



Disfigurement in the UK

May 2017

About disfigurement

Changing Faces uses the word 'disfigurement' as it is a succinct general term, widely understood by the general public and enshrined in law in the Equality Act 2010, which gives legal protection to people with 'severe disfigurements'.

It's important to note that not everyone likes the word 'disfigurement', preferring instead words like 'visible difference' or 'unusual appearance'. Where possible, we encourage the cause of the disfigurement to be explained (eg 'Jane has a cleft lip'; 'Abdul sustained burns in a house fire') because this is an informative way of describing the person's condition.

We use the word 'disfigurement' throughout this report to mean any condition, mark or scar that affects the appearance of a person's face, hands or body. There are many causes of disfigurement some of which are present at birth such as birthmarks and cranio-facial conditions but most are acquired during life including scarring from accidents, skin conditions like psoriasis and acne, facial and skin cancer, and after a stroke or a Bell's palsy. Disfigurement can affect anyone from any social or demographic group and at any time in life.

Although modern medicine and surgery are increasingly sophisticated, the reality is that they can rarely remove a disfigurement completely. And because the face is at the centre of every human being's self-image and the social canvas on which they portray and share their personality and signal their moods and intentions, facial disfigurement can greatly affect a person's self-worth and how others perceive and behave towards them. Disfigurements to other parts of the body can also affect self-image and how others react.

At least 1.3 million children, young people and adults in the UK are estimated to have significant disfigurements, including 569,000 with facial disfigurements; one in 111 in the population. They all have to live with a face or body that attracts intrusive attention and the stigma our culture associates with disfigurement. They report feeling self-conscious, isolated and friendless, facing teasing, ridicule and staring in public, low expectations in school, problems getting work, and stereotyping in the media because of the way they look.

Changing Faces publishes guidance on the correct language to use when discussing disfigurement. Please visit www.changingfaces.org.uk/mediaguidelines

Foreword:

The Rt Hon Dame Margaret Hodge DBE



I am delighted to have been asked to write the Foreword for this very important report because I have kept a watching eye on the experiences of people with disfigurements ever since the Disability Discrimination Act 1995 first addressed the issue. Changing Faces was responsible for ensuring that they were covered by that Act and when I was Minister for Disabled People in the early 2000s, I was made very aware of some of the challenges they faced.

But this Report tells it more starkly than I had appreciated – undoubtedly justifying the legal protection now existing under the Equality Act 2010 but suggesting that it is probably insufficient and inadequate.

What you will read is that the lives of people with all sorts of disfigurements to their face and body are disadvantaged by attitudes and behaviours towards them that belittle, undermine and understandably distress them. And the perpetrators are no one specific group but include all of us – everyone in our appearance-obsessed culture needs to take action to rectify this – and many of our institutions do too.

This Report tells me that people with disfigurements have been left behind in Britain's progress towards being a fair and equal society. I commend it to you – and hope you will commit to help make the changes so very obviously needed.

Margaret Hodge
May 2017



Executive Summary

This report *Disfigurement in the UK* is an urgent call to action to protect people who have a disfigurement from discrimination and unfairness, and to better their life chances and opportunities, and remove barriers to success and fulfillment.

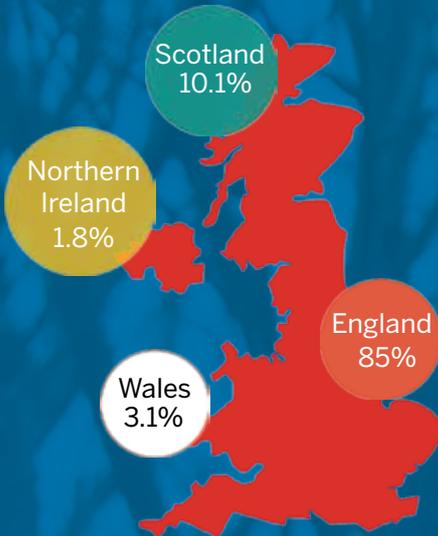
1. Four-fifths of people with a disfigurement who responded to our survey have experienced comments or unpleasantness from a stranger; almost half have experienced it from a shop assistant
2. Half of all school children who have a disfigurement experience discrimination because of it, and yet the ability of school leadership teams to deal with it appears limited
3. Four in ten people with a disfigurement say their appearance affected how well they did at school, and half said it impacted on their aspiration to stay in education post-16
4. Four-fifths have avoided applying for a job because they thought their appearance would hinder them at interview, or because new colleagues would make them uncomfortable
5. More than half think their condition hindered their career in some way, and 17% had left a job – or felt forced to leave – because of reactions to their appearance
6. 77% experienced an NHS employee making an assumption about them based on their appearance, and 67% had experienced an NHS employee making an assumption about their emotional health
7. Despite long-established links between disfigurement and emotional and psychological well-being, 75% of respondents reported being denied medical or surgical treatment for their condition on the basis that it was ‘cosmetic’ or unnecessary in some way
8. Almost half have felt vulnerable on public transport
9. Almost everyone has seen a meme or other social media post mocking disfigurement; none have ever had a complaint to a social media website upheld
10. Nine out of ten people who use dating websites have had uninvited, unpleasant remarks about their appearance from other users

Disfigurement in the UK speaks to a vastly unequal playing field in almost every aspect of life, leading people who have a disfigurement to have lower aspirations and expectations, and where they have resigned themselves to the inevitability of abuse and injustice. **This must stop. This report is a call to action for everyone who stands for equality and social justice.**

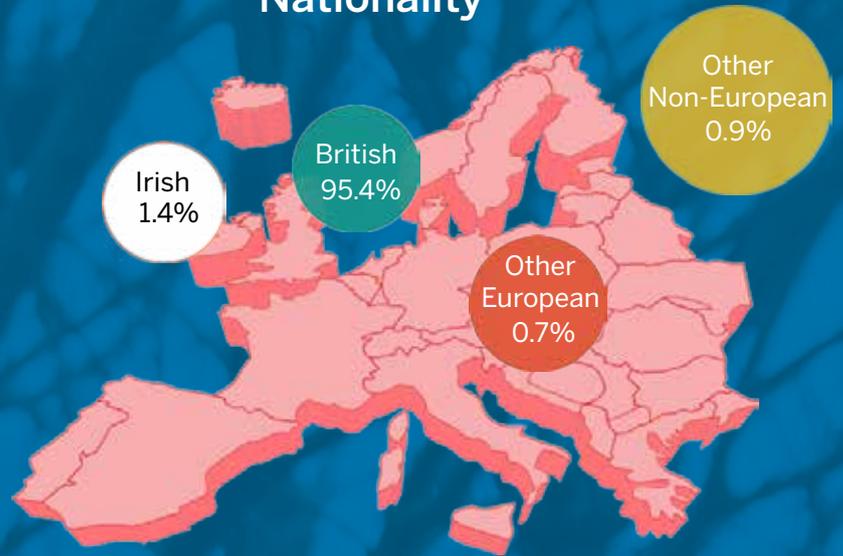
Methodology

Disfigurement in the UK is based on original research by Changing Faces. Between November 2016 and February 2017, a total of 806 validated respondents (confirmed as living in the UK and having a disfigurement) completed a survey on the Survey Monkey platform comprising of a maximum of 215 questions.

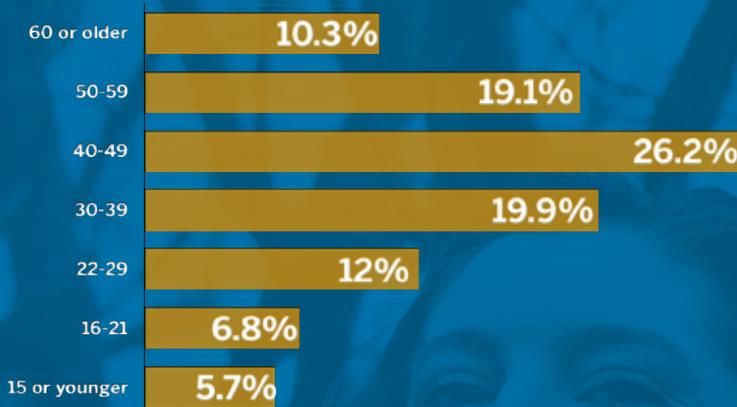
Country



Nationality



Age

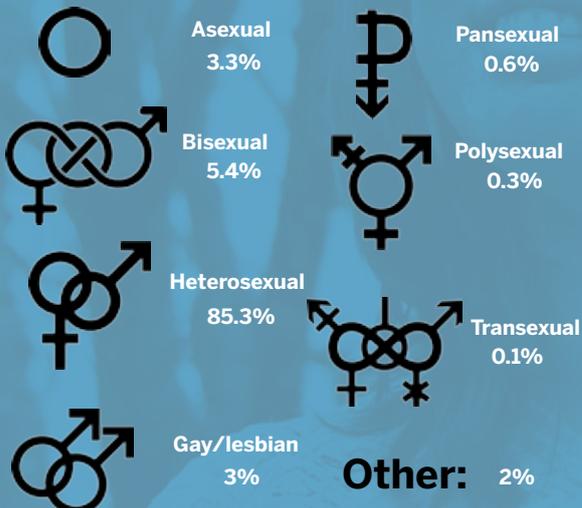


Gender

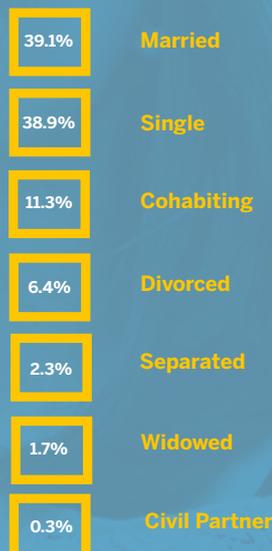
Male = 19.3% Transgender = 0.7%
 Female = 79.8% Intersex = 0.1%



Sexuality



Marital status



Religion

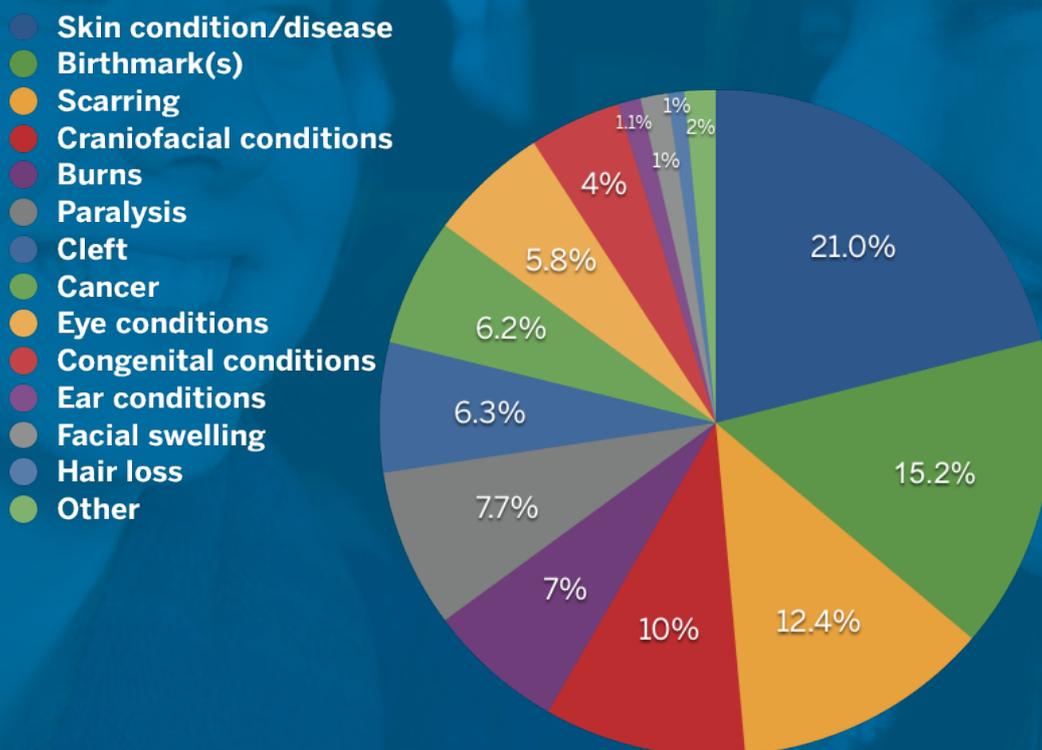


No religion	42.9%	Jewish	1%
Atheist	6.4%	Muslim	1.1%
Buddhist	0.9%	Sikh	0.4%
Christian	43.9%	Pagan/Wiccan	0.7%
Hindu	0.3%	Other	1.4%
Humanist	1%		

