the best surgical outcome possible'. This will be explained further in the 'Medical Model' section below.

Public awareness and general health education in society starts in a medical setting. There are many myths across society, and many factors such as ableism, prejudice and availability of sensationalised medical stories in tabloid newspapers that contribute to the sense of othering experienced by people with FD or disabilities. This means that intrusive questions in day-to-day life in communities and online are common across the globe.

"I feel like when I get questions online that if I can't even face people then definitely others wouldn't be able to. I have to face them and teach them how to ask survivors appropriately. If you're curious and ask questions with any survivor then you have to know what type of question is good for them."

"If anyone asks me and you say it's my fault then it hurts. But if you ask me in a gentle way what happened and are you ok right now. If you ask me this type of question then it helps… not everyone is like me and mostly people can't answer and that's why they can't come out in our society."

4. 'Victim blaming' heightens stigma, discrimination and abuse

Blame is often placed upon those affected, along with their parents. This can be reinforced by religious or traditional beliefs, particularly affecting women, along with 'Western' medical beliefs which can also lead to internalised shame.

The Face Equality Movement must align with intersecting movements such as gender equality in order to reduce the impact of the moral model of disfigurement, which disproportionately impacts upon women. A solution we will explore will be to align more closely with gender equality, women's rights and health movements, and to advocate for women-led support spaces that tackle the very specific impact on health stigma, and FD stigma on women.

Although the term 'victim' is a word often replaced with 'survivor' in face equality spaces, the term is often used to discuss the experiences of rape survivors who are often blamed for their experiences, as though they did something to provoke the attack. The same was observed with the FD community in Nepal and India, and so in order to shape understanding, the parallel has been made.

The belief that 'missing parts', or conditions like a CLP are caused by the mother using a knife during an eclipse came up a lot. Hospital workers told us, with the academic consultants also raising this potential limitation into early planning stages, that people will be less likely to be open about their beliefs when speaking to HCPs or 'outsiders'. This was reaffirmed in our own interviews.

There was an academic study being conducted separately, at the same time as our interviews, which was devoted to capturing potential super-natural, non-medical reasons for a CLP and when asked about whether they thought it had been caused by an eclipse, one mother asked, 'Is that really the reason', indicating that they were hoping the healthcare professional could clarify what they had been told.

There are often 'Western' medicine specific questions asked around potential causes for CLPs, including folic acid intake during pregnancy or family history. Questions that likely wouldn't appear in a 'Western' survey were whether parents 'cooked with cow dung', whether they 'walked in the hot sun or late at night', but also several questions asking about perceptions of CLPs relating to what 'Western' medicine might reject as pseudoscience.

It is often mothers, or women who are blamed for birthing a child with FD. Be it due to 'chopping vegetables during an eclipse', or they're told they 'didn't eat the right food', or 'enough food during pregnancy'. Accusations of alcoholism or having sex with family members are also made. There is also a belief that Leprosy is caused by having sex with a woman when she is on her period.

Consanguineous (when parties are blood relatives) marriages were raised consistently throughout the project, with some HCPs making candid comments about the prevalence of CLPs in Muslim communities, where such marriages may be more widely accepted.

Abandonment of mothers by fathers and inlawed families came up in multiple interviews. Trying to differentiate between potential causes of abandonment are hard. Stigmatising attitudes towards FD definitely plays a part, but seemingly fear of the cost of caring for a child with complex needs plays a crucial part too. One way to broaden the understanding into this area might be to look at more data on children either aborted, given up for adoption, or parents whose spouses of extended families have left them upon finding out the child had a disfigurement. Comparing this data according to income might be a worthwhile exercise in order to target interventions.

A mother interviewed in India spoke of being left in the hospital and told 'not to come home'. Her husband and in-laws didn't want her or the baby, but she didn't want to abandon the child, so she used to feed the baby whilst working on a daily wage basis. Eating only once a day so that she could feed her son on lady's maid wages. "I don't mind, as long as they're healthy". Around 5 years she started to see 'some improvement' which was when the wider family started to care a little for her.

