

# Exposing Human Rights Violations:



LIVING WITH THE STIGMA  
OF FACIAL DISFIGUREMENT  
IN AN LMIC

**MEXICO**



# ACKNOWLEDGEMENTS



We visited many organisations throughout Mexico who kindly gave up their time, and took time away from their busy schedules serving the FD community to meet with us and facilitate meetings with their beneficiaries:

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This report was written and illustrated by Phyllida Swift.

**“People are perfect when they are born and cannot be judged; it shows they are brave and can have anything, be anything, and have a facial difference, whatever.”**

**Adult male with a Cleft, and father to a baby with a Cleft**

## **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.

Existing studies into stigma reduction interventions often overlook disfigurement, but crossover with it in some ways, in the sense that there are existing systematic reviews which factor in Albinism or Leprosy which are both appearance affecting conditions (Jolley, 2021). There is a lack of high quality evidence, with consistent validation measures in place which can be rolled out worldwide to test the efficacy of interventions (Smythe et al., 2020). Recommendations however are that lived experience must be at

The majority of this project took place in a healthcare setting, given that the primary focus of most FEI member organisations is largely healthcare focused, 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 commonly appearing.

Interviews were conducted in both remote and urban parts of Oaxaca, Mexico City, Guadalajara, San Cristobal de la Casas and Tuxtla Gutiérrez either in hospitals, charity offices or in participant's homes.

Interviews were conducted in Spanish and in some cases other regional languages which were then translated into English by the original interviewer using automatic transcription software and then verified according to the audio recordings.

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.

As this was the second stage of the project, with interviews previously being conducted in India and Nepal for the same project, learnings about ideally conducting interviews outside of a hospital environment were applied, in addition to the whole interview being conducted in the relevant language and translated at a later date as opposed to in the moment.

Meeting interviewees in their homes made for more comfortable, open environments to open up.

## KEY FINDINGS

**1. Given support, parents can be fierce advocates for stigma reduction**

**2. Public stigma from families and immediate communities is prevalent, in the form of bullying or ostracisation, which can sometimes result in child abuse**

**3. Teachers don't know how to support children with FDs or disabilities, but charities and HCPs want to address this**

**4. Younger generations of parents are less likely to believe superstitions about supernatural causes of FD, but the guilt and blame culture remains**

**5. An empowering movement to centre the medical and social needs of the FD community in Mexico is something many people want, but resources to deliver it are limited, and government support is minimal**

**6. Aligning with disability movements in Mexico would be worthwhile, but ableism and a sense of distancing FD from disability could get in the way of progress**

# KEY SOLUTIONS

## Theoretical and strategic

1. Align with other equality and human rights movements, in particular disability and women's movements, to prevent disproportionate impact on women in low-income environments through abandonment or spouses travelling to the US for income. All whilst ensuring people with FD are protected and served by disability laws and initiatives.
2. The face equality movement must be inclusive of other languages, and must utilise the activists within the space that can translate and share existing resources.
3. A concerted effort to align with humanitarian services to better understand how many children with FDs are in orphanages worldwide is needed in order to understand the best method to prevent abandonment.
4. Intersectional approaches to reducing stigma are required in order to respect and consider how multiple identities affect the perception and experience of someone with FD. This includes but is not limited to religion and spirituality, socio-economic background, additional disability as well as FD, sexuality and language.
5. Research existing measurement tools used to build pre and post-intervention understanding of stigma, such as the Indigo tools for mental health stigma which could be adapted for disfigurement (Gronholm et al., 2023).

## Specific to explore in the immediate future

1. Parent and patient-led support and advocacy groups could be transformational in Mexico. Many similar groups exist across Europe and North America with much success, when leaders are appropriately trained. Such training could be adapted for Mexico and other countries across South and Central America.
2. Explore how the Cleft Care Companion App, and other digital tools such as parent Whatsapp groups can be utilised for proactive stigma reduction.
3. Test any existing stigma-related resources for HCPs and then develop training packages specifically for HCPs and charity workers in order to build their capacity to reduce stigma in line with their work.
4. Mexico, as a United Nations CRPD ratified country has 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. Build relationships with faith leaders and build out programmes of positive storytelling and exposure to FD.
6. Organisations working with the FD community in LMICs must report on and capture incidence of human rights violations such as abandonment or child abuse, which should be communicated back to local human rights organisations.

# INTERVIEWS:

Parent focus groups: **5 (multiple groups also had parents who also had an FD themselves)**