Methodology

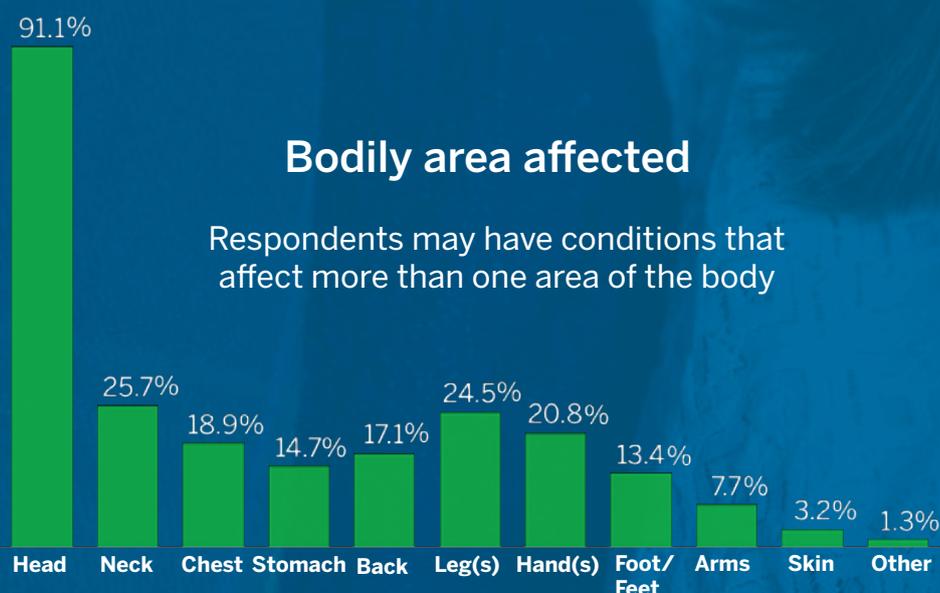
Participants were recruited through posts and advertisements on Facebook, Twitter, Instagram and LinkedIn, marketing emails from Changing Faces to its supporters including professional associations (e.g. of plastic surgeons) and from other support groups to their clients and supporters, and through the Changing Faces website. Whilst not a nationally representative sample, nor a representative sample of clients seeking help from the Changing Faces support service, it is a very significant and large survey of the real experiences of more than 800 people living with a disfigurement in the UK today.

Conditions causing disfigurement



Bodily area affected

Respondents may have conditions that affect more than one area of the body



The data was analysed by a professional in-house team at Changing Faces, including individuals with a background in public policy, research and analysis, and communications, a number of whom have relevant postgraduate qualifications. Not all results are included in this report, and some may form the basis of future reports or publications.



Introduction

For 25 years, Changing Faces has led efforts to improve the lives of people who have a disfigurement to their face or body. Throughout this time, the charity has collected thousands of case studies and personal histories that have powerfully demonstrated the prejudice and injustice faced by people with a disfigurement every day.

Those stories have provided the basis for campaigning, lobbying, and calls for change. This report provides significant contemporary data to add to the weight of these personal stories.

Disfigurement in the UK tells a depressing story but one that must be told. It highlights the way in which British society – which many would argue is *more* equal and *more* fair than ever before – needs to urgently address the way in which it treats people who look different, for whom there is extreme inequality and unfairness. It shows that disfigurement has been left behind in the equality stakes.

These findings are supported by an Implicit Attitudes Test¹ conducted for Changing Faces by COG Research in March 2017, which found that 67% of adults in the UK attach less positive attributes and characteristics to people who have a disfigurement. Whilst this shows a drop from 90% in 2008, it suggests that improvement is slow; disfigurement prejudice is still far higher than prejudice based on ethnicity or gender.

There are three recurring themes throughout *Disfigurement in the UK*:

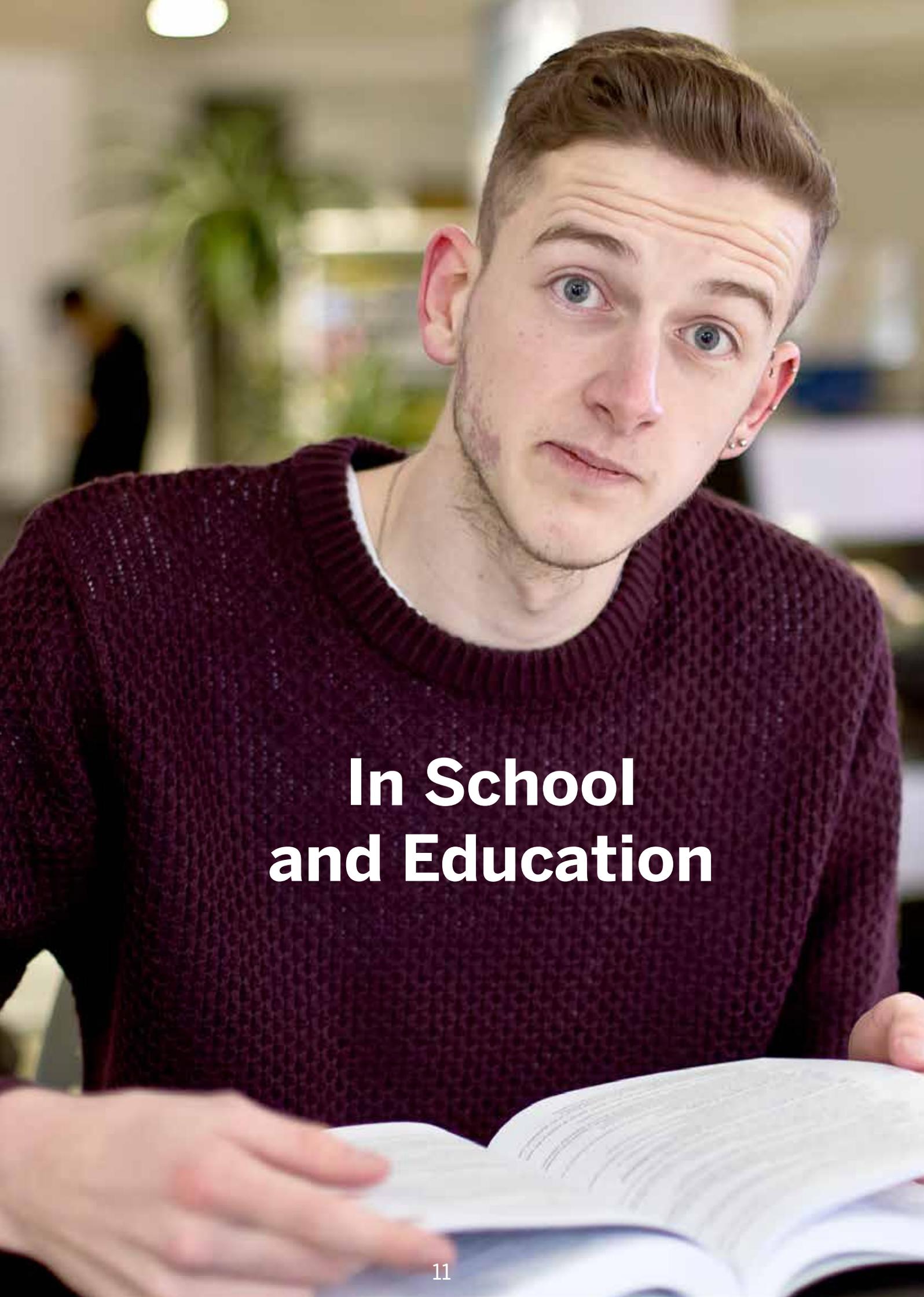
1. having a disfigurement can often lead to a lack of aspiration in education, in work, and in personal relationships, often confirmed by teachers, employers and others who have lower expectations of people
2. this lack of aspiration and opportunity can lead to a resignation that this is how things will always be, and consequently unfairness and discrimination go unchallenged
3. authorities who should stand up to prejudice are failing to do so effectively even when they are alerted to it.

Disfigurement in the UK speaks to a nation that needs to change. Not to any particular sector or agency or company, but to the wider society where it remains at best tolerated and at worst accepted that people who look different should be treated unfairly or unequally. To correct these injustices will take commitment and action at the highest level of government, but also requires action from every one of us in British society to recognise how we are all bystanders to this inequality, and to commit to ending it.

As the Face Equality campaign moves towards its second decade, *Disfigurement in the UK* shows powerfully why we must now turn the campaign into a movement. An unequal society negatively affects everyone and if we do not do so or do not succeed, people who have a disfigurement are prevented from reaching their full potential and will have a reduced quality of life as a result. The time for change is now.

Footnote

¹ Implicit Attitudes Test by COG Research for Changing Faces, March 2017

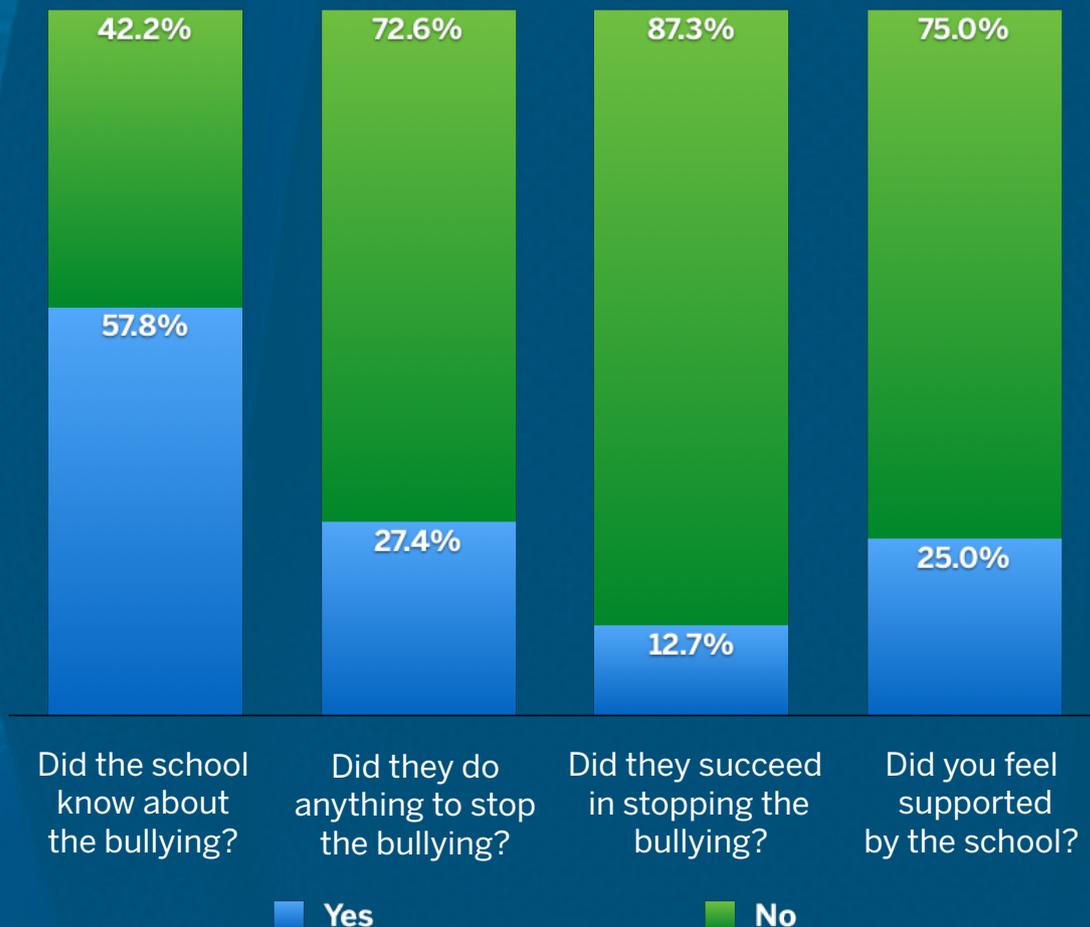
A young man with short brown hair and blue eyes is looking directly at the camera with a surprised expression. He is wearing a maroon, textured knit sweater. He is holding an open book in front of him, and his hands are visible on the pages. The background is a blurred indoor setting, possibly a library or a study area, with some greenery and a person in the distance.