There were incidences when the child was born when she wanted to bring the child, but they beat her. They beat her head, to the extent where she now has lasting pain whenever she has anxiety. 'But even though they beat me, I got the child treated and brought them to school'. "Now that he's talking and all, they're back'.

Breastfeeding a child with a CLP is a challenge, and so many mothers are reliant on formula, 'Milk was expensive and I couldn't afford it'. So one mother used to boil millet as soup to give to the child. "I told him, I will work hard for you. You will not go hungry again".

Now that she's older, she would 'raise her voice' if her inlaws tried to overpower her.

There is a belief in India and Nepal which revealed itself in several interviews which ties into long-held cultural beliefs about disfigurement, it is such that people believe seeing someone with a disfigurement will then taint or ruin the rest of their day, as though this person is a bad omen.

"The people here believe that when I'm waking up, and if I am seeing the face of this child, these type of people, my whole day will be spoiled."

Religion, moral and spiritual beliefs were common themes throughout the interviews, both as of stigmatising behaviours from extended families shunning parents of newborns with FD, to villages casting out those with disfigurements. But such beliefs were also a great source of inner strength and the ability to shrug off self-stigma. There was a common reoccurring theme amongst individuals and families affected by CLPs in India in the belief that God would ensure any wrongdoings, i.e. mistreating people with CLPs, would eventually be punished or balanced out.

"Today I am born with this and tomorrow anyone in your family might face the same thing. So it all depends on God and God is watching you and your actions. I think when people have that fear that their actions are being judged by God."

"First of all one has to be a good person and good human, that's what I'm teaching my sons also."

In Western medicine, traditional healing and spirituality are often disregarded as 'pseudoscientific theories'. But we must look at these disciplines in tandem, with an intention to not disregard the importance of traditional healing or cultural beliefs, but instead to build an understanding of the human impact of both, in such a way that puts the needs of individuals with FD first, in a truly holistic way.

Our interest is on belief systems that can increase stigma and thereby increase potential harm. Both the medical model and the spiritual models of FD have the potential to cause such harms.

There was a lot more discussion around what in Western medicine would be defined as a myth by healthcare professionals and charity workers, but less so amongst interviewees with lived experience of FD either personally or as a parent/carer. It's likely that some felt ashamed discussing beliefs that might have been previously challenged or made persons to feel foolish.

Despite trying to create an environment free from shaming, there is no doubt that given more time, and the addition of an interviewer from the interviewees respective community might have led people to be more open, as opposed to speaking to an 'outsider'. As observed also in the recent study from Dr Bruna Costa into the experiences of FD in the Somali community in the UK, which demonstrated stigmatising beliefs about the causes of FD specific to Somali culture which often led to families isolating themselves (Oliveira Costa, 2023).

5. Disfigurement as a disability

All too often disfigurement is regarded solely as a medical issue, and in this context as a global health issue. But in failing to make the intrinsic link of disfigurement also being regarded as a human rights issue we're neglecting to acknowledge the entirety of people's lives and their day to day needs outside of simply their medical journey, which makes up such a small part of what makes a person who they truly are.

THE SOCIAL MODEL

Identifying effective interventions to reduce the stigma of disfigurement are interconnected with both the human experiences of the disabled community, and the policies, services and movements in place for the disabled community which should be more inclusive of the FD community, especially in countries that have ratified the United Nations Convention on the Rights of Persons with Disabilities, which both India and Nepal have.

This essentially means that they have signed up to ensure their country-specific laws follow the human rights model of disability law, which states 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' (United Nations Convention on the Rights of Persons with Disabilities, 2006, Article 1).

Interviews both with those with FD, along with government officials and charity workers revealed that perspectives in Nepal and India in relation to disabled identity and legal status are similarly as complex and individualistic as across the globe.

Multiple participants had rare facial clefts, meaning clefts affecting the nose, eyes and cheeks, and/or associated speech or hearing impairments, but none identified as disabled.