Adults: **4 (two also were parents to a child with an FD)**

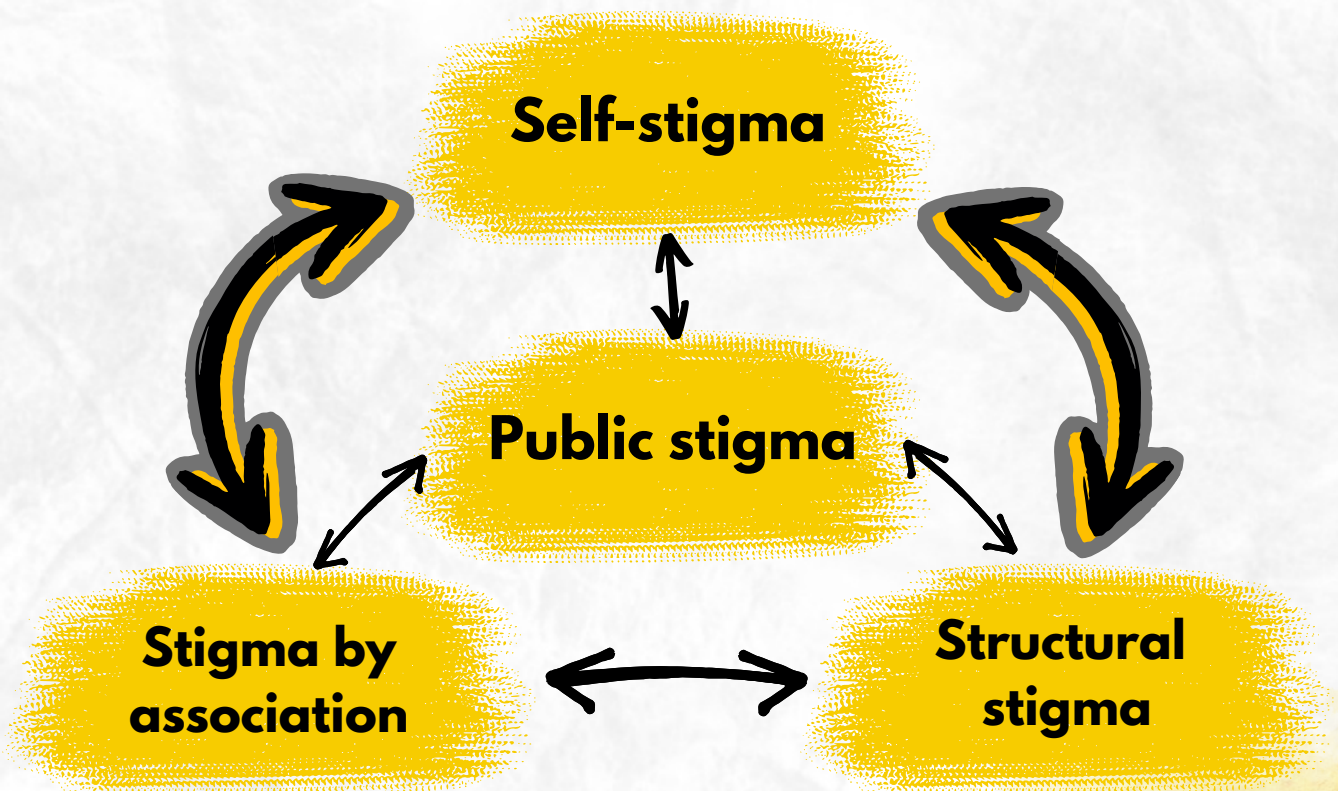
Parents: **5**

Charity workers/healthcare professionals/social workers: **15**

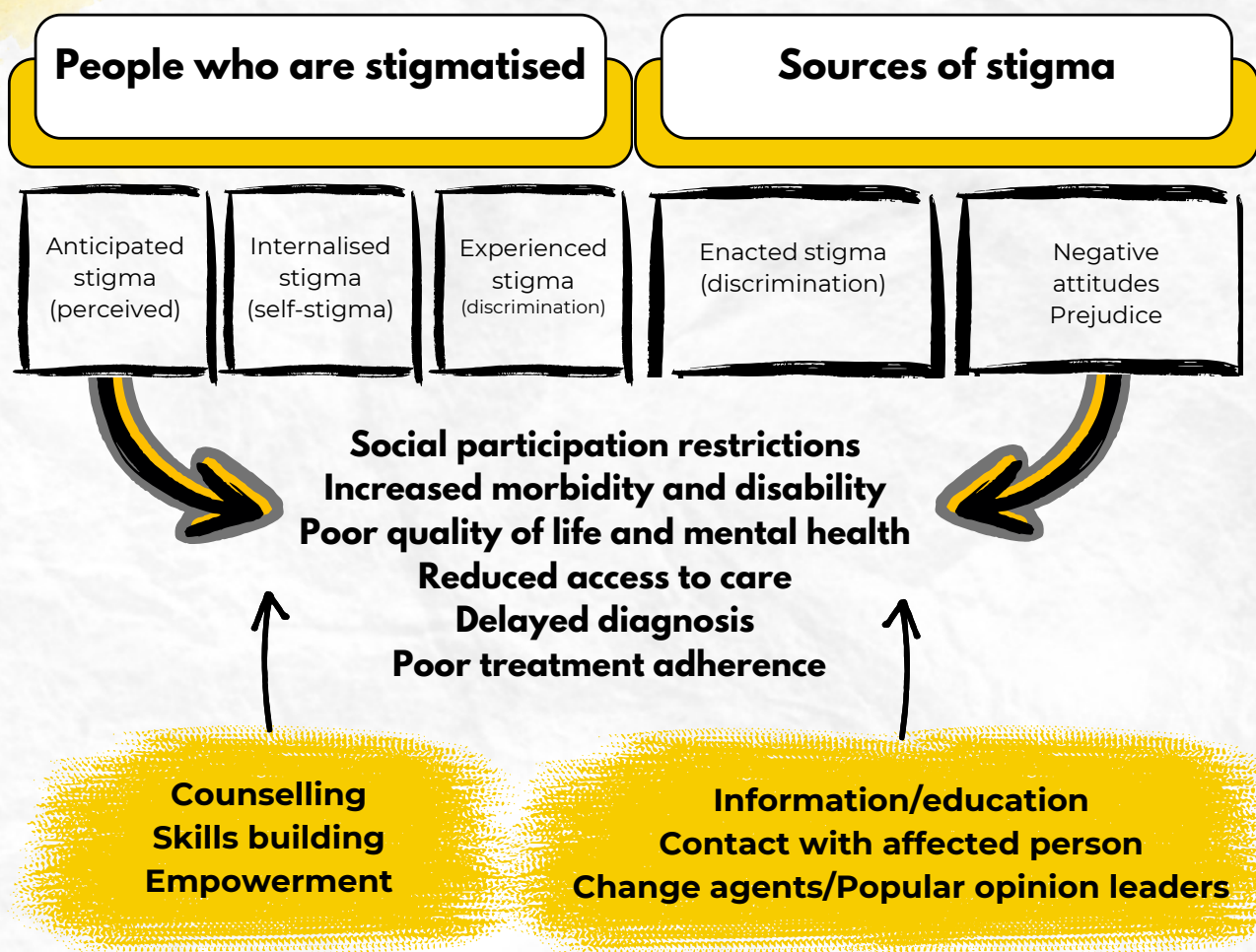
## Defining stigma

According to Bond, the UK network of organisations in International Development, “Stigma is commonly defined as the mark of disgrace associated with a particular circumstance or quality. People who are stigmatised are treated differently from other members of the community. They are usually marginalised and discriminated against, often neglected, abused or exploited, and always made to feel ashamed. It is unjust – and also in clear violation of the human rights of the person or people stigmatised.”

As per the previous report into FD stigma in India and Nepal, we continue to apply the Pryor and Reeder social stigma framework and definitions below, due to it being outlined well in a study by Rasset et al. (2022) on understanding the stigma of facial difference.



(Pryor and Reeder, 2011)



(An assessment and intervention model of health-related stigma (model modified from Weiss).

- 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. Given support, parents can be fierce advocates for stigma reduction

***“We should look at children, well, that we should look at everyone with the same loving gaze because everyone really deserves that love as parents, as society, to be accepted as they are and to have the best rights.”*** - Mother of child with Cleft

We observed an evident drive within many of the parents we spoke with to protect, advocate for, and often defend children with FD. Many groups were already mobilising, others were keen to start, but in need of some structure and support, which the Face Equality movement could provide.

That said, without the correct support, there could be a tendency to overprotect and focus too heavily on potentially harmful medical models of FD as a condition solely to be fixed as opposed to embraced.

Any person who stands in front of me and wants to humiliate me, well, maybe I'm very aggressive, but they don't dare to humiliate me because of my appearance or a video. Until today, they haven't dared. I think it's thanks to that confidence I conveyed, and I won't allow my son to suffer the same. I won't defend him with violence; I'll try to make it with an example and with education, so he knows how to get out of that situation gracefully.” - Father, both he and his son have a cleft

There are many successful parent-led support and advocacy groups across the US and Europe to support with speech, communication and resilience. The [European Cleft Organisation \(2007\)](#) specialises in delivering training for parent-led groups to become self-sufficient, which could be adapted and utilised across Latin America not only to advocate for children in a medical sense, but also to reduce societal stigma.

*“I think it's the parents. Because if the parents had confidence, fear can be overcome. Because confidence starts at home. If parents let the children develop better. And I feel that, starting with parents, to help us to come out.”* Adult with FD

The self-advocacy journey, is something the parents can set the tone for which can transfer positively into adult life if the parent acts as a role model. (Hirano & Rowe, 2016).

***“I think the biggest difficulty for me was comparing myself, I mean, why am I like this, right? Physically, why am I like this? Why am I not like my cousins? That is, physically, it was a big problem. But not for her. I mean, she accepts, she says, for example, about wearing glasses. It doesn't matter, mom, that I have my little ears, here I hold them with a little hairband and put on my glasses.”*** - Mother - both mother and daughter have Treacher Collins syndrome

Many of the parents we met were highly attuned to the role required of them to fend off any negativity whilst also setting a positive example and breaking down societal stigmas.

*“My daughter has bilateral microtia, on both sides. She practically doesn't hear 100%. So, my dream as a mother is to one day be able to talk to her, I mean, tell her, “Hey, let's go to lunch” and she would say “No, I don't want that”.* - Mother of child with Microtia

Humour, and comradery as above were evident in the parent focus groups, which appeared to bring out these proactive and positive attitudes from mothers and fathers with a sense of commonality across their experiences, which we observed as hugely positive and reassuring for those involved.

Several interviewees both had an FD themselves, and a child with FD, which meant that they were equipped to handle difficult questions and they clearly wanted to set a positive, supportive example:

*“I try to make my children happy and if we have to consult, if we have to go to therapy, maybe surgery later, but try to see, to do it for a better quality of life and also that the emotional part, we are taking care of it. The lack of information, tact, understanding, empathy, all this affects us a lot. Even now because, well, we focus more, right, on birth, but now, for example, I have doubts. I would like to have surgery, and I say, well, when my daughter asks me, why did you have the surgery? And I tell her, or she tells me, mom, I want to have surgery, and I tell her, no, you have to accept yourself as you are, right? That, how do I handle that?”*  
Mother - both mother and daughter have Treacher Collins syndrome

In terms of having to protect a child from negativity, be it from extended family members, other children or even teachers, we saw several examples of this:

*“Sometimes we see that our children are being watched. For example, Alex comes and tells me, “When are they going to fix my mouth? Because my classmates ask me”. As a grandma, sometimes I feel that this breaks me.”* - Grandma of a child with a Cleft.

***“I want my daughter to be happy, and the expectations I have are for her to have all the necessary resources to believe in her happiness, to have the knowledge, to have the emotional intelligence to be able to solve her problems and enjoy her life.”*** - Mother

Seeing parents with high expectations was brilliant to see, as an important tool to support their child’s success in life, which would likely play a role in reducing stigma too (Kirby et al., 2019).

*“Mum, someday I'm going to pilot that plane”, “ Is this how you are going to fly?” and I teach him. But his dream is to pilot a plane and I hope that his dream will come true, that's what I want the most.”* - Mother of a child with a CLP

We visited multiple parent-led non-profits in Mexico, operating with a similar ethos to those found often in North America. Understanding the needs of someone with FD definitely translated into effective, supportive and understanding organisations. Although the challenges of supporting both parents and the individuals directly affected by FD remain the same, and often there are two very different perspectives that require separate approaches, and often distinct, safe spaces for receiving wellbeing support.

For instance, parents might share experiences that might be triggering for their children around themes of grief or their first reactions when their child with FD was born. We were told of mothers rejecting their babies, which would no doubt be triggering for the person affected.

*“The mother rejected him. I was standing there, the other resident realised that I felt bad, so she finished the job... of all the things I have seen in medicine, that’s the worst thing I have ever seen, to see how the mother rejected the baby was horrible. It was very hard for me. Later on, I saw that the mother began to accept the child, she began to hug him, she began to cry because she had rejected him when he was born and I understand that, I mean, I also say that if I have a baby I would like him to be healthy, so I understand that part, but it is still very painful.”* - Cleft-affected HCP working with infants with CLPs.



This is a highly contentious issue, with the HCP above understanding the situation both from a personal perspective as someone Cleft-affected and as a medical professional responsible in part for encouraging the mother to bond with their child.

Having the time and resources to support parents to advocate for their children in a low income setting will of course present challenges. Studies in the USA have indicated that affluent parents from professional backgrounds are more confident and capable when it comes to advocating for their children (Taylor et al., 2019). Tailored support to reach families in lower income settings is necessary. This puts the onus back onto healthcare teams and charities with already stretched resources, but is essential to reaching families that may already be at a disadvantage. We were told that clinical teams often struggle to get patients to attend surgery, and returning for speech and language therapies is a further challenge, let alone to attending advocacy groups.

*“Twins we did the surgery to, that the parents brought them in to the hospital because in their town they were labelled as diabolical. So that’s why they let us do the surgery, otherwise they would not have let us do the surgery.” - Surgeon*

Travel, and issues surrounding remote communities needing to pay for travel to attend medical appointments was a commonly recurring theme across the interviews, which will be explored further in section 5 below relating to government support. For this reason, any community-led efforts would be challenging to deliver on a large scale outside of cities where gathering multiple people with FDs together in person would be difficult. Smile Foundation in South Africa has successfully led Whatsapp mothers’ groups titled ‘Cleft Friends’. We at FEI aim to better engage with such groups with a view to capacity building an advocacy and campaigning focus in addition to support.

Another area for consideration is avoiding the tendency for overprotection; several HCPs and persons with FD spoke of the negative impact of this on persons affected.

*“The first obstacle was financial. First because my parents are low-income. And the second was my parents’ fear, mainly my mom’s fear. She would come and feel how people stared at me, how they treated me, and she was afraid they would make fun of me... My mom was always afraid I would go out, and she would always pull me back, she was like, no, what if something happens to you, I’m very scared.” - Adult with Cleft*

The fears of a mother evidently prevented the person above from excelling in the areas they wished to, and the overprotection also impacted the wider family:

*"I love all of you, but it's because I take care of her, because she's not well, that's why, and I say "I'm fine", but my mom always says no. And my sisters followed my mom's pattern of taking care of me, and they would do the same to me, like they would take care of me more. And even my younger sister was always like that, as if they see me as if I were made of glass, and I could break any minute."* Adult with CLP

The founder of Treacher Collins MX, runs a shelter for patients and families seeking treatment in Guadalajara and also has a child with Treacher Collins. She recognises this tendency for overprotection in the mothers she works with, and actively tries to counteract it.