In School and Education

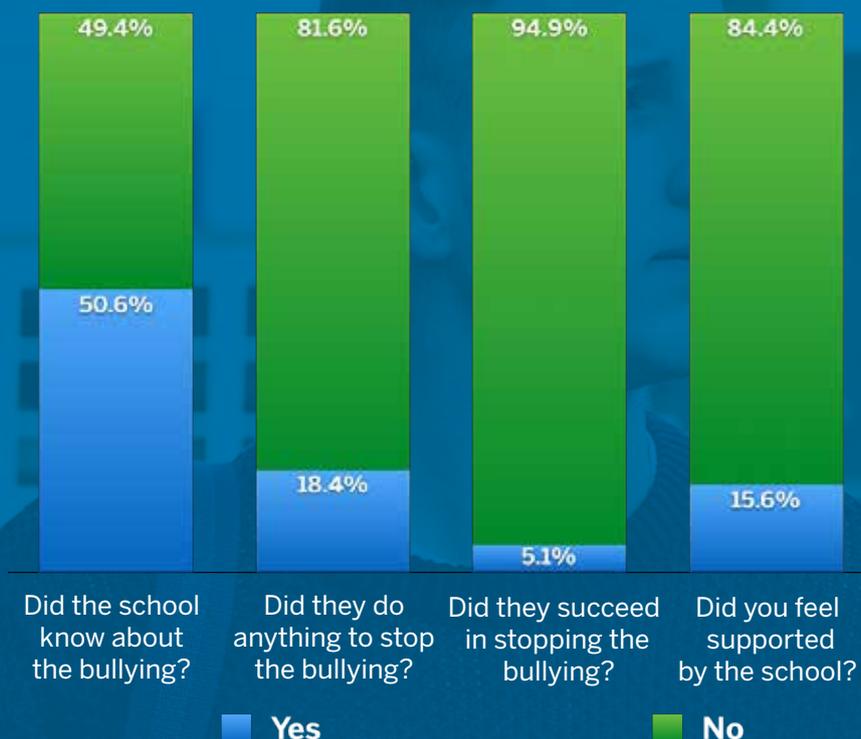
“My nickname at school was ‘scarface’. I couldn’t stop it, so I tried to ‘own’ it, I guess. I seemed to think it worked at the time, but I can’t deny it hasn’t affected me throughout my life.”

Every year, around 15,000 children in the UK are born with a disfigurement, and many more children acquire a disfigurement during their childhood. 86,000 are estimated to have a disfigurement, one in 124 in the under-16 school population. Whilst a ‘severe disfigurement’ is classed as a disability in the Equality Act 2010, and schools therefore have responsibilities under the Public Sector Equality Duty and other legislation, it is important to note that the presence of a disfiguring condition does not mean that the child has any learning difficulty or cognitive impairment nor, very often, any physical impairments either. The discrimination they face arises through other people’s attitudes and behaviours including teachers’ lower expectations because, for complex reasons, they find it hard to envisage a successful and happy future for a child with a disfigurement.

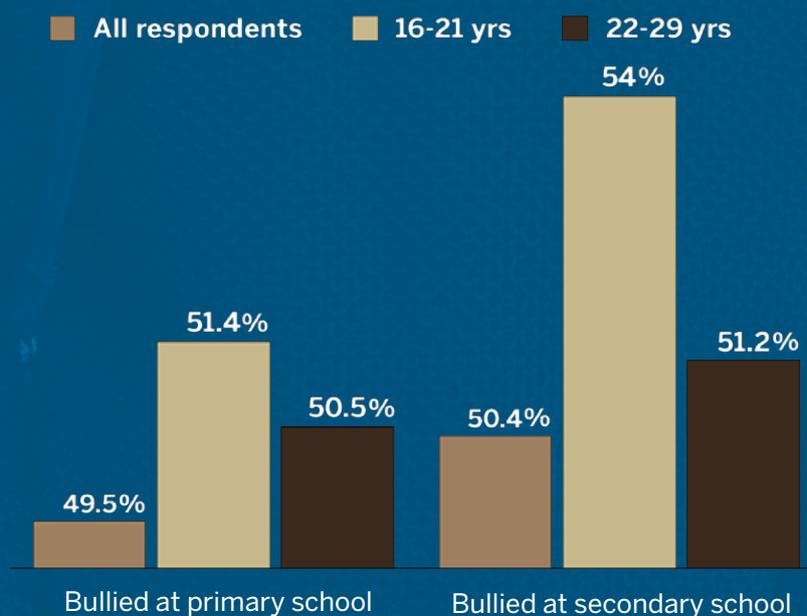
Two thirds (62.6%) of respondents to our survey were living with their disfigurement by the time they went to primary school, up to the age of eleven. Of those, almost half (49.5%) said that they experienced bullying that targeted their appearance. We asked respondents how effectively the school dealt with the bullying:



Slightly more respondents (66.2%) were living with a disfigurement by the time they reached secondary school, between the ages of eleven and sixteen, and slightly more than half (50.4%) experienced bullying that targeted their appearance. Of these 50.4%:



Respondents to our survey came from a wide spectrum of age ranges; further analysis of the answers to questions about school bullying do not reveal any significant improvement for younger respondents. (NB: The sample sizes in the 16-21 year old and 22-29 year old age groups are not big enough to be statistically significant, but are included here as an indicator.)



Based on the same samples, both age groups reported significantly more positive responses to how the school dealt with instances of bullying, and perceptions of support from the school were more than 25% for both age groups in both school categories. This suggests some progress from schools in recent years, possibly thanks to organisations such as the Anti Bullying Alliance and its member organisations of which Changing Faces is one.

This includes both Anti Bullying Week to which Changing Faces contributes each November, and also pro-inclusion endeavours, which are not straightforward, where Changing Faces focuses on increasing teachers' and Ofsted's expertise. However, when asked to rate schools' abilities to deal with bullying today on a scale of 1 to 10, with 1 being 'not at all confident' and 10 being 'very confident', the average score was just 3.8.

Thus, although there is some evidence of improvement from respondent cohorts who were most recently of school age, there is a significant perception amongst all respondents that a child with a disfigurement would be more likely to experience bullying today than when they were at school. 76.5% said they would expect bullying to be more likely, and 23.3% less likely. This may be because of the greatly increased media profile of bullying particularly relating to bullying on social media which has been reported as leading to self-harm and suicide.

Four out of ten (41.6%) of respondents said they felt their appearance affected how well they did at school, including in exams, and **43% said it had an impact on their ambition or aspiration in relation to college or university**. More than a fifth (22.3%) of respondents said that their appearance affected their decision on moving into further or higher education.

Whilst figures for primary and secondary school are similar, bullying appears to be much less commonplace in further and higher education, with 14.9% reporting that they experienced bullying that targeted their appearance. But whilst a marked improvement on the 1 in 2 figure in school, 1 in 7 is still alarmingly high.

Recommendations

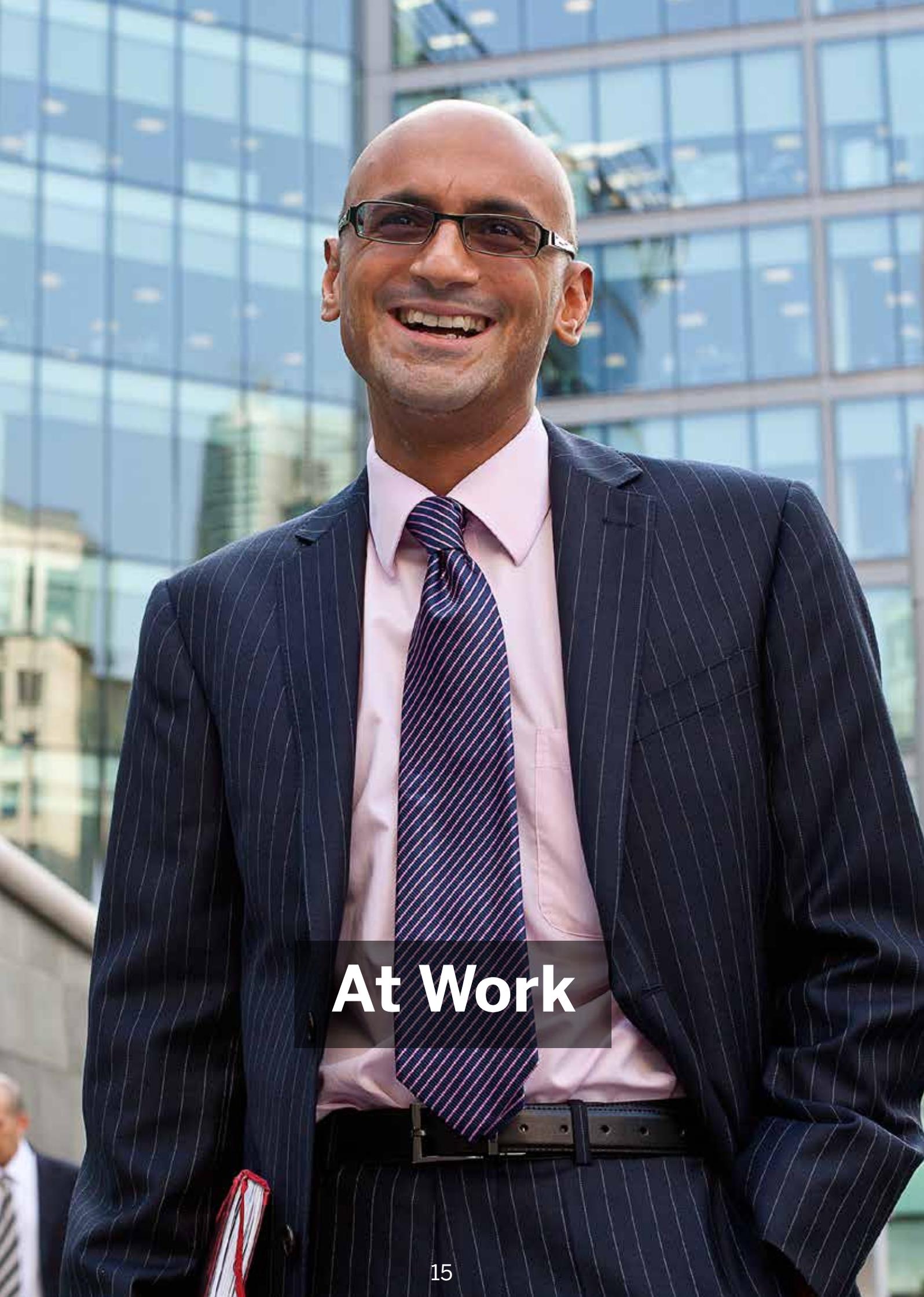
1a Schools, colleges and universities must ensure that disfigurement is included in their anti-bullying and equality policies, and have robust, measurable processes in place to respond effectively to allegations of bullying and mistreatment. They must comply with the Public Sector Equality Duty and Equality Act, which should lead to clear positive perceptions of people with disfigurements as part of both school and wider communities.