As is the case in Eurocentric advocacy spaces, the perception that FD can be 'fixed' and therefore isn't a disability, or is simply an aesthetic issue, and thereby doesn't prevent a person from going about their day to day life is a problematic notion. Advancements and availability of plastic surgery play into this false notion, but even in environments where healthcare or aesthetic surgeries aren't as accessible, and FDs may still cause day to day 'physical impairments', the overarching sense is one of disregarding the mental and physical impact of FD.

Perceptions of how FD intersects with disability in South Asia seem to be paralleled with that of North American and UK contexts in that unless the FD has a 'physical impairment' aspect to it, such as hearing or sight loss, it is not considered to be a disability on a personal level.

Similarly, interviews indicated that associating with being disabled is undesirable due to the corresponding stigma associated with widely recognised, medical model disabilities. Interview participants largely did not associate with being disabled, nor did they mention the social model.

MEDICAL MODEL

Although disability organisations, movements and policies such as the United Nations definition of disability, have moved away from the medical model in place of the social model, FD is still often considered only in a medical context, and the legal model largely follows the medical model in India and Nepal (Citizens for Justice and Peace, 2022).

A theory arose throughout the course of this pilot project, which is whether the social model could be regarded as a privileged, 'Westernised' perspective, which is relevant only when medical needs are met.

A conversation that was had with a social worker in India revealed their desires for the craniofacial sector which were that as soon as a child with a rare facial cleft was identified, that the child should be taken into care in order to prevent the common occurrence of death before surgery can take place. To conduct safe surgery, an infant must be of a certain weight. Malnourishment due to feeding difficulties is common for infants with rare facial cleft , and many die due to having to travel long distances in between appointments which can be costly for parents/carers living in remote areas who are reliant on tending to a farm, caring for other children, or reliant on a daily wage.

Poverty and geography heighten the medical model of FD and illustrate one of the fundamental differences between living with FD in an LMICS versus a High Income Country. *"There are places for people with this [disabilities] in Kathmandu, but not here."*

Medical studies on CLPs in Nigeria recommend for CLP to be considered a facial difference rather than a disability as a means of combating stigma and discrimination, but a more effective intervention could be to tackle the very route of disability stigma in tandem to FD stigma (Adeyemo et al., 2016). In doing so, HCPs will not be taking an ableist approach or increasing aversion to disability, and instead an affirmative approach to disability may empower and enable an individual to assert their legal rights as someone who has a place in the wider disability community.

The focus on delivering safe surgeries to those that need it in LMICs has evidently been the priority focus for decades, which is heavily reliant on the medical model, particularly in the context of seeking support from the WHO and generating support from donors and although moves to integrate psychosocial care are ever growing, this too is not equitable even in the most advanced healthcare systems in developed countries (Tolarova, 2016).

A senior surgeon interviewed in India noted that their job was just to 'deliver the best possible surgical outcome for best appearance', implying minimal scarring, maximum symmetry, and a face that conforms to the respective beauty ideals of pale and 'perfect' skin, and that this was how to ensure an individual did not experience stigma or discrimination. In parallel to this, comments made at the American CLP Palate Craniofacial Association Annual Meeting in 2023 were that surgeons in the USA believe that they must deliver as many cosmetic surgeries as possible, 'otherwise the patient will be bullied'.

Surgeons have gained status and a sense of mutual respect from their peers in attaining such a well-respected point in their careers, which appears heightened in South Asia where doctors are admired so highly. This could however often be perceived as arrogance, as observed in historic patient discussions through FEI, and although commitment to consistent personal development and training in surgical methods is commonplace in the sector, observations indicate attitudes towards development in terms of community centred approaches is regarded and less of a priority. A surgeon in India noted that 'prejudice does not exist in this organisation', which appeared to be in direct conflict with contemporary conversations about implicit bias being inherent in all humans (TEDx Talks, 2017).

