Destigmatising Facial Disfigurement

A shame-free guide for parents, carers and anyone looking to understand face equality

faceequalityinternational.org
@faceequalityint
This guide is aimed at parents and carers, recognising the power that they have to shape young minds to respect & understand difference.

Education starts at home, and we want to guide and encourage shame-free, open conversations that centre the real experiences of people who look different.

Although this guide is aimed at people who don’t have personal experience of disfigurement, it can be equally helpful for people who do.

You can find plenty of other tools and guidance materials for helping us to make face equality a reality on the Face Equality International website

"We can only hope that this helps to build greater human understanding of the wider experience of someone with a facial difference, and the need for global change when it comes to education to counteract ableism, lookism and prejudice towards facial difference."

KATHLEEN BOGART
How do we react when we meet someone with a facial difference?

• If you’re unsure of what to do or say, a smile or a friendly gesture can go a long way. All that anyone can really ask for is to be treated with kindness, respect, and in the same way that you would treat anyone else.

• Your child might say or ask something you think is rude or embarrassing. But try to acknowledge this rather than avoiding the interaction completely. If you feel you’ve made a mistake (we all do), then simply apologise, as it is unlikely you will offend someone if you make it clear that you want to get things right.

• Children’s inquisitiveness is natural. They often simply want to know that the person with a facial difference is okay. Try to encourage conversations that will establish common ground. For instance, ‘What’s your favourite movie?’, or ‘Are you having a good day?’. Shutting down questions would shut down an opportunity for your child to learn and to see people with facial differences as equals.

• Try not to start conversations with ‘what happened to you?’, or with other imposing questions simply about their appearance. Remember, that people with facial differences don’t owe you their story or an explanation of why they might look different to you. It is up to them whether they wish to share it, so take their lead and do not pry.
Believing that staring is rude might be well intentioned, but telling a child not to stare might mean that they simply don’t look or see someone at all, which can stifle the vital human interaction needed to form friendship. Try encouraging your child to truly see and embrace everyone. If you notice your child staring, encourage them to smile and say hello.

- Telling someone you don’t see their differences, their scars or their condition is not helpful. Everyone deserves to be seen, in their entirety. Pretending that you don’t see an aspect of someone’s identity indicates to them that you think this characteristic is negative.

- Never make assumptions around someone’s intelligence based upon their appearance, and make sure you’re directing conversation towards them if they are with another person.

"Let’s empower kids to be part of the solution, to challenge injustice, to take leadership from Disabled, Queer, Trans, Black, Indigenous, and people of color, to fight for the basic human rights of each other.

Belonging is one of those rights."

SORA IRIYE

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How do I talk to my child about facial difference?

- Curiosity shouldn’t be shut down. In order to normalise facial difference, open, constructive, shame-free conversations need to be had.

- When it comes to language, ‘facial difference’ is most widely accepted, with ‘disfigurement’ being the more medical and legal term which is enshrined in the UK Equality Act 2010. Avoid adding unnecessary negative adjectives or language like ‘awfully’ and ‘horribly’, which would indicate to a child that facial difference is a bad thing.

How do I encourage positive attitudes and behaviours?

- There are a lot of unhelpful narratives in the public domain which influence our biases. Many of which represent someone as villainous, or an object of pity. Even inspiring stories prevent normalisation. Try to seek out and understand the narratives that normalise difference, and are told by people with direct personal experience.

- People with facial differences often have their photos taken without their consent, or have their photos downloaded from their social media accounts and misused via memes and other derogatory content. This is a form of abuse akin to trolling, and often leads to abuse offline too.
• Representation and visibility are important for enabling someone with a facial difference to truly see themselves reflected in the books and media they consume. And exposing all young people to difference in a way that can normalise and destigmatise can also greatly improve the lives of people who look different. Increasing positive perceptions will reduce negative behaviours.

• Shaping young minds to appreciate appearance diversity can have a profound effect on society. We can help future generations to respect difference so that everyone is valued, treated equally, and has equitable access to education, employment and opportunity, regardless of facial appearance.

Face Equality International is the first and only alliance of organisations working globally to improve the life chances of people with facial differences. Made up of 35 NGOs, we are united by a shared mission to campaign for the fair and equal treatment of all, irrespective of facial appearance.