1b Teachers and all school staff should receive face equality training to build their knowledge, skills and confidence to ensure that all appearance prejudice is responded to and addressed, and discrimination is stamped out.

1c Face equality should be included in the school curriculum, and young people should be taught that people with disfigurements should be treated the same as everyone else. This should include teaching that people with disfigurements can live full, happy and fulfilled lives.

1d Teacher training providers must ensure that all initial teacher education includes content and guidance on bullying that targets appearance and creating inclusive educational settings which respect face equality.

1e Further and higher education agencies must work with schools to tackle the inequality of opportunity for people who have a disfigurement, and the lack of aspiration this often causes.



At Work

“Despite being a very high performer, I wasn’t able to take part in a photo shoot when the royal family visited because my image ‘didn’t fit’ with the company profile.”

“A colleague sent an email to all other colleagues and said [she] wouldn’t be in today as her facial boils have burst and taken her with them. He sent it from a shared work email so I saw it.”

“I was compared to another female colleague – a friend of mine – and we were called ‘the beauty and the beast.’”

Changing Faces has been working with employers to create knowledge and confidence around disfigurement for more than 20 years (since the Disability Discrimination Act 1995 first protected people with disfigurements after our successful lobbying). It has been the charity’s longest-running public campaign and certainly one of the most necessary, given the comments and stories received over the years.

One might hope that, with disfigurement included in the Equality Act 2010 and other changes to legislation, statutory regulations and guidance, the workplace would be a place where people who have a disfigurement can contribute without prejudice and harassment. Sadly the evidence suggests this is far from the case.

More than two-thirds (68.5%) of respondents to our survey are either employed (56.9%), self-employed (7.3%), or looking for work (4.3%), and 91.3% in total have been employed at some time in their lives.

Almost four-fifths (79.5%) have avoided applying for a job because of potential reactions at interview or from new colleagues, 40.8% think their appearance hindered or prevented them from getting a job, and **55.7% think that their condition affected their lifetime ambitions for their career. One in six (16.7%) of respondents have had their condition or appearance mentioned at a job interview** and, of these instances, in 82.6% of cases it was the interviewer who mentioned it.

“I was asked if my condition could get into the water supply.”

“The interviewer said, ‘You’ll have to wear thicker tights. No-one wants to look at that.’”

“I was told the interview was cancelled with immediate effect because of my appearance. If they’d known before they wouldn’t even have invited me for interview.”

Beyond the stage of the job interview, and once into a new role, things don't appear to get much better. **62.9% said that their appearance had been mentioned by work colleagues**, and 26.2% - more than a quarter – have experienced discrimination from colleagues at the same rank or level of employment. Almost a fifth (17.8%) report experiencing discrimination or unfairness from their manager.

“A co-worker regularly singled me out and made comments and jokes about my skin suggesting I had spent too much time in the sun or that I must enjoy my alcohol. It was distressing and I left because of it.”

This comment was not uncommon; even after being employed, some people feel that they have to leave because of the distress caused by people's comments. **17.1% of respondents said they had left a job voluntarily, or felt forced to leave a job, because of a reason in connection with their appearance.** Such instances are devastating for the individual concerned, but also for the employer who has failed to protect its employee from discrimination. Fewer than 1 in 20 (4.5%) respondents said that an employer had ever introduced training or other support to help other colleagues deal confidently with disfigurement.

“General assumption of stupidity, less important, not as good, my opinions, thoughts and feelings aren't respected. No direct comments about my appearance.”

“I feel like I am being treated as though I am stupid because I look different.”

“I think people take for granted what you are capable of doing and managing therefore not allowing you to progress in any chosen career. I think you have to work twice as hard so people can see you're worth something.”

Unpleasantness and discrimination does not have to be spoken or overt; being passed over for promotion, or assumptions being made about ability or intellectual capacity, can show someone feel that they are being treated unfairly. As the results of the Implicit Attitudes Test (see Introduction) show, people can hold on to bias without realising it, and this can affect even the most conscientious-minded employer and colleague.

“I spoke to my manager but was told ‘It's okay – we find it funny!’ and laughed.”

“I took early retirement [instead of complaining]. I was lucky to be in that position. Sometimes it’s better to walk away and live well.”

In almost all cases where respondents told us that they had complained about unfairness or discrimination, there was an overwhelming sense of helplessness – that it would be ‘their word against mine’, or ‘no point’ in raising a complaint. There is also a sense of resignation that such unpleasantness and discrimination is bound to take place, and so resistance becomes futile.

“I think I am about £15,000 a year lower than I could be.”

“Because I have not had the same promotion opportunities, I earn less than my peers.”

We saw earlier that more than half of respondents said they felt their condition had impacted on their career ambitions. It seems that the same can be said for salary, linked to the lack of career progression highlighted above. More than three-fifths of employed respondents (60.7%) earn at or below the national average of £26,500 per annum.

Recommendations

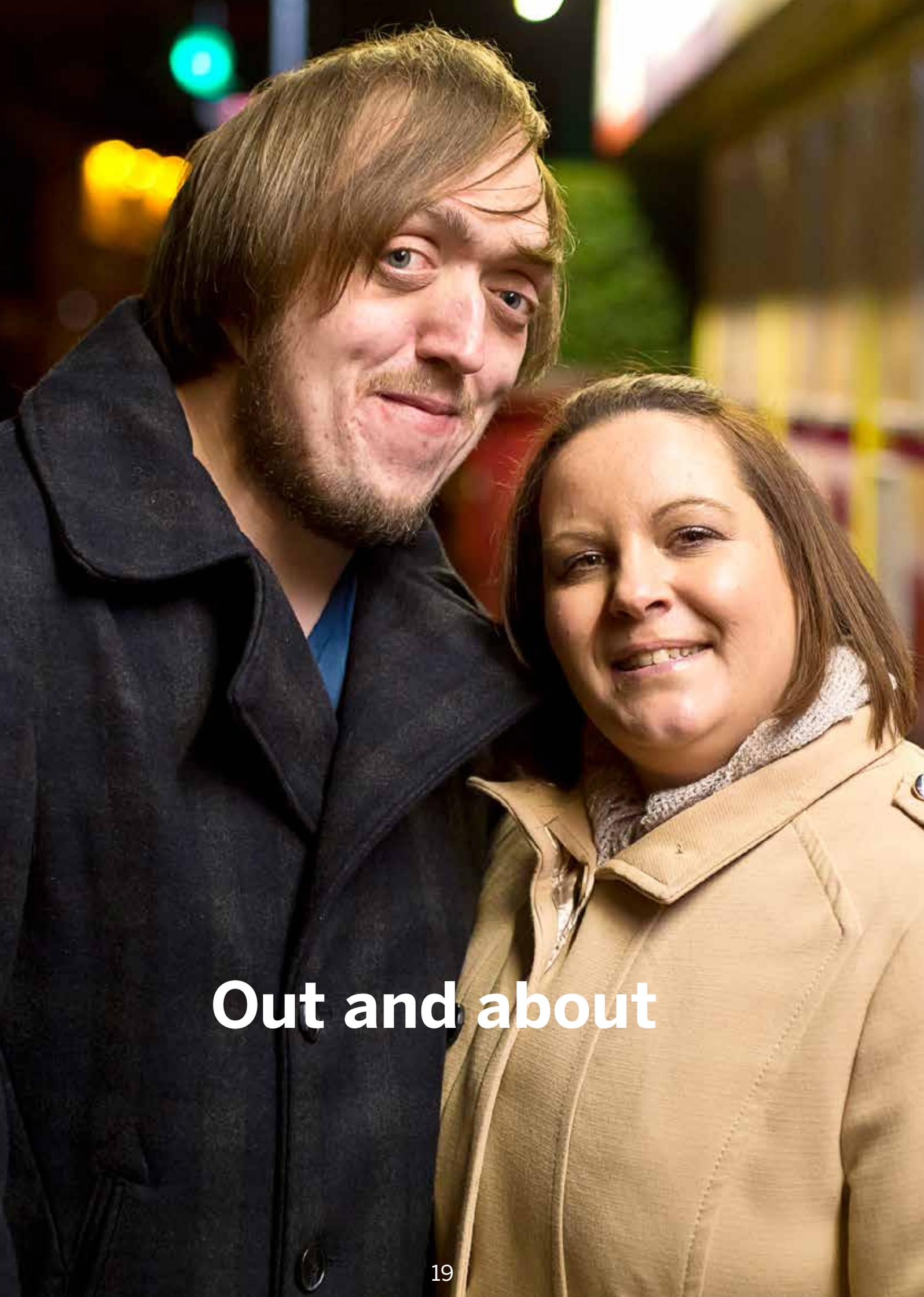
2a Trade and industry bodies must ensure that employers are aware of their legal obligations to ensure people with disfigurements are not treated unfairly or discriminated against in the workplace. This must include guidance on how to deal with the issue of disfigurement in the recruitment process.

2b Employers should include disfigurement in their equal opportunities monitoring forms so that they can measure equality of opportunity within their organisation, and work to ensure that their workforce is appropriately diverse. They must ensure their policies and practices are compliant with the Equality Act and Public Sector Equality Duty, where appropriate.

2c Employers should provide ‘disfigurement confidence’ training to ensure that their human resources function and all line managers feel informed, empowered and confident in dealing with applicants and colleagues who have or acquire a disfigurement, so that they don’t get overlooked for promotion and other opportunities.

2d Staff should receive face equality training to ensure that they do not treat colleagues or clients with appearance bias and discrimination.

2e Jobcentre, career services and recruitment and other employment agencies should ensure that their attitudes and biases are not influencing job seekers and candidates in their career aspirations.



Out and about

In most situations where we deal with other people, everyone's actions are governed by rules: in the workplace, in school, even online – though we will see failures in that area later in the report. But it seems that when people with disfigurements are out and about – in the street, on public transport, in a social setting, or shopping – normal rules of civilised society are ignored and people feel free to stare and gawp, to shout abuse and unpleasantness at them. **More than four-fifths (81.3%) of respondents have experienced staring, comments or unpleasantness from a stranger.**

Experiencing such unpleasantness which counts as harassment in law, can have a serious impact on someone's confidence in social situations. We asked respondents if they had ever decided not to visit a specific venue because of how people might react to their appearance. More than half (53.9%) had avoided a nightclub visit, 46.5% a pub, 41.3% a gym, 30.6% a café or restaurant, 28.1% a shop, and 20.7% had avoided a theatre trip.

Avoiding these situations is not always just because of the possibility of comments from other customers or members of the public. 28.1% of people have avoided going into a shop, but 45.8% of all respondents had experienced a comment or unpleasantness from a shop assistant.

Almost a quarter (24.5%) had such comments from a member of bar staff, 23.5% from nightclub or security staff, and 20% from staff in a restaurant. **More than a third (36.1%) have experienced unpleasant comments from people in parks and open spaces.**

Despite these relatively high incidences of harassment, rudeness, unpleasantness and intrusive behaviour, there is an unwillingness to report such incidents or to complain. Of all those respondents who reported having such an experience, only 14.1% complained – more than eight in ten did not.

“I have been threatened with a knife because of ‘my face.’”

“I always have to do a mini risk assessment before going out. I have to assess what sort of people might be there and who might comment on my appearance.”

“If I go to a restaurant I have to be able to position myself so I’m facing away from everyone.”