Condition-specific services, conferences and organisations with a focus on medical research as a whole, often disproportionately prioritise surgical, technological and theoretical advancement of specific techniques and tools. This hierarchical approach which places psychosocial and community-based approaches to care for the FD community as the lowest priority will arguably lead to the goal posts moving further and further away with constant advancements in technology, methods and tools. This funnels funding and resources consistently in a 'medical' direction.

As opposed to reducing the need for unnecessary cosmetic interventions by reducing societal pressures to conform to appearance ideals, or reducing stigma and thereby mental wellbeing concerns by reducing discrimination and human rights violations in society as a priority, thereby reducing the demand on expensive medical services or mental health interventions. A solution for FEI will always be to advocate for a holistic approach to FD, beyond the historical approach of a solely medical issue in need of 'fixing'. Our society first approach aims to accept people as they are, and there is no reason why this affirmative approach shouldn't be embraced in medical settings too.

MORAL MODEL

The 'victim blaming' section above speaks in detail to the prevalence of the moral model of facial difference and disability in India and Nepal, given that the myths and misconceptions about FD often place stigma on the person affected, or their parents, by blaming them.

Recommended actions from Dr Kathleen Bogart to reduce the impact of the moral model of disfigurement/disability in cultures where it is common are to bring the topic to the forefront of community conversations if contact with those affected is minimal, to collaboratively implement community driven solutions, and to learn how cultural identity influences understanding of disability. This project has definitely enabled us to better understand how to approach the topic of disability and FD in India and Nepal (Jost, 2021).

LEGAL MODEL

The argument for disfigurements to be universally regarded as a disability by law is arguably stronger in a low-income setting, where disability status could be pivotal to seeking vital, expensive treatments such as surgery or medication.

As in the UK and often in the USA, interviews with charity workers in India indicated that CLPs are not regarded legally as a disability, worthy of disability status and benefits, 'because it can be fixed'. This is circular logic, because a CLP should clearly be considered (at least) a temporary disability during such a time where surgery, nutrition, speech therapy are accessed, especially given all of which have associated costs attached which could benefit from the financial support of disability status or legal recognition.

It's common for service users to write to charities and their healthcare providers in order to seek letters of endorsement to gain disability status, which is often unsuccessful according to charity workers who could speak to several occasions when the relevant authorities denied persons with disfigurements disability status.

Government support and adequate legal protection are all necessary to ensure people with disfigurements no longer experience discrimination and human rights violations. An important observation in a low-income and/or remote setting is that the 'disabling' effect of FD is heightened when access to healthcare is not possible.

4. Conclusions

The positive impact of interpersonal connections are documented to likely be the best method to reduce stigma on a deeper level, whereby becoming used to seeing facial difference, where it is once again normalised, can be a way to reduce multiple forms of stigma (Rohwerder, 2018). This was further supported by the interviews conducted.

Policymakers must ensure that disfigurement is included in disability rights and inclusion initiatives. United Nations CRPD ratified countries have a duty to serve the disfigurement community, and so the UN would benefit from increasing representation and seeking expert advice from the disfigurement community.

Personal contact is likely the most effective, although not always possible, as this 'humanises' the person affected, as research in HIV stigma reduction has found (Andersson et al., 2020). This generally involves education to challenge any misconceptions whilst encouraging positive interactions and connections with someone living with a stigmatised identity.

A potential solution or adaptation could be to adapt and evolve such programmes to build in destigmatising principles to create appearance inclusive school environments. If tools were to be developed with a research base, a baseline survey or measurement tool such as the EMIC scale, which measures stigma in affected persons and in communities (Weiss et al., 1992). These tools have been validated across cultures, including in India and Nepal as a measure for monitoring a reduction in bias or stigmatising behaviours. In discussing this with charities, there was interest, but as ever, the problem is often around time and resources. This is a solution that FEI and its partners would be keen to work towards in future.