***"Well, let's say parents' overprotection. It's an everyday thing with me. I have always said that Treacher Collins is not death. If you tell them "don't try it or don't do it," then many times that limits the children, and that's where we work a lot on "mom, let him experiment," I mean, he's a child. Yes, he has abilities, so there's also a constant struggle with moms on that because we need to let them experiment in their own way."*** - Nurse, mother and charity leader

There is clearly an opportunity to work more closely with parents in Mexico and beyond to build advocacy movements that both empower the FD community, ensure they're getting the care they need, and to reduce stigma across society. Tools such as the Cleft Care Companion App, an app developed to educate and refer patients and families affected by Clefts, could be expanded upon to include advocacy resources whilst ensuring all educational tools take a proactive approach to reducing stigma by dispelling myths and reducing shame (Smerica et al., 2023).

Such programmes should ensure they reach remote and potentially disadvantaged communities to ensure they can access the benefits of being part of a supportive community. The potential benefits of such a group could be reduced internalised stigma and stigma by association. This would reduce any wellbeing challenges posed by low self-esteem or social anxiety, thereby reducing the burden on HCPs and schools if young people with FDs have supportive families enabling them to thrive (Halioua, 2010).



## **2. Public stigma from families and immediate communities is prevalent, in the form of bullying or ostracisation, which can sometimes result in child abuse**

The most stark, extreme observations tend to come out of conversations with HCPs. In part because they can recall numerous cases as opposed to simply their own, but also because they are less likely to conceal experiences that might bring on feelings of shame or embarrassment (Adeyemo et al., 2016).

***“There are many barriers that they face, for example, first of all, the communities. There are many communities where, because of the culture, because of many factors, a person who has a facial difference is marginalised, right? I remember when I came here, I had the case of a little boy... My sister is a social worker at the civil hospital, right? And when I started working here, she told me, look there is a little boy, her aunt came to me, and told me that this boy is locked up. The family found out that he had a lip and palate and they locked him up, and then the aunt was very worried because the grandfather didn't want him, the uncles didn't want him, and the child was locked up. We invited him here, he came and the mother was more convinced of her love for the little one, because at the beginning the mother herself hid him out of fear and also because she didn't know what was happening. In the end this baby is with us, he has a cleft lip and palate and he also has a club foot, so they are born with their little feet like this, inwards.”*** - Social worker

We heard several extreme stories from HCPs and charity workers in Mexico about children with Clefts being hidden away, where parents try to give babies away to a hospital, and in one case, sold. Speculative reasons were that they would be sold for organs, or as part of the prevalent human trafficking industry across Central America (Hispanics in Philanthropy, 2021). Other human rights issues such as child marriage, domestic abuse and being prevented from attending school came up several times in conversation. This has parallels with research reviewed in preparation for this project in other LMICs, for instance, 22% of respondents to a survey in Nigeria had been treated like an outcast by neighbors, friends and relatives due to having a child with a Cleft.

Other experiences from interviewees were of hostility and bullying from both extended family members and communities.

***“Oh, look at that child, he doesn't speak well!... who do understand that there are children born like this. But most people say no, or when they see a baby, they sometimes mock, they mock a baby like that or say 'oh, how ugly your child is,' I don't know. That's why when my baby was born, I hardly took him out here in town, I took him out when we went to Oaxaca because they don't say anything there, but here, there are people who are closed-minded who sometimes tell you things”*** - Mother of a boy with a Cleft in a remote area

Instances of parents being hesitant to take their babies out in public due to fear of reactions came up several times in the interviews.

***“One lady told me, they say that this happens because God is punishing us for something bad we have done and I thought, well, sir, what did we do, I believe in God and I say, sir, what did we do, they tell me that it was a punishment from God because we did something bad and I felt that I was the only one, I wanted to hide my child, to cover him up when we went out, I wanted to hide him.”*** - Mother of a child with FD

The face equality movement is very much dependent on people with facial differences being seen, heard, and having the opportunity to thrive in society. If hidden away, either forcibly or as a coping mechanism for abuse, change simply isn't going to happen at the rate it should. There must be support measures in place for parents to counteract negativity from strangers, and we must reach society with sensitization campaigns to increase representation and exposure to facial difference to prevent this human rights violation from continuing.

***“Sometimes among family members, or among neighbors, among us here, we discriminate. But for us, discrimination is, is a different sense, so to speak, because, ah, it's because they did something, ah, or they're paying for their sin, their wrongdoing, right? They did something. And now... Now let them enjoy it, right? Let them relish it, I don't know. But that's the way we discriminate among ourselves. Blaming.”*** - Parent

Abandonment of mothers by fathers of children with FD came up a lot in interviews, similarly to those conducted in India and Nepal, posing the need for aligning with women's movements in LMICs to better serve mothers who may be disadvantaged in such a way, given women are more likely to be affected by stigma (Bond, 2017). In terms of existing women's movements, the [White Ribbon Alliance](#) recently highlighted in a campaign where they asked 1.3 million women about their health and wellbeing priorities, financial security and work came out top, alongside free or affordable healthcare (White Ribbon Alliance, 2018).

***“We have a single mum whose father [of her child] abandoned her to her fate, and he told her that when the child had surgery, he was still not completely well because his cleft was very severe and so he found another family, he had another child and when his other child was born he said that he didn't want the other one because the other one wasn't normal and he was. He said he didn't want the other one anymore. We have many, many cases like that.”*** - Social worker

***“We have had entire families that have separated because the mother defends her son [who abandoned his child] and the mother-in-law, the aunts, they marginalise the children. We’ve had patients that have left their community because they can't stand the pressure. We’ve had a family with a beautiful girl, whose mother-in-law told her to leave her, to lose her, to abandon her, and now that the girl has had the operation, no one can even tell that she has a cleft lip and palate. Her husband had to choose between his family, and he chose his daughter and his wife and, well, they don't see the grandparents anymore.”*** - Social worker

The issue of abandonment was very much the impetus for our project to explore the relation between stigma and human rights violations. What limited research exists, tells us that in Nigeria, a quarter of respondents wished their child with a cleft lip and/or palate (CLP) had never been born, and two of the participants wanted to abandon their baby at the hospital (Adeyemo et al., 2016). The most concerning aspect of this is that beyond anecdotal evidence such as the stories outlined here or stories of children with FD and disabilities being found in orphanages worldwide, this is a grossly under-recorded issue.

The disregard for the life of a child with a facial difference is a human rights issue that cuts across several United Nations human rights priorities, from disability to the rights of a child. Yet, to our knowledge, in the Universal Periodic Review, by which the civil society and other parties can make recommendations or call out ways in which United Nations countries should be upholding their responsibilities to the human rights of their communities, there have been zero mentions of disfigurement.

Importantly, there is a United Nations Independent Expert on Albinism, whereby strong examples of the discrimination of the wider FD community are often brought to the UN for discussion. *“Persons with albinism were a unique group whose human rights issues had generally gone unnoticed for centuries, the result being deeply engraved stigma, discrimination and violence against them across various countries. More often than the general population, persons with albinism and their relatives were vulnerable to accusations of witchcraft, ritual attacks, and faced risks of killing and maiming, including live amputation of limbs, rape, grave robbery, and trafficking in persons and body parts, as the study showed. Hence, countries where such accusations and attacks were rife also implied more danger for human rights defenders with albinism”* (United Nations Human Rights Council, 2023, para. 4).



*“We see from the moment they stare at them, from the curiosity, I would say, also, from this part of what happened to them, from astonishment, from different emotions that are not so nice. It's like that part of us that's not used to seeing different things and it's what makes them feel uncomfortable, like “why are you looking at me so much?” “what's wrong with me?” But it is that part of first discrimination, that part of staring and feeling uncomfortable, it is also that part of the teasing, when they are younger or in teenagers the teasing, or also in the communities, especially in the families, it's like, “what happened?” “What did you do wrong to deserve this?” Or the curses that've been heard in this part.” - Social worker*

Programmes, interventions and humanitarian efforts worldwide are failing to reach infants with disfigurements with specific efforts to prevent valuable human lives from being disregarded.

Healthcare professionals (HCPs) interviewed are very much aware of this issue, and yet the charities they're attached to are largely focused on delivering surgeries, as opposed to providing homes or shelter for abandoned children. We hear of the lucky few who are adopted by their HCPs or someone known to their healthcare team, who on occasion can take in a child with FD, such as the founder of Fundacion Contreras in Oaxaca who adopted a young girl, but this is not universal. A study to better understand exactly how many children with FDs are currently in orphanages worldwide would be a distressing but necessary study, from which point something must be done to stop this from happening.

There definitely appeared to be a sense that older generations were more prejudiced and likely to impose stigmatising behaviours (more on this in section 4).

Positive exposure to people with disfigurements to reduce implicit bias has been repeatedly proven to effectively improve attitudes and several studies into the experiences of the FD community in LMICs have pointed to the need for public awareness campaigns with government support (Stone, 2022).

Several campaigns already exist through the likes of Smile Train Latin America or Leporinos, an artist depicting Clefts, which have highly positive imagery of the Cleft community across marketing channels (Smile Train Latinoamérica [@smiletrain.la], n.d.; Leporinos, n.d.). There is a real opportunity to accelerate the face equality movement across Mexico and Latin America, which at the moment is being inhibited by a lot of messaging and resources solely being available in English. But the most pressing issue is that the majority of existing efforts are limited to Cleft-care, when there are countless other FDs in need of similar efforts, be it burns, skin conditions or other craniofacial conditions.

Community-based rehabilitation practice, such as leafleting, storytelling and producing media coverage could be led effectively by parents in Mexico with positive results. Such efforts have worked well in West Africa where parents that would have previously denied having a child with a disability, then publicly acknowledged their children and this led to a reduction in cases of abuse and discrimination (Coe, 2013).