Approximately half of respondents to our survey had a disfigurement that they had acquired (such as a scar from burns or surgery, eczema or other skin condition) rather than one with which they were born. Of those who had acquired their condition, mark or scar since childhood, we asked them if they visited specific types of venue more, the same, or less than before they acquired their disfigurement. A quarter (25.7%) visit pubs much less often, 26% the gym, and 34.9% visit nightclubs much less. The average score (from 5) across all types of venue was 2.8, meaning most people are taking part in such activities less often since acquiring their disfigurement.

“On one occasion I had a guy on the tube who said my parents must have done something wrong [for me to look like I do] and that I should pray to the Lord for forgiveness – I was just back at work after losing my dad. I moved down the carriage but he followed me. If I had not been getting off I would have pulled the alarm cord because he was harassing me. Everyone else ignored the situation.”

*“I was on a train going to work, while heavily pregnant. There were some builders who were calling me a tramp, and said ‘Oh my god, who’d f**k that?’*

Despite work by Changing Faces with Transport for London, South West Trains and other providers, public transport remains intimidating for people with disfigurements, especially those who cannot drive due to their condition (which accounted for 1 in 12 of respondents to our survey). **Almost half (49%) said they have felt vulnerable on public transport.** Some respondents told us that when they reported incidents to drivers or other public transport employees, they were brushed off or advised just to wait for the next service.

A third of respondents (32.3%) said that their condition or appearance had influenced a decision on where to go on holiday. Whilst a large majority (86.4%) always go on holiday with family or friends, many said that they avoided certain countries or situations.

“I am hesitant at visiting countries where a cleft is seen as evil, a mark of the devil, or associated with the supernatural.”

“Australia was once a country where I felt very comfortable but on a recent visit I was told by friends and strangers that my appearance ‘did not go down well’ and I should try to ‘get some more work done.’ I was also handed cards bearing the names of plastic surgeons.”

Responses to our survey show that discrimination is not an issue just for the UK. One in eight respondents said they had experienced discrimination on holiday in the UK, and the same proportion had experienced it in Europe (14.8% and 14.1% respectively).

“When travelling to Canada, the airport authorities assumed my altered appearance was the result of heavy drug use and detained me until a full explanation had been given.”

“In clothes shops I have been asked not to try on clothes because of my skin condition.”

“In France I’ve been refused entry to bars when my friends were let in.”

“I was in Italy and this old lady started staring and calling me ugly, shouting ‘go and kill yourself.’”

Recommendations

3a Building on Changing Faces’ work with the British Beer & Pub Association, other industry and trade bodies must develop guidelines and training for staff to ensure they are confident in dealing with customers and visitors who have a disfigurement.

3b Operators of public transport franchises should run poster and advertising campaigns on face equality to encourage passengers not to stare, and to treat everyone with respect. Train guards and public transport staff must be given training to be able to deal with people with disfigurements, and give help when it is needed.

3c Police and local authorities need to do more to inform people that abusing someone with a disfigurement is a hate crime, including shouting names and other abuse in public places. This will also encourage people who have a disfigurement to feel more confident to report such incidents.

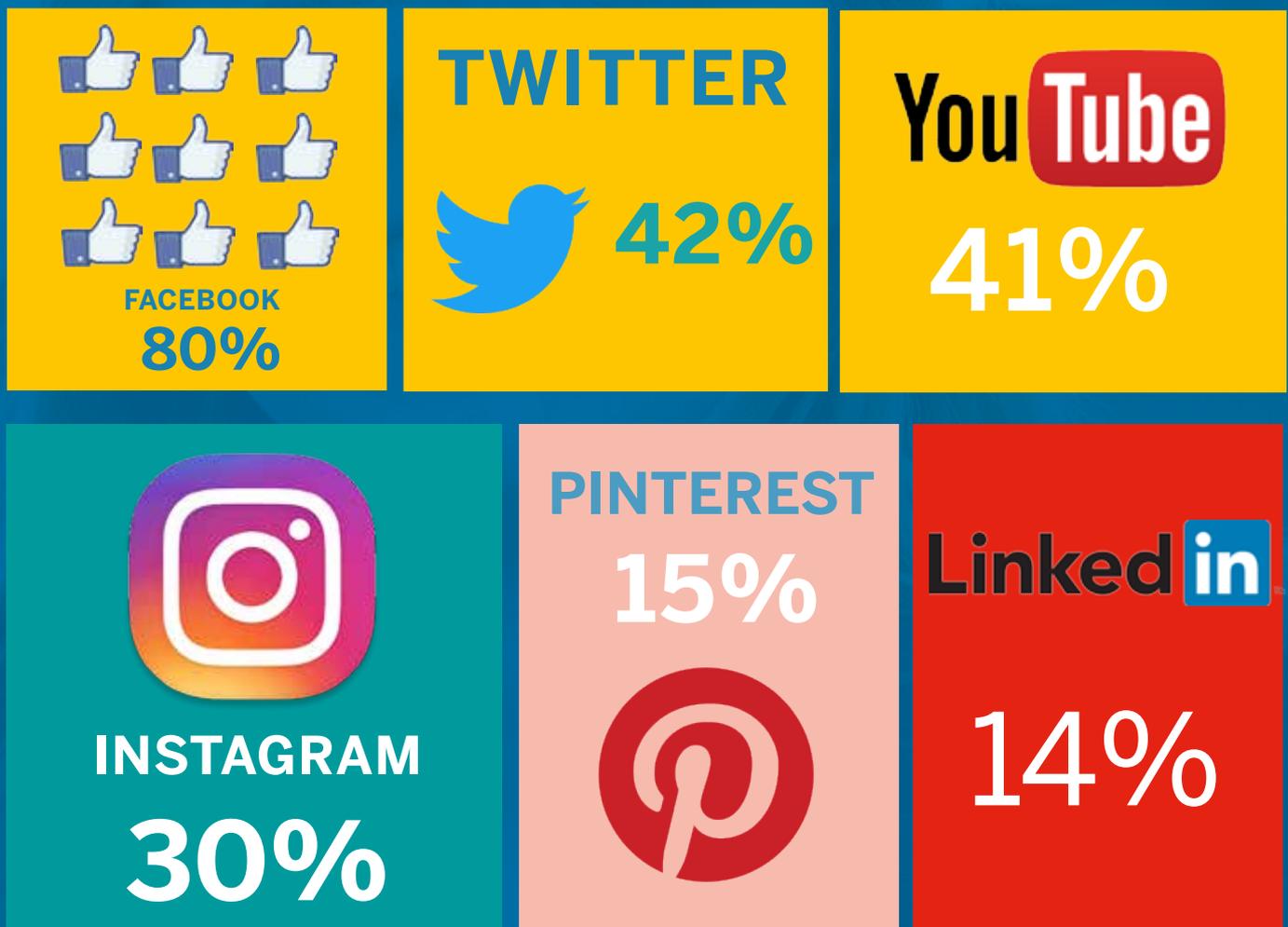


Social media

Social media is undoubtedly a force for good, and has revolutionised communications and friendship the world over. Changing Faces has been an enthusiastic adopter of social media, encouraging users and champions to use the various platforms to share their stories and amplify campaigns and personal stories.

But as the media are never afraid to report, and occasionally sensationalise, there are some who use social media to attack people targeting a range of personal attributes, including their appearance. Our survey revealed that people with a disfigurement experience shockingly high levels of abuse and 'trolling', and that there is very little faith in the ability or willingness of social media websites themselves to tackle the problem and provide help and support.

Social media channels regularly used by respondents



“Social media is 99% about image. I feel intimidated by it so although I use it I’m very careful with no posting pictures of myself.”

Almost all respondents to our survey – 96% of them – have seen a photo, meme or other content on social media that mocked someone’s appearance. We might take heart that only one in ten had been the target themselves, but that is still a disturbingly high figure and could account for why three in ten (29%) respondents said that their social media profile photo or avatar is not an image of their face.

“The whole world has spent 56 years telling me I am too ugly to live. I am unlikely to put my picture up anywhere now. Bitten too many times.”

“I was likened to a dead squirrel.”

“After appearing on a television programme about my condition, an individual contacted me via social media to express an opinion that I should not be allowed on tv.”

In January 2017, Changing Faces was alerted to a meme that was being shared on Facebook and Twitter, mocking a man from Glasgow who had an unusual appearance caused by a congenital condition. It had been shared thousands of times, and Changing Faces reported the post to both social media sites.

Within 24 hours, both sites said that the image didn’t breach their community guidelines or terms and conditions. Even the obvious breach of copyright – the image had been taken by the man’s brother – didn’t warrant its removal from either site.

It’s unsurprising, then, that respondents have little or no faith in social media websites’ ability or willingness to tackle ‘trolling’ on their platforms. Numerous respondents told us that their images had been used without their consent and in some cases had been turned into memes. In every case, the social media platforms failed to take any action.

There is recognition that social media can be a useful tool for keeping in touch with friends, creating online communities, and for empowering people to tell their stories and make their voices heard. But almost all the comments we received acknowledged the difficulties in ‘policing’ the sites and preventing those with negative intentions from causing harm.

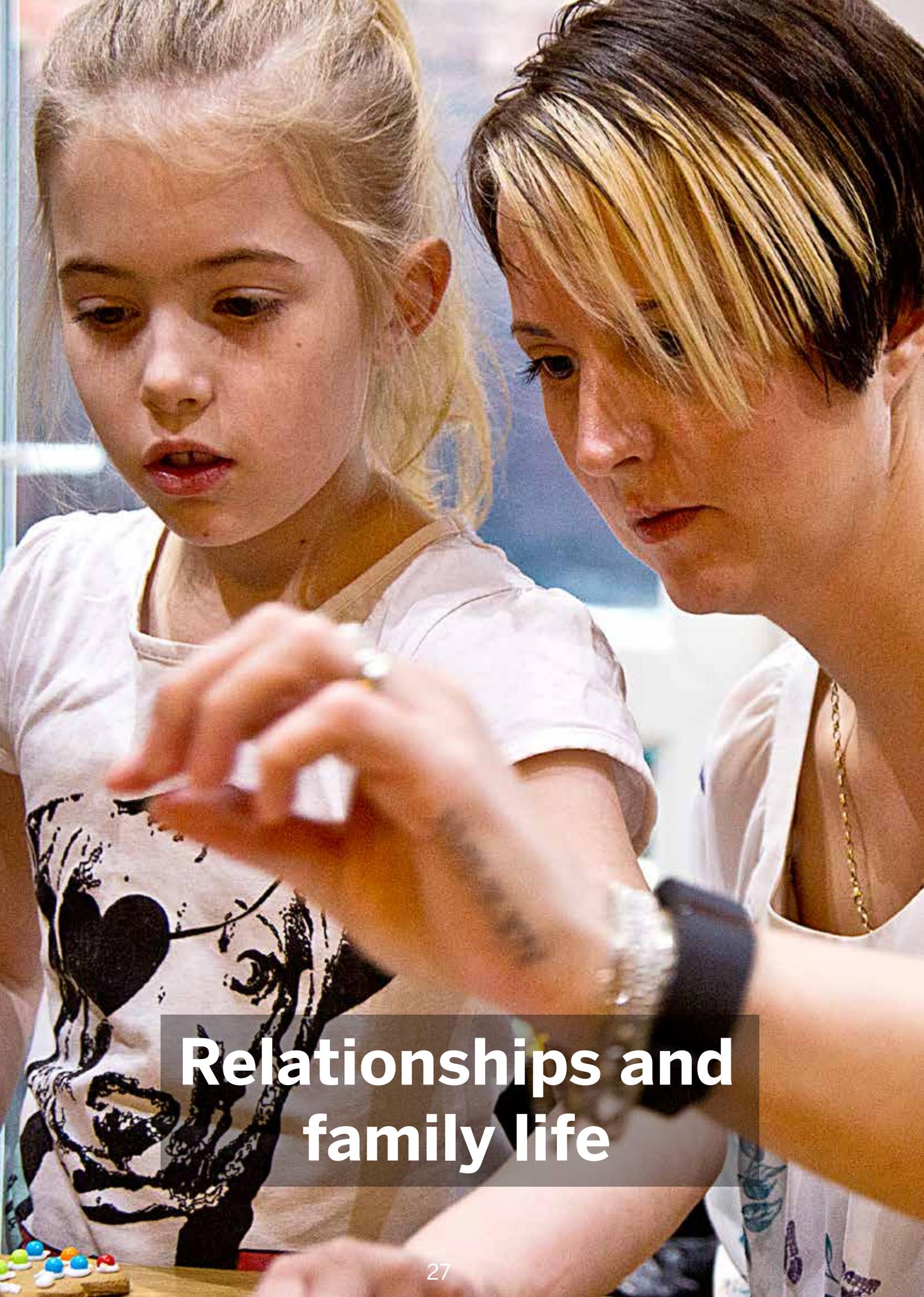
“[Social media] has opened up a lovely world of connecting with other people with disfigurements. But has also opened up the world for those who use it to abuse others anonymously. I love social media but I’m glad it wasn’t around when I was a teenager.”