Education programmes in Europe and North America such as The Wonder Project, where speakers with disfigurements go into schools to share their stories, alongside speaking to the story of Wonder which involves a young boy with FD attending school, have been anecdotally recorded as making a positive impact, although validation studies have not been conducted. Similarly, projects in Ghana where Jono Lancaster, a British activist with an FD, has attended schools to share his story have landed well, but research is needed to track and prove a reduction in stigmatising attitudes and behaviours both in the immediate aftermath in schools, and over the course of the attendees' lives.

Easily adapted and disseminated validation tools should be adopted by charities working across the disability and FD space in order to build capacity. A solution FEI would like to work towards is building a cross-cutting, validated resource and measurement scale that can prove a reduction in stigma across all FDs and disabilities. Many condition-specific outreach programmes and schools resources exist across the third sector, but this increases silos and minimises impact.

The risk also is that focusing too closely on one condition such as CLP, particularly in a school with a child with that FD, programmes can actually draw more attention and make bullying or stigma worse. The good intentions of care providers must be weighed up with the actual measured results of an educational intervention, which have been shown to have mixed efficacy when adopted in developing countries as a sole method to reduce stigma (Rohwerder, 2018).

An easily adopted solution in health settings could be the use of positive stories and health education folded into promotion of healthcare services for people with FD. This should feed into the way service providers and charities promote and fundraise for their services, in that all should adopt principles of destigmatisation.

Promotional materials for CLP surgery delivery should as a standard use visual, written and verbal storytelling. This could go a long way to reducing psychosocial challenges for individuals in the future.

5. Limitations

The majority of interviews were in a medical setting, so in only being able to speak to 'patients' receiving services, we're not yet fully understanding the needs of the most underserved members of the community.

Several of the interviewees in India were also working in the hospital, which meant that the perspectives were predominantly gained from those in paid positions. That being said, they could still speak to previous experiences of stigma and discrimination.

Interviews were translated directly in real-time during the interview by the assisting charity worker or healthcare professional which could have been improved with a professional translator.

Whist access to basic healthcare in LMICs is so limited and inequitable, interacting in a healthcare setting can also reinforce stigma by pathologising individuals whose lives are so much more than their medical experiences. .

Given resources available, the majority of interviewed participants had CLPs, second to that were rare facial clefts, other craniofacial conditions, scars and then skin conditions. Speaking to a more diverse pool of the FD community would have been more representative.

Academics raised at the outset that creating an environment which was safe for people to open up would benefit from the interviewer being from the relevant community, better still if they had personal experience. This was not possible in the circumstances, whereby interviews would be translated and conducted by a charity or healthcare worker.

Translations in themselves meant that some quotes were translated directly whereas others will have been paraphrased or may be subject to changeability with translating into English.

Reaching remote communities affected by disfigurement is a challenge that must be addressed. As a result of these findings, FEI will be adapting our membership model to be more inclusive of grassroots groups and individuals wishing to be part of the wider Face Equality Movement. This way, we hope to reach and serve the most underserved members of the FD community, by working with healthcare communities, but not being solely reliant upon them.

7. INTERVIEW QUESTIONS

1. The interview questions went through several iterations both in the early planning stages, and after the interviews began. The questions below are the final versions used.
2. (x) indicates where we would refer to the person's specific FD according to the appropriate/self-identified language
3. What is your dream, if you could do anything in life what would you wish to do?
4. Is there anything/has anything ever stopped you or gotten in the way of you from fulfilling that dream?
5. We're particularly interested in your experience of living with an (x). Can you tell us how you feel about your (x) on a day-to-day basis?
6. Are people with (x) treated differently in your culture/community to those that don't have (x)?
7. How does this relate to your own experiences, and how you've been treated by others? Reference: school, community, media, government, healthcare as prompts
8. Are there any specific beliefs about (x) or the causes of (x) in your community?
9. Growing up, did you have others you could look to, who also had (x) as positive role models, or perhaps in the media/social media? Do you have any role models now?
10. Do you have any recommendations for ways that organisations like us could reduce stigma and discrimination? What do you think needs to be done in society?
11. Is there anything else you'd like to see from charities, government, HCPs, community that would make your life easier?

FOR MORE INFO:

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