*“Not just the lip, it's the lip, the palate, the nose, the teeth, the ear, many things and also all the social aspects, all the support, the support networks, the institutions, the family, I think that the ideal thing would be to make people aware of it through information. Information, maybe, I don't know, commercial posters, videos, where, very quickly, where it would be very concrete about the whole process, all the suffering that families sometimes go through or everything that they go through, in other words, everything that has to happen for a patient to have surgery is tremendous.” - Patient coordinator*

If there are children being abandoned and hidden away, this is an extreme issue that must be brought to governments, policymakers and charity leaders for immediate attention, and the resources that exist in certain fields of disfigurement care, must be shared across the sector to ensure no child gets left behind.

### **3. Teachers don't know how to support children with FDs or disabilities, but charities and healthcare professionals want to address this**

*“So I think that the best way to grow or advance in this aspect is information. For example, in one of the cases of bullying that we have right now, the mother told me that she would like us, someone from the team, to go and give a talk at the child's school, but a general talk, to parents, students, teachers, so that they would be aware of the process that a cleft lip and palate patient goes through, because here in Mexico there are many jokes, many jokes, many things about cleft lip and palate patients, the way they talk, the way they look, right? So, I think our culture and fake news don't help much either.” - Patient coordinator*

Many of the organisations we spoke with either had existing schools programmes, were in the process of developing them, or they were asking us for guidance on where to start and whether there are existing resources.

***“So, we have been told that it would be good to give a talk in schools, to raise awareness, for them to see that, I mean, the whole process, the whole struggle that a patient with a facial difference has to go through, not just cleft palate, but any other facial difference, that it's not very simple, it's not easy. And in addition to them seeing all that, that this also generates empathy, people need to see them as equals, which is something that makes a big difference, we are the same” - Social worker***

When resources are limited already to deliver surgical and multi-disciplinary care, charities are wanting to do more on a community level to prevent the challenges their patients are experiencing in school, but there is not one universal, validated way to do this. Without support, charities could actually make bullying worse and increase stigma relating to FD, particularly if solely focused on medical models of FD which see it simply as something to 'fix' through surgery. Many condition-specific outreach programmes and schools resources exist across the third sector, but this increases silos and minimises impact.

*"We know that society is very damaged and in a year my daughter is going to be three years old, and she will be going to school. I don't know how children are going to take it."* - Father

There were several mentions of the book and film versions of Wonder:

*"I think, even from the movie, Wonder, I think of 20 people who know her, 10 tell me she's the girl from the movie, does she have the disease? Does she have the disease of that little boy in the movie? I tell them, ah, yes, but it's not a disease, it's a condition."* - Mother of a child with Treacher Collins syndrome

Wonder is a story about a child with Treacher Collins syndrome attending school, being used with students, which could provide an opportunity for existing resources developed by US organisations myFace and the Children's Craniofacial Association to be adapted for Mexico and wider Latin America. This programme for primary school aged children focuses on building empathy, fostering kindness at school, and most importantly, focusing on the similarities and shared interests people with facial differences have as opposed to focusing on everything that makes someone with FD 'different', which would likely increase stigma (Stigma, Disability and Development, 2017).

Although there are some flaws in the film, given the use of prosthetics in place of an actor with lived experience, and the potentially problematic 'inspiration porn' like storyline, the film does evoke strong reactions from young people, and the story itself is very true to life for both a child with FD and the impact on their wider family.

The target audience for schools must be inclusive of teachers, given we heard several examples where teachers were actively excluding children with FDs and disabilities, where the teachers were actually the perpetrators of bullying, and many just simply didn't know how to support a child with FD.

*"The teachers themselves started to act as if they didn't want to accept him anymore because supposedly he still needed to learn to read and write, and they sent him to remedial classes, so I felt like there was discrimination, and I decided it would be better to take him out of school."* - Mother of a child with Treacher Collins syndrome

*“And in schools it is a process of empathy and awareness-raising with students and teachers, because in many cases the teachers themselves are the ones who bully.”*

*“It was a bit difficult at school because the teacher told me that she complained that I couldn’t listen to her well... I even had a problem with that because at first, she said she didn't understand her (her daughter) and she couldn’t listen to her, so she told me that I should look for a special school to educate my daughter. But I told her that there was nothing wrong with my daughter, that with surgery, with treatment, with therapy she would get better, but that was difficult.” - Parent of a child with a Cleft*

*“There were more boys than girls, and they would talk to me about how I looked and how I spoke. I always have the memories, them saying that I looked like a boy because of the way I looked and spoke.” - Adult with Cleft*

***“We have a mum who tells us that her son is mistreated, they bully him horribly, the teachers don’t listen, they don't do anything. At that age we have many little patients who are going through situations like that.” - Social worker***

There were countless examples of challenges at school that were not being dealt with effectively by teachers, and this is very much paralleled with experiences recorded across the globe for the FD community, which was the reason we at FEI launched an [education hub on our website back in 2021](#) (Face Equality International, 2021). This hosts research and resources such as a teachers guide for creating appearance inclusive schools (Parnell et al., 2021).

One adult we spoke to told of bullying both from peers and teachers which led her to leave school. She was a nurse, who also had a child with a Cleft:

*“I think it was about thirteen, but what was more difficult for me was that I came from a very poor family, and my mom, who was uneducated, was bullied, and that's where I faced a lot of bullying, and when I was post-surgery, I would get pushed and hit sometimes... The truth is, I had a little problem with a teacher, and I dropped out of that year, and there was a teacher who didn't like me. He didn't like me, and I left.” - Adult with a CLP*

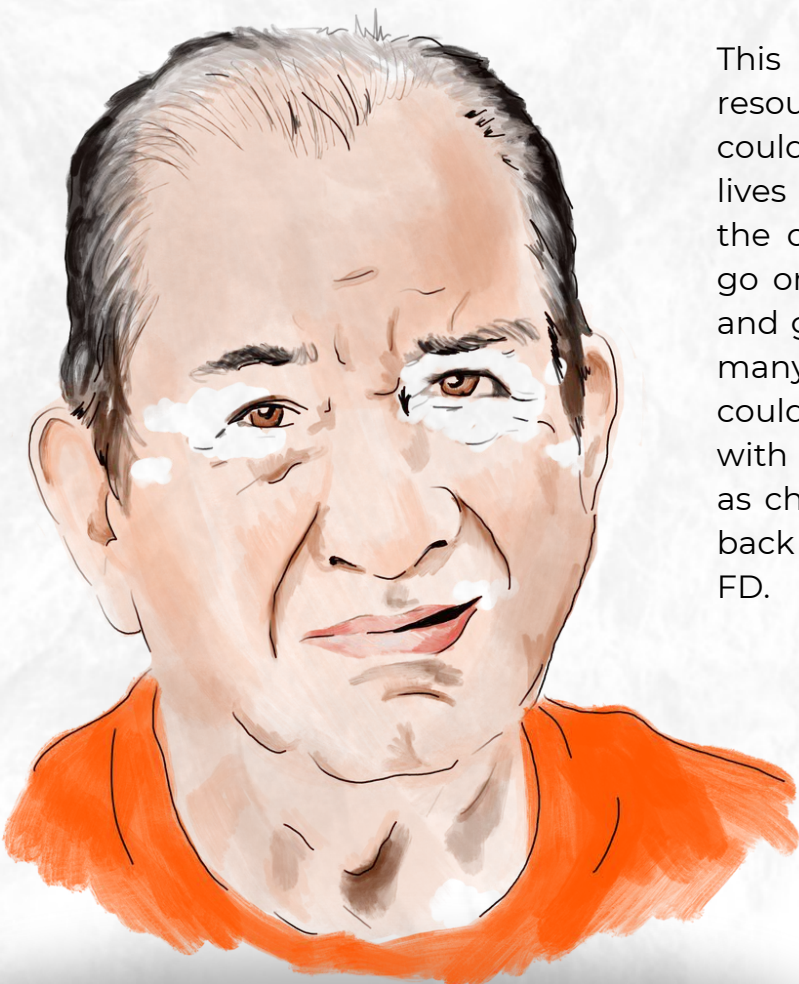
*“However, unfortunately, a couple of years ago, this wasn't visible or normalized, and the bullying was very intense. I'm not saying I was able to change everyone's mindset during my student years by demonstrating that this is physical and doesn't define me as a person. In the end, I think I had won the hearts of many classmates who recognize me wherever I go, not because of my scars, but for the person I was with them, for the attitude I always had with them, and not because of my scars. They know me by my name and not by my scars.” - Male with Cleft*

There is evidently a great desire amongst charities to disseminate interventions in schools that can make the lives of the FD community easier. With many non profits delivering services across Latin America, a joined up, collaborative approach would help to ease the burden. There are also organisations such as FEI member, Aproquen (1991) already working in many schools to deliver burn prevention programmes, which could likely be bolstered by anti-stigma messaging being woven into the materials.

Such efforts would benefit from validation studies and academic input to ensure the programmes can be proven to effectively change stigmatising behaviours over a period of time. This could be done through pre and post intervention scales and interviews such as the EMIC scale which has been validated for use in destigmatisation of neglected tropical diseases (Peters et al., 2014). EMIC measures community stigma with questions asked of the community in which the intervention took place, along with similar questions asked to individuals living with the stigmatised identity in order to measure anticipated stigma or the impact of stigmatising behaviours.

It is of course very difficult to keep track of numerous participants and the potential change in attitudes and behaviours over a period of time, particularly if focusing on community interventions where participants may withhold their true attitudes. Measuring the experiences of the FD community themselves, or implicit bias tests might be more effective (Hartung et al., 2019).

This work takes a lot of time and resources, but the long-term effects could have immeasurable impact on the lives of the FD community. As a result the opportunity to thrive in school and go on to seek economic empowerment and give back to their community, as so many people with FDs often want to do could be possible. Several interviewees with personal experience were working as charity or HCPs as a means of giving back and improving care for others with FD.