“I think in most aspects [social media is] a positive thing to connect people, but I think memes can lead people to ridicule people with disfigurements very easily without them really considering what they’re doing or saying.”

“I think social media is a great outlet to raise awareness and show people how to remain positive when they are different. It can also encourage negative comments which is disheartening.”

Recommendations

- 4a** Social media platforms must revise their community guidelines and terms and conditions to ensure they take a zero-tolerance approach in tackling trolling and abuse that targets people with a disfigurement. They should organise face equality training for any staff who deal with user complaints.
- 4b** Social media platforms should take decisive action against individual users who repeatedly troll and abuse people with a disfigurement. This should include temporary or permanent exclusion from the platform.
- 4c** Building on recent efforts to tackle threats of sexual violence on social media, the Home Office and Ministry of Justice should ensure that agencies in the criminal justice system better protect people with disfigurements from people who abuse online.



Relationships and family life

“I don’t think I have been seen as boyfriend material by many girls over the years, or even one-night-stand material.”

It is all too easy to take for granted that most people will meet a life partner, ‘settle down’ and have children, and we often hear the phrase, ‘there’s someone out there for everyone’. Sadly, our research exposes the untruth and misconception in this and shows that dating, relationships and family life can be incredibly difficult – although not impossible – for some people who have a disfigurement.

Whilst 58% of respondents said they were in a relationship, of those who said they were not, only 16% said they were actively looking for a relationship whilst 30% said that they have never dated and have never considered dating. This could suggest a concerning lack of aspiration and a resignation to spending their lives alone. Six in ten (60%) respondents said that they had avoided dating or going on a date because of their appearance.

Almost a third (32%) of respondents said they had used a dating app or website. Of these, 44% said that their condition was visible in their profile photo, and **92% said they received negative comments or feedback about their appearance.**

Three in ten respondents (29%) said they had disclosed their condition beforehand to someone they were meeting for a date, but almost twice as many (57%) said they hadn’t. Whilst some had positive stories to tell, the overwhelming majority had negative experiences to share.

“They just commented that being one-eyed was a drawback.”

“He saw the scars, called me a psycho, and refused to speak to me again.”

“On one memorable Saturday night, a man I’d been talking to all evening pushed my hair back gently from my face and said in a quiet, thoughtful voice, ‘You know, you’d be so beautiful if you weren’t so ugly.’”

“I’ve been called ugly. I’ve been told that someone couldn’t handle being with someone who looks like me.”

Of course, many people with disfigurements successfully navigate the world of dating and find themselves in long-term relationships and marriage, and 30% of respondents are in long term relationships of more than six years, and 43% are married or in a civil partnership. But even a wedding – ‘the happiest day of your life’, we’re told – is not without its challenges.

“I was terrified about being judged in my wedding dress. I even got abuse from a stranger outside the church.”

“I was stood in the bridal shop, waiting to try on a dress. In an incredibly patronising voice, the shop assistant asked me if I was a bridesmaid. I told her that I was the bride. She said, ‘Oh, I didn’t realise that people like you got married.’”

“I didn’t want to get married because I can’t smile great.”

One respondent, who acquired her disfigurement when already married, said that if events had happened in reverse she would not have got married.

“I did not have the condition when I got married. I would not have been happy being photographed in my wedding photos if I did have it then.”

Most conditions that cause disfigurement do not affect fertility, and 92% of respondents said that their condition didn’t affect their ability to have children. However, of this 92%, more than three quarters (76%) said that their disfigurement had impacted on their decision to have children.

“I question having children because I wouldn’t want them to grow up like me.”

“I was told by my parents not to have children. I internalised this and thought I did not want children until it was too late to have them.”

“People have said that I shouldn’t have children as they’ll be upset by my scars.”

“I was told it would be best if I gave my son up so he wouldn’t be bullied.”

“[Someone said to me], ‘Imagine having to grow up with a father who looks like that.’”

Almost half (47%) of respondents have children and, of those, 13% have a child who has a disfigurement. Some reported comments from other parents, and of their children being bullied because of their parent’s appearance.

“Other parents avoided me because I was ‘disabled’ and their children weren’t allowed to come to tea so my children had fewer friends – bullied at secondary school for having a mum with a funny eye.”

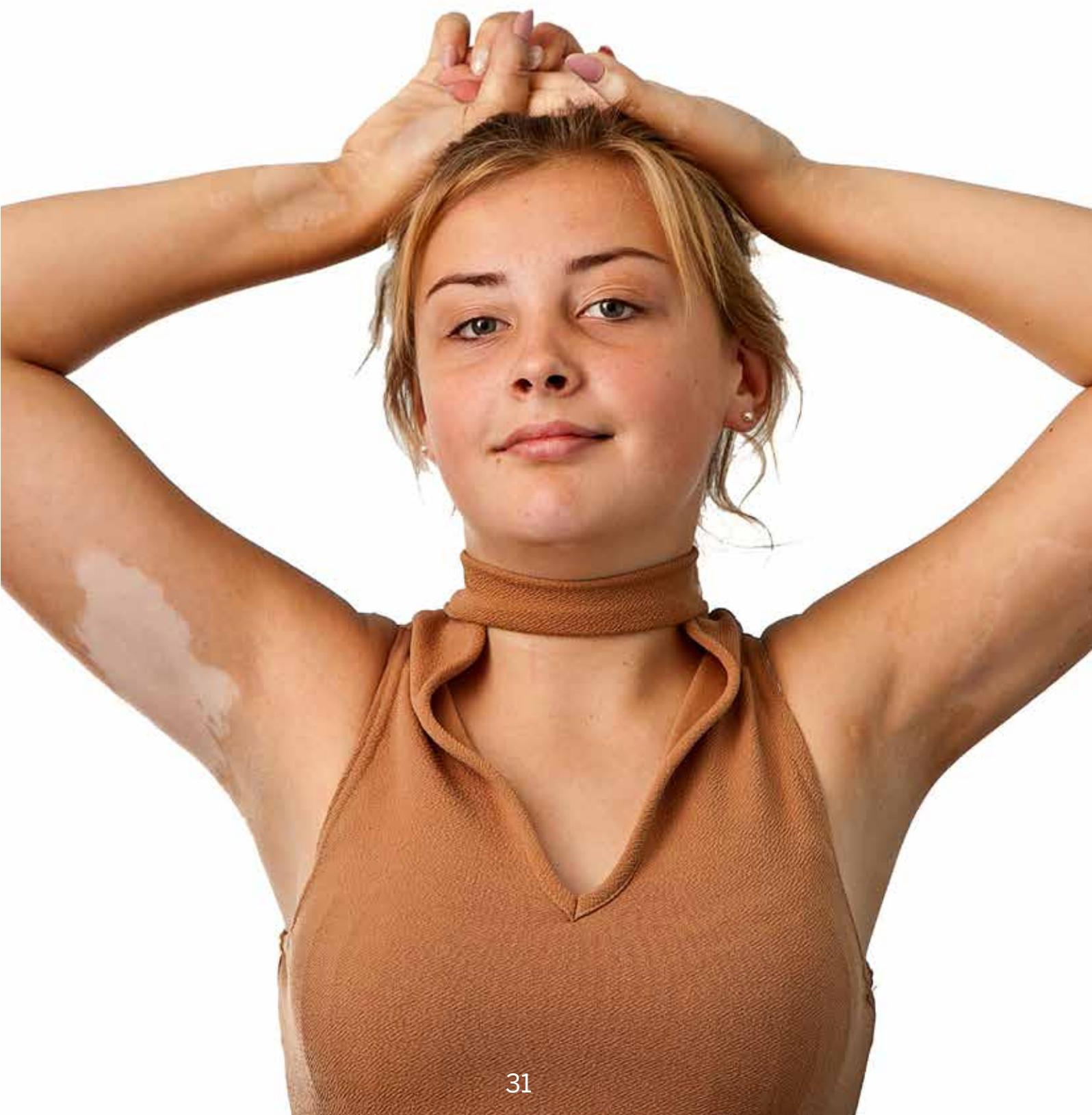
Recommendations

5a Dating apps and websites should use models in advertising campaigns who have an unusual appearance to help to ‘normalise’ disfigurement. They should also ensure appropriate resources are in place to quickly and effectively tackle instances of abuse on their platforms.

5b The wedding industry should develop guidelines and help to ensure that wedding service providers are disfigurement confident and do not discriminate, using work by the British Beer & Pub Association as an example.

5c Charities, fostering agencies and local authorities should include parents with a disfigurement in their campaigns, again to normalise disfigurement and show that people who look different can make excellent parents – like everyone else.

Health care



“One GP said that I had the cold sore virus all over even when it had been diagnosed as eczema. This was upsetting for me. Nobody has suggested counselling or help to stop scratching and I have been too embarrassed to ask, and I think it won’t be available. I have been told that I just have to not scratch but I have not been offered any support.”

Changing Faces has been concerned about the lack of psychosocial care for people with skin and other disfiguring conditions for many years. Through the ‘Look At Me’ campaign, two reports have highlighted what the quote above suggests: that there is a paucity of psychosocial care throughout the NHS.

The psychological impact of living with a disfigurement cannot be overestimated. As every section of this report shows, it can have a devastating impact on almost all aspects of a person’s life. We asked respondents on a scale of 1 to 10 how much impact they felt their condition had on their life, and whilst the average was 5.5 – in the middle of the range – 42% of respondents said it had a severe or very severe impact.

We also asked on a scale of 1 to 10 how confident respondents felt about living with their condition day to day. The average was 5.6, just above the middle of the scale.

Respondents’ perception of their own state of health was generally positive. On a 1 to 10 scale, the average rating was 6.6, with 31.5% with poor or very poor perceptions of health.

We asked respondents how well they felt their healthcare professionals recognised the psychosocial impact of their condition. Whilst the average was 4.8, it is of note that almost one fifth (19.8%) answered ‘not at all’ and almost two-fifths (38.9%) said their healthcare professionals had very little understanding.

Similarly, when asked about how well their healthcare professionals respond to their psychosocial needs, 22.8% said ‘not at all’ and 39.8% recorded a poor response. The average was 4.7.

These results are alarming, and suggest that there is an urgent need for further training and development within the NHS. Additionally, **77% of respondents had experienced an NHS employee making an assumption about them based on their appearance**, and 67% had experienced an NHS employee making an assumption about their emotional health.

Despite long-established links between disfigurement and emotional and psychological well-being, **75% of respondents reported being denied medical or surgical treatment for their condition on the basis that it was ‘cosmetic’** or unnecessary in some way. Unsurprisingly, 22% of respondents have resorted to paying for private medical treatment.

Many respondents reported frustrations with General Practitioners (GPs) who don't understand their condition or appeared unwilling to understand the psychological complexities. Given time pressures on GPs, and the broad range of the knowledge required for general practice, we recognise that they cannot be an expert on all conditions. But as the following quotes show, there is a need for greater understanding and empathy.

“Some doctors assume you’re dirty and have no idea about my illness.”

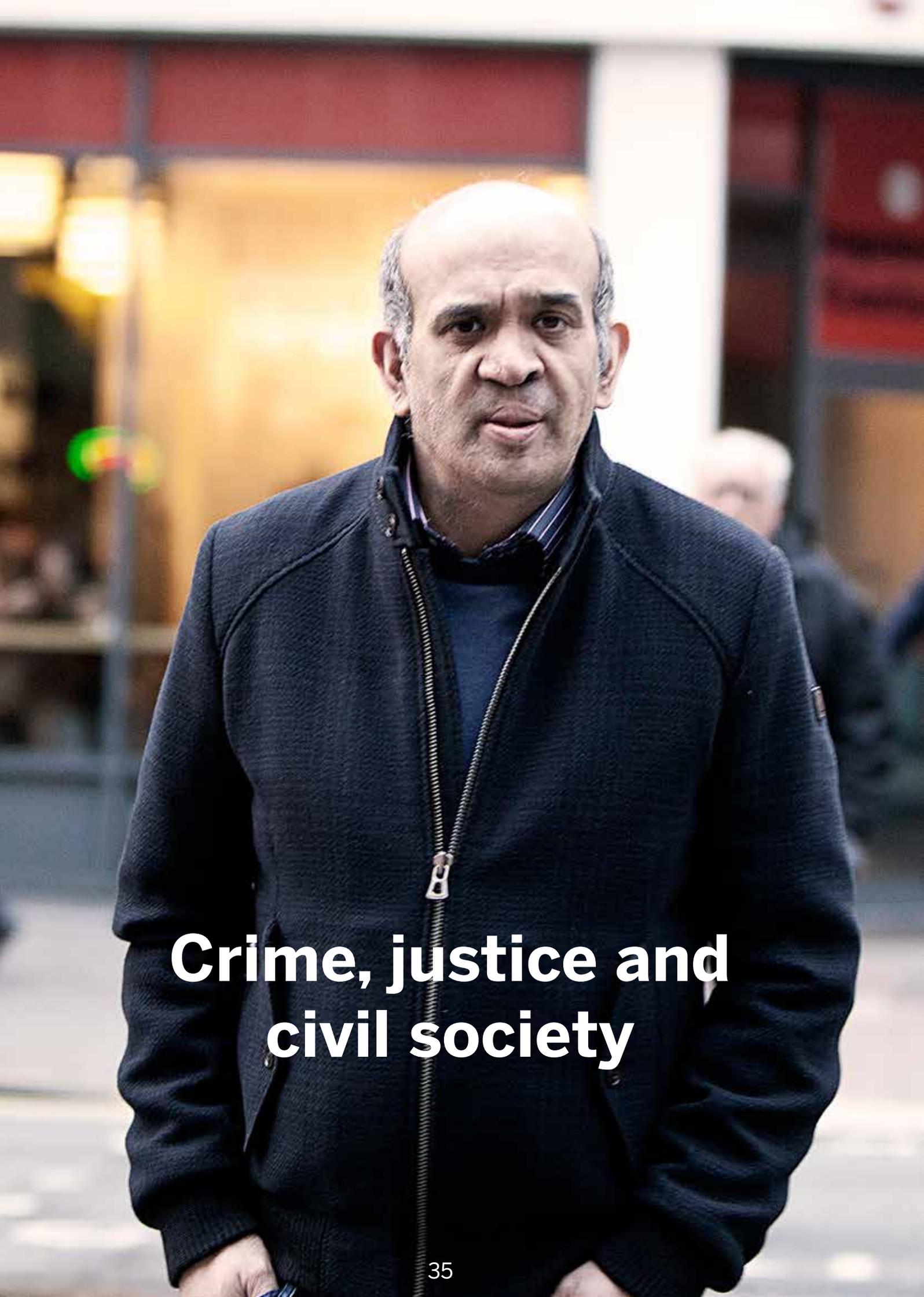
“My GP has usually been very supportive but each one has admitted to having no expertise and asked me to advise them on what I felt I needed from a referral.”

“My GP is useless and classes my condition as cosmetic. ‘It’s all cosmetic and we don’t do cosmetic.’”

Recommendations

- 6a** The NHS and related organisations throughout England, Northern Ireland, Scotland and Wales must make it a priority to reduce health inequalities as a result of disfigurement and ensure patients with disfigurements are treated fairly and respectfully.
- 6b** All health care staff must receive training and guidance on how to deal with the issue of disfigurement and ensure that they are not making negative assumptions about patients with disfiguring conditions.
- 6c** Clinical Commissioning Groups and Health Boards should provide adequate staff and resources to meet the psychosocial needs of patients to ensure the best patient outcome.
- 6d** Every health care professional working directly with patients with disfiguring conditions (both clinical and non-clinical) must receive training on recognising and addressing the psychosocial impact of disfiguring conditions.



A middle-aged man with a balding head and dark hair on the sides is standing in a city street. He is wearing a dark blue or black zip-up jacket over a dark blue t-shirt. He has a serious expression and is looking directly at the camera. The background is a blurred city street with buildings and lights.

Crime, justice and civil society

“Police need to be more present. When you’re surrounded by a group of slightly drunk girls at a bus stop at Halloween and they make fun of your ‘costume’ and laugh in your face, what can you do? You can’t report it.”

In the two decades since the Macpherson Report exposed ‘institutional racism’ in the Metropolitan Police, police services around the country have given much focus to the way in which they deal with minority communities and with hate crime. Indeed, new hate crime legislation has been passed, and the Ministry of Justice now routinely record hate crime statistics for annual publication.

However, awareness of disfigurement hate crime is very low. Where it is recorded, police and other criminal justice agencies record disfigurement hate crime under the disability heading, so detailed analysis of statistics is difficult.

In this research, we asked respondents to agree with one of the following statements:

- Hate crime focused on a person’s disfigurement is not yet a crime
- Hate crime focused on a person’s disfigurement is a crime

Disfigurement hate crime is a hate crime but alarmingly, more than four in ten (41%) of respondents did not believe it is.

A third of respondents (33%) have been the victim of a disfigurement hate crime, but of those only 30% reported the crime to the police. This could be due to low trust in the police: only 22% think the police take hate crime seriously, and just 26% think the police would deal with a hate crime properly. This distrust is echoed in respondents’ views of the courts: 25% think the courts take hate crime seriously, and generally view sentencing as being too lenient.

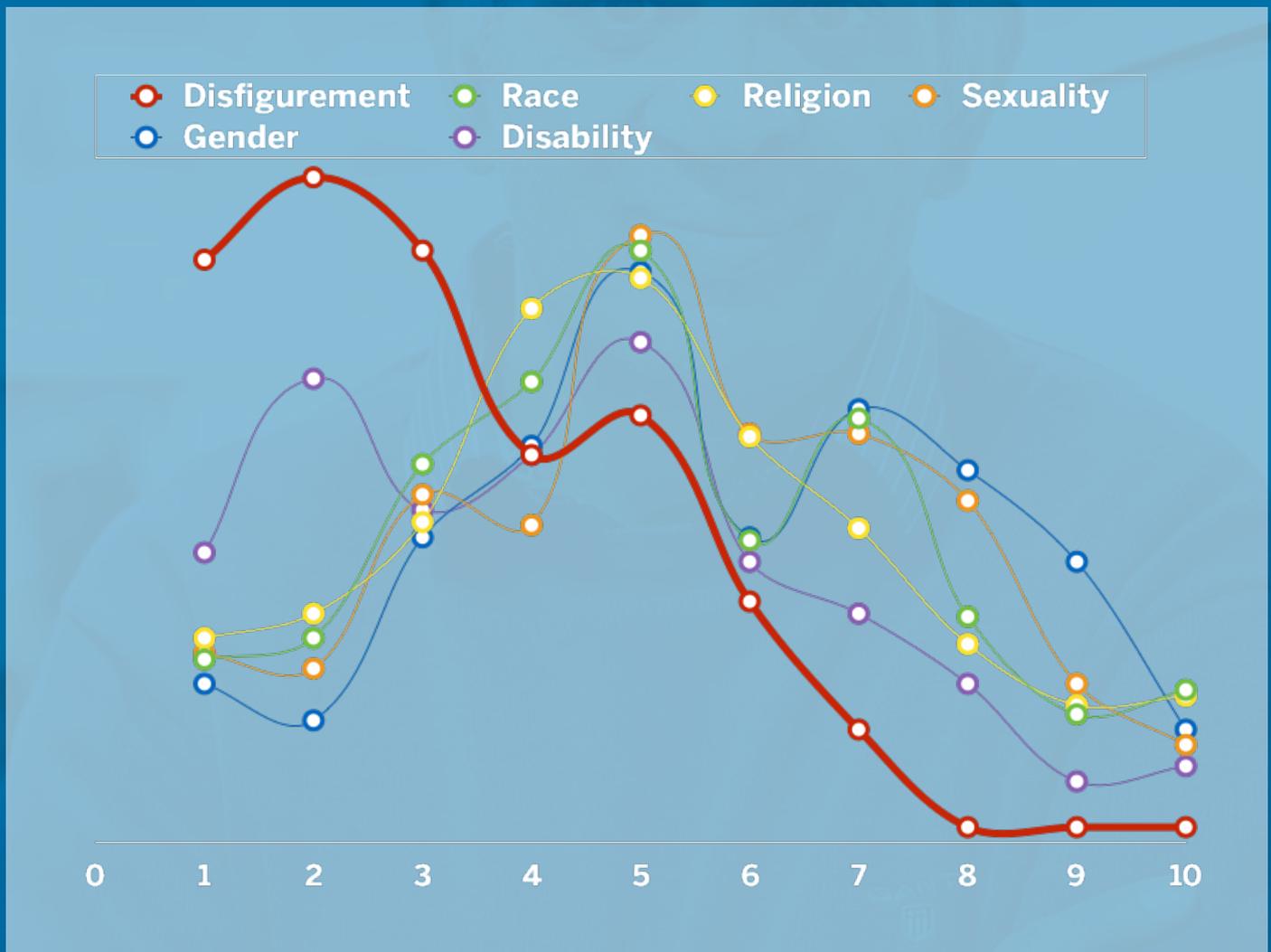
When asked whether they thought they had equal access to justice – such as to the civil courts – as a person who does not have a disfigurement, 31% of respondents said they didn’t think they did have equal access, or didn’t know.

We also asked respondents to agree with one of the following statements:

- The Equality Act 2010 gives protection to people with disabilities but not with disfigurements
- The Equality Act 2010 gives protection to people with disabilities and/or disfigurements
- Neither

The Equality Act 2010 does include 'severe disfigurement' as a protected characteristic, but almost half (48%) of respondents thought that it did not, or didn't know. **Only one in eight (12%) respondents felt that the Equality Act 2010 had improved their lives in any way.** 41% said that it had not improved their life, and 47% didn't know.

We were interested to establish respondents' views on how face equality sits alongside other areas of equality, such as gender equality and race equality. We asked respondents to rate six areas of equality on a scale of 1 to 10, with 1 being 'not at all equal' and 10 being 'very equal'.



The heavy weighting at the not equal end of the scale for disfigurement echoes what Changing Faces hears very frequently: that face equality is the poor relation of equality campaigns, and often forgotten.

That is not to say that there are still not huge equality issues in the UK for many groups - the gender pay gap still exists, and black, Asian and minority ethnic people are still more likely to die in custody than any other group - but people's *perception* of equality for people who have a disfigurement is way behind other groups.