## 4. Younger generations of parents are less likely to believe superstitions about supernatural causes of FD, but the guilt and blame culture remains

Perceptions of Clefts are ever-evolving, in Mexico in particular, there are Mayan statues depicting craniofacial syndromes dated back to 200 BC (Aleman & Martinez, 2022). Many interviewees within this project could recall long-standing beliefs that were potentially outdated by modern 'Westernised' medicine in relation to supernatural causes and prevention methods for facial differences.

Respect for both traditional and Western theories should be given in any approach to reduce stigma, in that both modern medical models of FD, and more spiritual or moral models of FD can be problematic. Both reinforce stigma and associated wellbeing challenges for those affected and so neither discipline should be regarded as superior. Any efforts to work with the FD community should maintain a positive 'dialogue' between the two conceptions, with public health and patient centered outcomes taking priority (Castro, 1995).

From a supernatural standpoint:

*"There are families living in some communities that are very deep-rooted, and suffer from this discrimination. There are communities here that even though they are close to the centre, they still don't know what cleft lip and palate is, they think "that it is contagious", and they have even said, we have some cases where the parents have been told to let the baby die, because it is not going to be normal so it's better to leave him. So, the discrimination is more so from their own communities, or where they come from." - Social worker*

And from a medical standpoint:

***"When she was born, I asked, why was she born like this? And the doctor told me, "this is usually seen when parents use drugs," when neither her father nor I have ever used drugs, so I feel a burden, I mean, it's my fault, I did something, that's why my girl is like this." - Mother of a child with Treacher Collins syndrome***

It appears perceptions and general health education is impacted by geography, socioeconomic background and language, given the 364 varieties of indigenous languages recognised throughout Mexico (O'Neill, 2020). Intersectional approaches to reducing stigma should be considered, which is an argument for working on a very local level with specific interventions delivered by members of the relevant community as a way to level and resonate with specific communities.

***“Yes, the parents. Some of them, even when the doctor arrives [the hospital], for example, the surgeons explain to them what the causes are, the parents can more or less calm down a bit, but when they arrive, they are devastated. The guilt of not knowing what or why it happened to them, “why they were telling me this”, if they did all the treatment, etc. Some have even talked about envy, bewitchment and all those things, that there is not just one, the beliefs they have about CLP. But in very remote communities they are still very, very, very attached to all these beliefs.” - Social worker***

Exposure to FD through media or immediate communities likely plays a role in the reduction of stigmatising beliefs over time. Further interventions could be developed to reach remote communities through similar means of storytelling. Contact between stigmatised groups and others whereby a sense of shared experience in a levelled way, where preconceptions can be dispelled is known to be highly effective, with ‘interpersonal connection’ being the best form of stigma reduction. In practice, as this is likely not a medical priority, it can be difficult to resource (UNICEF, 2020).

That said, there are organisations that are leading the way on this, such as Nepal Leprosy Trust with their community based rehabilitation programmes whereby if there are issues in a patient’s community such as exclusion or abuse, they will send a ‘Community Counselor’ to address the community with education and sensitisation (Muldoon et al., 2022). Other initiatives include the Indigo partnership, which uses many research-led scales to measure and track a reduction in mental health stigma in LMICs (The INDIGO Network, n.d.).

*“They didn't directly say, 'It's your fault,' but they did make her feel like it was her fault because she didn't take care of herself or questioned why it happened. They started looking for reasons, indirectly implying someone's fault. There was a moment when she even felt bad. Personally, I was always in depression or in a room during my pregnancy. It was quite regular. I tried to do everything right, everything was fine, but when I was with the indigenous people, they did ceremonies for fear, and I felt fear for [my grandson] with Down syndrome.” - Grandmother of boy with Cleft and Downs syndrome*

Supernatural beliefs vary in some degrees, but all place blame in some way on the parents, most often the mother, who is expected to wear a piece of red fabric around their waist, in particular during an eclipse, to ensure a child isn't born with a Cleft.

*“They say that when a woman is pregnant, when you are inside the house and you go outside, and with, I don't know, the reflection of the moon, that's when children are born like this. That's why people here, when women are pregnant, put a bucket of water under the bed when the moon is full, or tie a red ribbon around the belly, so that children aren't born like this. That's the belief here.” - Social worker*

This blame culture presents itself as punishment for wrongdoing or sin, which extends to many types of FD or disability.

*“Here in Mexico, there is a myth that it is because you often get very angry, it happens in the body and we lose the colour of our skin. That’s a myth that I have heard about Vitiligo, and with other differences or something like that, well, in more distant communities it is said that something bad was done by the family that the child is paying for it, or some other genetic situation.”*

The above is a prime example of the moral model of FD, which is essentially the idea that the person or surrounding family affected by FD deserve to be punished for some reason, and the visible difference itself is the punishment (Jost, 2021). This is paralleled with the moral model of disability, again which in many cultures across the world is seen as punishment for wrongdoings in present or past lives. The difference however, is that disfigurement is quite literally used as punishment in terms of acid and burn violence, which we were told by a burns non-profit in Mexico City is increasingly used by drug cartels.

Religion can play both a positive and negative role when it comes to FD. As above, religion can be used as a sense that God’s will is to punish persons with FD, but at the same time, God can be used as an explanation:

*“There’s a saying that... God gives the... toughest battles to His best soldiers, and that’s true. He won’t give a child with a disability or a mentally weak person. If that person can’t take care of themselves, how will they take care of another? We have to learn to live with that.”*

*This is not always helpful. Faith can however be a source of strength through adversity, a much needed sense of community, especially where communities might support people in poverty or disadvantage.*





*"So, what I have may be temporary, something I can overcome, something I can bear and transform into happiness, ultimately into good luck because I'm happy with who I am and not with what is unfortunately here. I thank God very much for that." - Man with Cleft, also father to boy with Cleft*

The same man also said:

*"Most people grow up believing they are perfect, facially speaking, but they don't know that life takes many turns. God forbid, something might happen in an accident, and life itself will teach them that it's not always perfect. They might have an accident, disfigure their face, go through many things because I've seen many people who had a very high ego, and suddenly they fall. It can be very traumatizing for them, something like that. I don't know how to explain it. I have always believed, and it has been instilled in me, that God doesn't punish, but he makes you learn in the worst way."*

Working with faith leaders is known to be an effective way to reduce stigma, particularly if stigmatising beliefs are rooted in spiritual practice which could be open to interpretation or modernisation (Minot, 2023).

*"God doesn't punish, but He makes the person understand. People are perfect when they are born and cannot be judged; it shows they are brave and can have anything, be anything, and have a facial difference, whatever." - Man with Cleft, also father to boy with Cleft*

*"It's that we've had personal problems for a year. When the husband goes elsewhere, life is so different, they seek other people. And he did it once and said, 'forgive me, I won't do it again,' and unfortunately, he didn't realize, he didn't regret it and did it again. And the child realizes, and that's what he always says, 'dad doesn't love me because I was born like this, that's why dad preferred another family.'" - Mother of boy with Cleft*

The above demonstrates how if the guilt and self-blame culture surrounding FD goes unaddressed, it could then pass directly on to the child, especially if parents are displaying behaviours of neglect towards a child.

*'Mommy, mommy, why wasn't I born like this?' It had never crossed his mind before, never. And I don't know why he thought, 'why wasn't I born like his cousin?' And that's not, no, he asks sometimes, ah, why are you asking me that, my love? Then he stands up and holds on and says, I don't understand, mommy, why wasn't I born like that? I told him, because God wanted to send you like this, that's why. But they love me, I tell him, yes, I love you, son. And then, why isn't dad with my child? He doesn't love me, right?*

*No, I told him, 'dad has to work to help us.' Because we depend on that, my love, I told him, so that he can send us money, to be able to go to your doctor, because, I said, we need it, it's not much"*

Self-blame and guilt have been examined in relation to weight-stigma, which may draw helpful comparisons with FD as another appearance-related stigma (Castonguay, 2017).

*"Because I used to drink a lot. Before, I used to drink a lot...I don't believe in those things. But people do believe it. Like I said, they look for the culprit, and here the culprit they look for is me." - Father of baby with Cleft*

The correlation between disfigurement and associated self-blame undoubtedly has an impact on self-stigma and courtesy stigma, and thereby mental wellbeing. Healthcare practitioners must be equipped with appropriate language and resources which can help to shift this culture of blame, given this is also reinforced by the medical model of FD which very much focuses on the mother avoiding alcohol and taking folic acid for example. Meaningful responsibility is of course a priority, but blame is evidently harmful and can have generational impact.

## **5. An empowering movement to centre the medical and social needs of the FD community in Mexico is something many people want, but resources to deliver it are limited, and government support is minimal**

*"We did the campaign, you could say, in Latin America, Illuminate your differences. So we painted our hands with colors, painted them on our faces, illuminate your differences. Wanting to tell people, all people, that we are all different, and our differences also make us unique, and what they did was use different colors and painted their hair in a way to highlight the difference in the face, and she was making the point that what makes you different also makes you unique." - Charity leader*

Mexico is a vast, diverse country in terms of culture, language and geography. We visited urban areas with well-established hospitals and thriving economies, along with areas with very limited resources stretched across vast distances. It was in these communities where we saw the highest levels of poverty, with poor housing and incredibly difficult circumstances for sustaining a child with a health condition. When asked how the face equality campaign might serve these communities, one social worker told us:

*"It would be from both physical and virtual, to reach those communities that are very far away where there is no information. There are many communities that don't even have doctors or nurses. So it is very complicated, but we could start from that part and if in social networks, in civilisation." - Charity worker*

We visited Chiapas, which had high proportions of Indigenous communities as well as an evident presence of drug cartels and the associated violence that comes with this presence. Many human rights organisations and movements operated in this region, working with women in underage marriages or as victims of domestic abuse.

*“Knowledge, above all, explaining... what it is and how we can support or how we can be empathetic with the other person, because empathy is something that’s being forgotten nationally and globally, little by little, and then people with facial differences and other disabilities and diseases are unfortunately even more affected.”* - Charity worker

Amongst a challenging environment, what we did witness was a strong desire for change, and a pretty clear idea on how to get there, by leading with education and storytelling as in other social justice movements in Mexico which have brought about change such as for the LGBT+ community (McCaughan, 2015). The problem is, that government support specifically for the FD community is limited, be it through inadequate financial provision for those qualifying as disabled, or with FD not being regarded as a disability at all.