In just the last three months, through the #WhereIsDisfigurement campaign, which draws attention to the omission of disfigurement as an equality issue, Changing Faces has highlighted six diversity and inclusion themed reports from charities, public bodies and government that have no mention of disfigurement. Recent examples have included reports from the BBC, the House of Lords and the Shaw Trust.

This is disappointing from a policy perspective especially as Changing Faces worked closely with the Equality & Human Rights Commission to produce a Code of Practice and Non-Statutory Guidance in 2010 when the Equality Act became law, but it is also hugely insulting to people who have a disfigurement who find that their needs are being repeatedly ignored.

Our respondents appear to be highly politically engaged, with 88% participating in the EU Referendum in 2016, and 83% saying that they would be very likely to vote in a general election (although the survey was completed before the 2017 general election was called). But, echoing experiences of the police and justice agencies, trust in politicians is low: only 30% think politicians deal with the issue of disfigurement well.

Recommendations

7a The Home Office and Ministry of Justice in England and Wales, the PSNI in Northern Ireland and Police Scotland must invest in a public information campaign to increase awareness of disfigurement hate crime, ensuring that front line criminal justice staff are appropriately trained to deal with complaints.

7b The Equality & Human Rights Commission must invest in raising awareness of the Equality Act, both in order to increase adherence to it but also to reassure people with a disfigurement that the Act protects them, and to encourage them to come forward when things happen. The Commission should also encourage other bodies to ensure disfigurement features in their diversity and inclusion research, strategies and reports.

7c The legal profession, including professional bodies, HM Courts & Tribunals Service and other regulators must be given training to ensure that they do not discriminate against clients with a disfigurement or anyone in the legal system.

7d Elected officials should affirm their support for face equality to ensure their constituents know that they are aware of the issue and can be relied upon to support legislation and projects to reduce discrimination.



The Media



In early 2009, Channel 5 television took the bold step to have a newsreader for a week who had a facial disfigurement: it was James Partridge, founder and Chief Executive of Changing Faces. He presented the lunchtime news to no noticeable change in viewing statistics: any concern that having someone with a disfigurement reading the news might impact on viewing figures appeared unfounded.

But aside from occasional programmes including people such as Katie Piper, more than eight years on little has changed in the media and there has been very little improvement. Whilst there are occasional articles in the media, which often serve to sensationalise or 'tragedise' disfigurement, the only sight of people with disfigurements in the mainstream media is often in programmes with offensive titles such as 'The Undateables' (Channel 4) and 'Freak Show' (BBC Three). Indeed, the BBC's five year Diversity Strategy, published in late 2016, contained no mention of disfigurement whatsoever.

"Disfigurement just doesn't exist in the media. We're invisible, and that says to me that the people running media companies don't care about us. Yes, you see more people in wheelchairs in programmes, but where are people who look different? Where are the birthmarks? Where are the burn scars? It's pathetic."

It's unsurprising, then, that respondents to our survey said they felt that the media does not represent disfigurement well. More than two-fifths (42.2%) of respondents couldn't remember when they last saw someone with a disfigurement – whether real or fictional – in a newspaper or on television. When asked to rate the frequency of seeing people with disfigurements on television, more than a third (33.5%) said it was 'not at all representative', whilst a total of 83.2% said representation was low or very low. Just 0.5% of respondents said television was 'very representative' and 1.8% said it was good or very good.

When asked how realistic the depiction of people with disfigurements was on television, a quarter (25.2%) said it was not at all realistic and 62.4% of respondents said it was unrealistic or very unrealistic. Only 2% said they thought depictions were very realistic.

Those completing the survey are highly engaged with the media. 88.1% said they watch at least one hour of television each week, and 72.3% listen to radio at least once each week. Almost half (47.9%) read a national newspaper at least once a week, and a third (33.7%) read a local or regional newspaper at least once each week.

Perhaps reflecting Changing Faces' modest successes at seeking redress from newspapers via industry regulators, respondents showed moderate faith in those regulators to take action if Changing Faces were to complain again. When asked about the Independent Press Standards Organisation (IPSO), 84% said they would expect them to take the complaint 'moderately' or 'very' seriously. Almost 9 in 10 (87.8%) said they would expect Ofcom to take a similar complaint as seriously.

Recommendations

8a All terrestrial broadcasters should ensure that people with disfigurements feature in their factual, documentary and news outputs but ensure that it is done in a sensitive, accurate way, avoiding sensationalist or offensive titles.

8b Disfigurement must be normalised on television by including characters who have an unusual appearance in soaps, dramas and other programming, with care taken to ensure the disfigurement does not suggest villainy, untrustworthiness or any other negative characteristic. Programme makers should strive to use actors who have disfigurements themselves where possible, rather than using prosthetics or make-up.

8c Media regulators such as IPSO and Ofcom must adopt guidelines on the portrayal of disfigurement in print and broadcast media, and ensure that complaints about the portrayal of disfigurement are taken seriously, handled quickly and effectively, and statistics on such complaints and their outcomes are published annually.

Summary of Recommendations

1. In school and education

1a Schools, colleges and universities must ensure that disfigurement is included in their anti-bullying and equality policies, and have robust, measurable processes in place to respond effectively to allegations of bullying and mistreatment. They must comply with the Public Sector Equality Duty and Equality Act, which should lead to clear positive perceptions of people with disfigurements as part of both school and wider communities.

1b Teachers and all school staff should receive face equality training to build their knowledge, skills and confidence to ensure that all appearance prejudice is responded to and addressed, and discrimination is stamped out.

1c Face equality should be included in the school curriculum, and young people should be taught that people with disfigurements should be treated the same as everyone else. This should include teaching that people with disfigurements can live full, happy and fulfilled lives.

1d Teacher training providers must ensure that all initial teacher education includes content and guidance on bullying that targets appearance and creating inclusive educational settings which respect face equality.

1e Further and higher education agencies must work with schools to tackle the inequality of opportunity for people who have a disfigurement, and the lack of aspiration this often causes.

2. In the workplace

2a Trade and industry bodies must ensure that employers are aware of their legal obligations to ensure people with disfigurements are not treated unfairly or discriminated against in the workplace. This must include guidance on how to deal with the issue of disfigurement in the recruitment process.

2b Employers should include disfigurement in their equal opportunities monitoring forms so that they can measure equality of opportunity within their organisation, and work to ensure that their workforce is appropriately diverse. They must ensure their policies and practices are compliant with the Equality Act and Public Sector Equality Duty, where appropriate.

2c Employers should provide 'disfigurement confidence' training to ensure that their human resources function and all line managers feel informed, empowered and confident in dealing with applicants and colleagues who have or acquire a disfigurement, so that they don't get overlooked for promotion and other opportunities.

2d Staff should receive face equality training to ensure that they do not treat colleagues or clients with appearance bias and discrimination.

2e Jobcentre, career services and recruitment and other employment agencies should ensure that their attitudes and biases are not influencing job seekers and candidates in their career aspirations.

3. Out and about

3a Building on Changing Faces' work with the British Beer & Pub Association, other industry and trade bodies must develop guidelines and training for staff to ensure they are confident in dealing with customers and visitors who have a disfigurement.

3b Operators of public transport franchises should run poster and advertising campaigns on face equality to encourage passengers not to stare, and to treat everyone with respect. Train guards and public transport staff must be given training to be able to deal with people with disfigurements, and give them help when it is needed.

3c Police and local authorities need to do more to inform people that abusing someone with a disfigurement is a hate crime, including shouting names and other abuse in public places. This will also encourage people who have a disfigurement to feel more confident to report such incidents.

4. Social media

4a Social media platforms must revise their community guidelines and terms and conditions to ensure they take a zero-tolerance approach in tackling trolling and abuse that targets people with a disfigurement. They should organise face equality training for any staff who deal with user complaints.

4b Social media platforms should take decisive action against individual users who repeatedly troll and abuse people with a disfigurement. This should include temporary or permanent exclusion from the platform.

4c Building on recent efforts to tackle threats of sexual violence on social media, the Home Office and Ministry of Justice should ensure that agencies in the criminal justice system better protect people with disfigurements from people who abuse online.

5. Relationships & family

5a Dating apps and websites should use models in advertising campaigns who have an unusual appearance to help to 'normalise' disfigurement. They should also ensure appropriate resources are in place to quickly and effectively tackle instances of abuse on their platforms.

5b The wedding industry should develop guidelines and help to ensure that wedding service providers are disfigurement confident and do not discriminate, using work by the British Beer & Pub Association as an example.

5c Charities, fostering agencies and local authorities should include parents with a disfigurement in their campaigns, again to normalise disfigurement and show that people who look different can make excellent parents – like everyone else.

6. Health care

6a The NHS and health related organisations throughout England, Northern Ireland, Scotland and Wales must make it a priority to reduce health inequalities as a result of disfigurement and ensure patients with disfigurements are treated fairly and respectfully.

6b All health care staff must receive training and guidance on how to deal with the issue of disfigurement and ensure that they are not making negative assumptions about patients with disfiguring conditions.

6c Clinical Commissioning Groups and Health Boards should provide adequate staff and resources to meet the psychosocial needs of patients to ensure the best patient outcome.

6d Every health care professional working directly with patients with disfiguring conditions (both clinical and non-clinical) must receive training on recognising and addressing the psychosocial impact of disfiguring conditions.

7. Crime, justice & civil society

7a The Home Office and Ministry of Justice in England and Wales, the PSNI in Northern Ireland and Police Scotland must invest in a public information campaign to increase awareness of disfigurement hate crime, ensuring that front line criminal justice staff are appropriately trained to deal with complaints.

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We are also grateful to the many support groups, charities and professional organisations, and individuals, who shared information about the survey and encouraged their clients, supporters and members to complete it.

The Changing Faces team who led this work were Henrietta Spalding, Steve Taylor, Rehana Browne, Rodney Appleyard, and Phyllida Swift. We are especially grateful to our two student volunteers, Ameesha Patel and Isabel Sahli for their valuable contributions. Everyone in the Changing Faces team played an important role in enabling this report to be produced.

Our thanks go to the Changing Faces users who appear in the images in this report, and to Yakub Merchant for giving so freely of his time as our photographer.

Finally, we wish to record our thanks to Dame Margaret Hodge for providing the Foreword to the report and for her long-standing and ongoing support of Changing Faces.

About Changing Faces

Changing Faces began its work in 1992 to help people who have a disfigurement find a way to live the life they want.

We are caring campaigners – caring and empowering in supportive, friendly, positive and inspiring ways, and campaigning in our education and advocacy work by being forthright, informed, counter-cultural and determined.

We are here to help people conquer fears, take the first steps and ultimately take control, by being on a client's side and by their side as they define their own sense of identity, their purpose and realise their dreams. We help build people's confidence to live their life on their terms. And we challenge prejudice, respect differences and speak to a world that needs to change.

What we do

- Support adults, children and families to live confident, happy lives through our emotional support service, and the national Skin Camouflage Service
- Train health care professionals to provide our unique package of support alongside medical treatment or surgery
- Educate and inform businesses, the NHS and public bodies, schools, and the media to develop new beliefs, expectations and practices
- Influence opinion formers in parliament and government to ensure our important message is heard
- Challenge the public and policy makers to think differently and create a fair society
- Stand up to prejudice wherever it appears, strengthening the case for face equality

Today Changing Faces is a £1.8m charity which employs around 30 staff, supported by hundreds of volunteers across the UK. The team includes professionals from psychology, social work, counselling, teaching, health economics, human rights law, local government, management, public relations, communications and fundraising.

To find out more about Changing Faces, please visit changingfaces.org.uk, or follow us on social media:

 facebook.com/ChangingFacesUK

 twitter.com/FaceEquality

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