*“They are very, very, very beautiful and very admirable stories of everything that the family has to face, even from the separation of the father, from abandonment, etc. So I think that if it is an awareness campaign, we can start with the patients and the family, what they would like or how they would like to be heard through your support or through organisations, or campaigns like this one. I think that would be my biggest request, that the patients and families themselves have a voice, that many times society takes it away from them, that “you can’t speak” or “I don’t care what you think”, so that they can speak for themselves and say everything they feel and think and everything they’ve been through.”* - Charity worker and psychologist

Bringing communities together through informal peer support was clearly having a profoundly positive impact with certain charities able to deliver this level of care in an urban environment.

*“Obviously, when you’re at the foundation, everyone meets each other, your children meet each other, see your different hair, see your different facial features, but that doesn’t always happen, people have more life, are more positive, more vulnerable. So, I just want to talk about that a little later, and that it’s also not the same when here, for example, they can meet other children with Treacher Collins, other mothers, know other experiences, whereas other children who don’t have that opportunity, who are isolated and in communities where they are the only ones, then other experiences come, and well, they become role models.”*

Most, if not all interviewees faced financial challenges in providing for children with FDs and covering medical care.

*“So, that's one tool. Another one is mandibular distractors, like bidirectional ones, they don't have coverage either. What we try to do is to have contact with people from the United States, with the CCI as well, but with families who have mandibular distraction. But in the United States, for example, surely in England and other countries, the device is removed and discarded, they are made of titanium. In Mexico, we can use this device 10 or 15 times more. This device. But in Mexico, it costs us more than a million pesos. A million pesos is 20,000 dollars.”*

There's also a perception that the Mexican government is accepting of foreign aid, but less so of national advocacy efforts.

*“If something foreign comes to help, we accept it. But if something is national, it doesn't happen. So, it's more acceptable when someone comes from a foreign country and helps people in any way, they take it more seriously. The government takes it more seriously.”* - Mother of child with FD and charity leader

*“Federal government. They give programmes or support in food, clothing, various things. They have social workers there as well. But yes, there are patients who have separated from their families because they are not being supported. We have patients who live alone, who have no company the day of their surgery because they have no family, so yes, there are many very complicated cases and there are many who, thank God, don't have to go through that as their support network is large and maybe they don't have much money but they get support from their uncle, the grandmother... who are very loving with the children, but there are very few who are like that, completely empathetic with the whole family.”* - Social worker



The intersection between disfigurement and poverty is a tricky issue to navigate because undoubtedly poverty must heighten challenges and health inequities for individuals and families affected, sometimes also making it harder to earn an income if the person faces discrimination in school or work. Equally poverty might be a precursor to an acquired facial difference such as burns, which are prevalent in Central America due to many families cooking with an open fire or stove as highlighted in a study in Chiapas where we visited (Zoeller, 2021). Open fire cooking also causes issues with children attending surgery as they must show no signs of illness or flu like symptoms before receiving surgery, but inhaling smoke meant that children visited had persistent coughs.

*“Another barrier is the economic, the distance to [the hospital] the communities are very far away, the access is hard, the transport. We have families who walk 3 - 4 hours to get to the bus stop and from there another 8 hours, so that is also a huge problem. We have a lot of families who have to go through that, they come here and give the children follow-up and everything, so it’s another type of barrier, economic too, isn't it?”* - Patient coordinator

Disability status for patients with disfigurements in Mexico, even if temporary, could be life-changing. In the early stages of life, where access to medical treatments is necessary for a child to eat, to breathe or to speak, to have financial support simply to attend hospital treatments could be life-changing.

*“I have intentions to go, well, to go illegally to the United States, to give them the best that can be given. I think about myself, I have four children. I would like to give them what they want, right? But unfortunately, the salary here is very low, you can't buy many things. You see, without an education, yes. Limited salary, limited salary. And if you don't work for a day, then there's no food and so on.”* - Father of baby with Cleft

Caring for a child with FD often comes with the financial burden of healthcare. For instance, sun screen for a child with Albinism or Vitiligo is essential. Surgery to enable safe breathing and eating is often required for children with congenital craniofacial conditions. Having the financial means to pay for formula when breast feeding is not possible due is also a factor for children with an FD that affects the mouth.. The cost of travelling to medical appointments alone is too much for families living long distances from hospitals and living off of their land.

*“In many cases the father is a farmer, the family doesn't have an income, but what they sow, what they produce is for their own consumption, and they don't earn anything.”* - Social worker

Government support for people with FDs is clearly limited given what we were told by individuals and organisations. Those with craniofacial conditions that have a 'physical impairment aspect to them were classed legally as a disability, and thereby persons could claim financial support from the government, but the amount given is not sufficient to cover necessary medical equipment such as hearing aids.

*"Here in Mexico, part of the problem is that reconstructive surgeries are considered cosmetic by the health sector. This means individuals have to cover the costs independently because they are not covered by insurance, social security in Mexico."*

The Mexican government failed to support the recognition of Treacher Collins as a rare disease as told to us by a mother of a child with Treacher Collins syndrome who died:

*"We intend to pressure the government for visibility, acceptance, and mainly to create a registry of people living with a rare disease... We achieved it a year ago, a census was conducted in November that lasted two weeks, and the government removed it without telling us why. We believe it's because it exceeded what the government expected."*

*"Children [with Treacher Collins syndrome] normally die within three months here in Mexico. They usually die before 3 years, because there is not enough research, not enough people attending to this situation. So that's what they are looking into. It's a large number of people with rare diseases that the government is denying, not accepting."*

Support for other facial differences that are less likely to qualify as a disability is even harder to come by:

*"In Mexico, there are support programmes for people with disabilities, as far as we know and from information from patients and from various institutions, cleft lip and palate is not seen as a disability... I was just looking at the requirements they ask for a social welfare programme. They ask in their community, and they are told to bring a certificate saying that they are a patient but they still don't get approval and the help, because CLP is not really classified as a disability. Many times, families who get the help use this support to pay for travel, medication, and so on. So this is the dilemma, not knowing if it really is a disability... Yes, because it's not being done. In fact, many of our patients, I tell you, have asked us for proof because they do the paperwork and they tell us that CLP is not classified as a disability as such and they don't get accepted. We have some patients who have disability support but because they have some other condition, some syndrome or something else and they do, but cleft lip and palate is not being taken into account here as a disability." - Social worker*

This is clearly a contentious issue, which we'll expand upon further in the section below specific to disability, but in terms of government supported campaigns, the fact that FDs are not universally considered a disability evidently causes many problems.

Evidently social norms and media representation play a role in Mexico, as in many other parts of the world where public perceptions are influenced by Hollywood films where disfigurements are often placed upon immoral, evil or vulnerable characters (Douglas & Reese, 2017).

*"When you're little, that's very important. Because we have bullying. Some of our patients, they need to wear a mask. And it's more stigma with a mask than with a scar. Because when they take out the mask, people say, oh, okay, I thought it was worse, because there are a lot of movies and things that the characters, that they are terrible."* - Psychologist

Poor media representation gets in the way of dispelling myths, and undermines efforts to educate the general public on respect and empathy for the FD community. Equally, it can be seen to permit stigmatising behaviours such as staring, name-calling or teasing given films tell us these characters with FD are worthy of disdain.

*"And that would be very good, like having the right information, but that would make people see that they are also human beings who also feel, think, hurt, and that sometimes a little question, a word or a stare makes them feel very uncomfortable."* - Patient coordinator

In terms of advocacy, the government has shown some support for acid and burn survivors campaigning for tougher sentencing for perpetrators, and there are ever-evolving laws surrounding financial or legal autonomy for people with functional impairments for example, but support for the FD community is limited (Espinosa, 2022). Yet there are many potential activists in Mexico that we met, some of whom are now working in healthcare as doctors and nurses as a way to give back to their community.

*"Maybe at each stage there is an obstacle, but you can always overcome it. And now I've finished my degree, I'm a doctor and I'm looking forward to continuing to improve myself. So, the dreams I've had so far, I've fulfilled, and they can be fulfilled. And that's what I'll keep to myself."* - HCP with a FD

One interviewee stood out as a powerful potential activist, who delivered the following statement with zero guidance on our part:

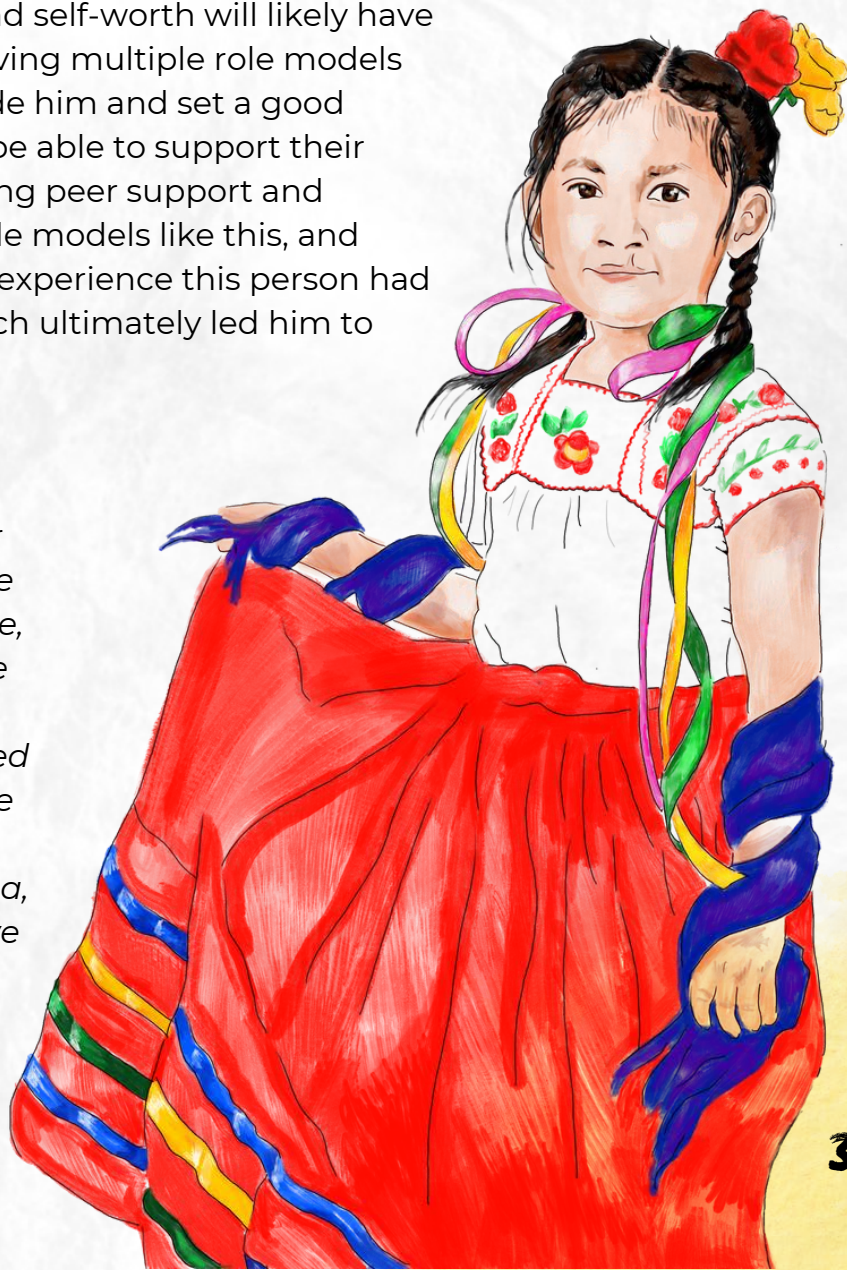
*"My father, my grandfather and my brothers also live with cleft. I want to tell everyone to stop discriminating against people because of their scar. Physical conditions do not define a person, it is really what you have in your heart that should matter. I have experienced a lot of discrimination in my childhood, it has been very very difficult to get out of that hole and thank God, I got out. Now I have a very beautiful family, a family that loves me for who I am. I want to keep working hard so that people who see me will recognize me because my good heart and not my scar, and for all the love that I give to all those people that cross my path, it can be a greeting, a hug to anyone who needs it, a good morning, a good afternoon. That kindness is what should really exist in the streets, and not to pointing out at people because of a scar. That's been enough."*

He went on:

*"I won't hide it; I haven't hidden it, and I won't hide it. I am like this, and this is how I will continue to be, and it's who I am."*

This individual came from several generations of men with Clefts and was a father to a young boy with a Cleft. His levels of confidence, self-assurance and self-worth will likely have been positively impacted by having multiple role models with shared experiences to guide him and set a good example. Organisations would be able to support their patients immensely by facilitating peer support and mentorship through positive role models like this, and thereby emulating the positive experience this person had of being surrounded by FD which ultimately led him to embrace and take pride in it.

Both organisations and individuals want to bring about change together with the wider global FD community, *"We have information, we have the people, we don't have the funds, but we can contribute a lot regarding everything that has been worked on here because, in addition, we work with all of Latin America, with Spain as well, with Panama, with Costa Rica, I mentioned, we have... Costa Rica, Panama, Argentina, Ecuador, Paraguay, Colombia, Guatemala, Mexico, Spain."* - Charity leader





## 6. Aligning with disability movements in Mexico would be worthwhile, but ableism and a sense of distancing FD from disability could get in the way of progress

The CRPD, national law and models of disability in Mexico:

Mexico has ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which is effectively a pledge to ensure legal policies and protections within Mexico align with the ethos of the CRPD, a convention to protect and serve the disabled community.

The CRPD is based on the human rights model of disability, where people are disabled by the interaction between their impairment and socially-constructed barriers. These barriers can be many and varied in nature, including attitudinal barriers such as stereotypes, physical barriers such as inaccessible buildings, and structural barriers accessing health and social security systems. The human rights model puts the emphasis on society to dismantle these barriers, and provides a model of disability policy to inform this approach, as described by Lawson & Beckett (2020).

The definition of disability in law in Mexico is:

*“Any person who, due to congenital or acquired reasons, has one or more deficiencies of a physical, mental, intellectual or sensory nature, whether permanent or temporary and which, when interacting with the barriers imposed by the social environment, may prevent their full and effective inclusion, on equal terms with others” (Disability:IN, n.d., para. 1).”*

The reference to ‘social environment’ within this definition should theoretically give adequate protection to those with disfigurements who often face social barriers, (see Saunders, 2020a for further discussion of social barriers). The ‘temporary’ provision should also provide protection or support to those with FDs that can be treated, in that they could temporarily be considered a disability. This should make accessing expensive treatment that much easier. However, in reality, the numerous social barriers faced by the FD community are not afforded the same priority for protections or services as people with other types of disability, irrespective of whether or not the facial difference presents challenging medical realities.

The gaps between the theoretical policy approach to disability, and the practice of giving disability rights has been noted by the CRPD:

“While there was an acceptance of the human rights model of disability by the State party, there was a conflict between the new paradigm and antiquated notions of disability in the broader Mexican society” (The Committee on the Rights of Persons with Disabilities, 2022, para. 7).

And the conflict was apparent from speaking to people with FD in Mexico too. Despite the significant social barriers facing people with FD, the interviews revealed that disability status is not afforded to all persons in Mexico with disfigurements, even where a child with a cleft is dependent on medical intervention to eat, speak and, in some cases, hear. This can mean that they miss out on support programmes and much-needed financial assistance.

*“In Mexico, there are support programmes for people with disabilities, as far as we know and from information from patients and from various institutions, cleft lip and palate is not seen as a disability... I was just looking at the requirements they ask for a social welfare programme. They ask in their community, and they are told to bring a certificate saying that they are a patient but they still don't get approval and the help, because CLP is not really classified as a disability. Many times, families who get the help use this support to pay for travel, medication, and so on.”*

Medical treatment, surgery and related services (such as help with speech, nutrition, feeding and more) are not easily accessible for many people with FD. Some people are able to access these services through charities without cost but this is enabling the government to relinquish responsibility:

*“From [the organisations] point of view, CLP is not a disability, it should not necessarily fall into this classification because it doesn't prevent some other situation at a neurological level, at a motor level, and so on. No... it doesn't imply that the child with CLP can't and shouldn't have a normal life because it does not imply any other activity that affects his or her daily life. When we have a comprehensive treatment, that is my opinion.” - Charity/Social Worker*

*“Well here in Mexico there is a catalogue of syndromes and diseases that we call disability, but for me cleft lip and palate with a good treatment would not be a disability because having a cleft lip and palate does not imply any other anomaly in its functioning at a physical level but a small scar but it does not involve any other activity. But when we don't have a good treatment, a good follow-up surgery or something like that in terms of speech, that is where it does make a difference, in that part as we have handled it in [the organisation], it is a disability caused because there is no follow-up as such.” - Charity worker*

‘Follow-up’ was an issue we heard of many times throughout the interviews; many patients, particularly those living in remote areas which were far from hospitals, would often fail to attend follow up appointments after a first surgery for a cleft lip and or palate. This increases the likelihood of challenges with feeding or speaking, leading to an increased risk of further stigmatisation.

And where medical treatment is available, patients with FD do not always feel listened to or understood. Some of those interviewed felt pressure to seek surgeries that go beyond the functional into the aesthetic. One participant highlighted the impact of this pressure on lived experience:

*"In the end, so many surgeries create trauma, and you don't have the need to go through so many surgeries, obviously not functional, but more and more and more create the trauma and there's no need to do anything."* Mother of child with Treacher Collins Syndrome

This suggests that, in a stark contrast to the human rights model of disability, the person living with a disfigurement is expected to seek treatment in order to assimilate what's considered a 'normal' face, to fit in, seeking symmetry, minimal scarring or laser treatment to reduce visibility of visible difference (Swift & Bogart 2021).

The approach from the medical community to families finding out their child has a disfigurement or disability also sometimes appears to be problematic:

*"If you don't want this baby, you can abort it," he told me. I said, 'but it's a baby,' 'but there are people who don't want these babies, because it's a burden for you, you're young, you can have another baby if you want.'" - Mother*

A disfigurement doesn't have to have an impact on someone's ability to 'fit in', or to find fulfilling work, or to seek a high level of education and achievement. It is the disabling social barriers of FD which need to change to become more inclusive. As outlined in this report, the challenges presented by stigma alone are immense.

## **Intersectional reality:**

People with a FD and one or more additional disabilities sometimes face intersecting and potentially heightened stigma:

*He not only has a cleft palate but also Down syndrome, making it a bit more complicated globally because it's challenging to normalize things since we haven't normalized them yet. Children with these diagnoses are indeed different, but they have all the rights and benefits, as the brother mentioned. It's about raising them with love... I think we have determined what is considered 'normal' based on what has become common, and we don't see it in other spheres or diversities. In my family's case, with a lot of love, it's about building a secure self-esteem, a healthy self-esteem for himself, so that he feels safe. Also, making him a human being so that in the future, he is entirely self-aware and independent of us. That's from my part, thank you very much."* - Mother

There may be increased stigma attached to intellectual disabilities in Mexico, which is known to be associated with discrimination and stigma (Katz et al., 2016). This is further indicated here:

*“Many, as I'm going to say, many have their children born here with developmental problems or something else. In fact, they hide them. They hide them so that the dad and mom don't get discriminated or blamed... So, what I thought was, no, why would we hide the baby girl? Let's look for a solution, let's move forward, no matter if there's no money, but there, God, God will guide us, right?... When she was still unoperated, we would take her out on the street.”*

An area where disfigurement and disability clearly intersect beyond physical impairments or physical barriers is in the psychological impact and the potential associated mental health problems, which may again be more likely to be regarded as a disability. Many psychosocial challenges were revealed throughout the interviews.

*“Well, my mother told me that during my whole life, even if I don't remember it, when I was in kindergarten, she says that I used to look at my scar in the mirror a lot and I used to grab my face. I used to say that because I had the scar, I wasn't like other children. There was no difference between my siblings and me.”*  
- HCP with Cleft

Some HCPs and psychologists told us about the prevalence of eating disorders:

*“Food is another huge problem, because of bullying and all that, sometimes they stop eating, or they get depressed, or I don't know, and that's another one, isn't it? That's another factor that also plays a part in the patients not being able to make progress in their treatment, right?”* - Psychologist

*“Especially right now, this week, we have evaluations for surgeries of many teenagers who are going to have surgery next week, and about three or four of them had weight problems because they don't eat, they don't like to look at themselves in the mirror.”* - Social worker

## **Disability, Facial Difference and identity:**

Facial difference is not universally regarded as a disability either socially or legally, and thereby this community is often overlooked when it comes to programmes, services and laws that are constantly evolving to serve the disabled community.

Societal stigma tends to lead parents to reiterate that their child is 'normal', not disabled. Internalised stigma, or internalised ableism could be shaping a parental perspective to their child's disfigurement and an unwillingness to relate to disability. As one mother told us:

*"The dream most mothers of children with cleft lip and palate have is that people see them as a normal child. That they forget about the big taboos that he won't be able to speak, that he is a child who is not normal. We just want people to understand that it is an aesthetic problem, that it has a solution, that they are normal children, they play, they are rebellious, they fight... they need to forget that taboo, because children with cleft lip and palate will speak and will speak much better than we do."*

This tendency to disassociate 'physical impairments' was also evident in adults with FD:

*"Because I'm not the only one, I walk down the street and see many people like this. Let's not just talk about me with my scar on my lip; there are many disabilities that I think of when I feel sad about my son's condition. I thank God that it's only this. There are many who are paralyzed with many existing syndromes right now" - Adult with a Cleft*



This accords with research elsewhere in the world too, where people with FD have often been found to reject a disabled identity because disability is seen as something that affects function, not appearance (Saunders 2020b). Yet social exclusion and societal barriers are something to unify both those that do and don't identify as disabled.

The face equality movement has consistently consulted upon the best approach to aligning with disability rights movements, and the pros and cons of taking a one-size fits all approach to whether a disfigurement is a disability. The perceptions of the FD community themselves are very variable from person to person and place to place, the same goes for the medical and charitable communities devoted to working with this community. We at FEI often hear a reluctance from the FD community to identify as disabled under the conventional medical and legal model found in the UK and USA.

This is what led us to conduct an 18 month long strategic review which resulted in us setting the ultimate strategy to gather recognition of disfigurement as an independent equality and human rights issue, but this doesn't negate the fact that we advocate for disability laws worldwide to be inclusive of and give protection to persons with disfigurements on the grounds that people with disfigurements experience physical, medical, social and psychological challenges and barriers across global society (Face Equality International, 2022).

Aversion to disability could be an issue across the medical and charity sector both in Mexico and across the world, given the pervasive ableism that exists across Mexico and global society (International Disability Alliance, 2020). Understandably, those caring for the FD community do not want to subject individuals and families to stigmatising behaviours, and are therefore reluctant to assert that FD is a disability. Unfortunately, this might then inhibit access to disability rights, and of course, further perpetuates disability stigma.

"[The surgeons] have also taught us that it (a Cleft Lip/Palate) is not a disability, but it does cause disability. For example, speech, feeding, many things. In Mexico it is not generally seen as a disability, but it would be great if was also considered as one." - Social worker

A study in Nigeria concluded that HCPs should be equipped with tools to reduce stigma, discrimination and structural inequalities, whilst also encouraging that 'CLP should be considered a facial difference rather than a disability.' This creates a paradox; denying that people with FD are disabled may be helpful in reducing enacted stigma against them, but counterproductive at the same time in reducing available legal protection and economic empowerment opportunities for a facial difference alone.

There are adults and parents affected by FD in Mexico actively trying to challenge ableism, and those that understand the impact that HCP's attitudes have on them.

*"So, here, socially, personally, for example, as the cleft is not visible, people don't tend to say anything to me. I mean, no, generally, they don't know they have a cleft lip and palate. What they notice is the facial aspect, the Down syndrome, and sometimes they have told me that he looks like he has Down syndrome, right? But when I take him to appointments, on two or three occasions, they have said, 'Oh, this, your baby is not sick. It's not true. Initially, they did say something like that to me, but later they said, 'No, I mean, he's not sick. He has a disability, but he's not sick.' Sometimes their comments bothered me until I told them, 'No, I mean, people are not prepared, or society is not prepared, to be different. They shouldn't stigmatize or point fingers as if it's something bad, but simply acknowledge it as something different, which is entirely human.'"*

Comparatively, some parents of children with disfigurements that also affect hearing have a more proactive, positive approach to disability.

“We know the road is difficult; we know we have to go through different things, but I feel that it shouldn't be an impediment for us to achieve our objectives, in this case, with our children, that they can be happy and, yes, they are aware they have Treacher Collins, but it's not something that intimidates them and makes them not want to go out into this world.”

Ultimately, there would be benefits from aligning disability rights groups, community groups, and collectively supporting the needs of children and adults with disfigurements and disabilities. This could lead to reduction in stigma associated with ‘impairments’ of any kind, and would ultimately enable people with disfigurements to access vital services. Aversion to disability will ultimately inhibit the enjoyment of disability rights, and it will contribute to disability stigma.

## 4. CONCLUSION

There was an evident sense of progressiveness to Mexican culture at this point in time, with many successful human rights movements bringing about social change and inclusion of marginalised communities. Attitudes to mental health and the LGBTQ+ community for example were largely very inclusive, with many groups also expressing similarly positive attitudes towards disability.

As is the case across the world, such progressive movements often do not extend adequately to the facial difference community. But there is a great deal of infrastructure and existing humanitarian efforts and government support that should be extended to those with appearance affecting conditions. This is dependent on building critical mass, ensuring that further research is both conducted and taken on by policymakers, and equipping healthcare providers with the tools required to deliver holistic care both in and outside of a hospital setting.

The fact that many facial differences in Mexico are not regarded as a disability is problematic, given the high levels of poverty in the country which can heighten health challenges. This has legal, economic and social consequences in that support afforded to those with disability status would increase access to social and economic empowerment whilst preventing further poverty inequity and human rights challenges. Citizens would have the opportunity to contribute to a thriving economy, and Mexico's social inclusion efforts will continue to advance. Yet at present, there are several grassroots, underfunded organisations propping up the government's oversight of the FD community.

Patient and family groups, along with non-profits and healthcare providers are already unified in many ways towards social change, but their efforts are siloed and under-resourced, with a lack of centralised support. Reaching society to reduce stigma and human rights violations through education in schools and across the media is already going on, but could be bolstered to have a far greater impact, especially if resources are shared and organisations unite to have a bigger impact. Scarcity of resources could be pushing organisations further apart as opposed to bringing them together.

As was the case in the report into India and Nepal, interventions to effectively reduce stigma and the associated discrimination experienced by people with FDs are under researched and under funded. A universal set of resources could be developed across organisations in Mexico and across Latin America to reduce disfigurement stigma, and could do a world of good. Associated validation scales and measurement tools such as EMIC or Indigo are also a challenge, and the need to develop pre and post intervention measurements that are easily applied and adapted to different cultural contexts, across a variety of languages are essential to responsibly reducing stigma (The INDIGO Network, n.d.; Weiss, 1997).

There are existing educational tools for schools, HCPs and for wider society, but many have not been developed in co-creation with the community or with support from the wider sector, and they could actually increase stigma as opposed to eradicate it, especially if focused too heavily on disassociating from disability.

Intersectional approaches to reducing stigma, shoulder to shoulder with the disabled community would be very successful in Mexico given adequate funding and support from the government. A commitment to abolishing the human rights violations still experienced by the FD community will take a unified approach from wider society too, from healthcare, schools, businesses to online communities and media channels. Such a commitment is required by human rights defenders to prevent issues of child abandonment, infanticide, being hidden away or denied an education.

## 5. LIMITATIONS

All interviewees had received medical treatment or charitable services of some kind, and so interviews were arranged through charities or hospitals. This means that we weren't hearing from the most underrepresented members of the FD community.

Interviews with people with lived experience were only conducted with individuals and parents with congenital craniofacial conditions. Aside from that we spoke with charity, social and healthcare workers who had worked with people with wider FDs such as burns and skin conditions.



Given this project was funded and supported by Smile Train, the majority of participants had CLPs. The surgical services available to infants born with Clefts is well established across the globe thanks to organisations like Smile Train whereas access for the wider FD community is likely harder to come by. Reaching these communities is thereby incredibly important.

Mexico is an upper middle income country, and although we spoke with many people experiencing poverty, the hospitals and services in Mexico are largely well established and funded (Hamadeh et al., 2022). Given our project focuses on LMICs, we might have been able to gain a deeper understanding into stigma and human rights in a lower income environment.

Some interviews and focus groups were led by charity workers from the relevant geography, others were conducted by a Spanish social worker. If interviews were conducted by someone local and known to the participants, this may have led to more open and levelled conversations.

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## 6. INTERVIEW QUESTIONS

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.

(x) indicates where we would refer to the person's specific FD according to the appropriate/self identified language

1. What is your dream, if you could do anything in life what would you wish to do?
2. Is there anything/has anything ever stopped you or gotten in the way of you from fulfilling that dream?
3. 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?
4. Are people with (x) treated differently in your culture/community to those that don't have (x)?
5. How does this relate to your own experiences, and how you've been treated by others? Reference: school, community, media, government, healthcare as prompts
6. Are there any specific beliefs about (x) or the causes of (x) in your community?
7. 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?
8. 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?
9. Is there anything else you'd like to see from charities, government, HCPs, community that would make your life easier?

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