

face equality



Changing
the way you face
disfigurement
faces

“Because I have facial burns, I stand out.

People stare at me, children look away when they see me – then they look again. People ask, ‘what happened to you then?’ – as if there is something odd about me.

I’m happy with the way I look, but are you?

Sometimes I feel as if you’d like me to blend in, get my face fixed; you judge me as being someone who is perhaps a sad figure, bravely coping... or somehow less attractive, less capable than you are – even less of a person. You probably do this unconsciously, not deliberately, unwittingly...

There are over one million people in the UK who have a disfigurement, over 500,000 to their face – either present at birth or acquired from an accident, cancer surgery, a skin or eye condition, or facial paralysis.

Every day, they are exposed to these assumptions, just like me – and the staring, awkwardness and occasional blatant rudeness that can result.

We experience ‘facial prejudice’ and ‘facial discrimination.’ What we want is *face equality*.

Face equality is not about getting rid of my noticeable face, but valuing and treating me as an equal.

If face equality existed you might still see me as unusual but you would not judge me as unfortunate or inferior.

You can help make face equality a reality.

So I urge you to stand out and show your support for face equality. Do something

different so we can all
change the way we
face disfigurement.



James Partridge OBE
Chief Executive,
Changing Faces

What's the challenge?

One in every 111 people in the UK today has a significant disfigurement to their face. Disfigurement can affect anyone at any time across age, ethnicity and background.

A public attitude survey conducted in January 2008 showed that 90% of the general public find it difficult to attach positive qualities to people with disfigurements.

It showed that whilst not believing they do this, they implicitly judge people with disfigurements as being less attractive, less likely to succeed, less socially skilled and less likely to lead happy lives.

The scale of the bias against people with disfigurements in the UK survey was stronger than that found in similar surveys conducted in the USA on other issues such as race, sexuality, age and gender.

To find out more about this important new survey go to www.changingfaces.org.uk

What's the impact?

Each year, thousands of children, young people and adults with disfigurements, and their families, contact *Changing Faces* and tell us of the personal and social challenges they face.

'Sometimes it's not just other children who can be horrid, but their parents. I have only ever been to one birthday party! Younger children rely on parents to help invite guests, but I never was invited!'

'I got more and more disheartened when interview after interview I would walk into the room and see the panel's faces when they looked up and saw me. I lost confidence and would give a bad interview.'



Every day, people with disfigurements have to confront three big cultural assumptions about the way they look.

People with disfigurements are expected to live only a second-rate life, as 'good looks' are believed to be the key to success.

'I have a lumpy birthmark which covers one side of my face. I often get comments like, 'it must be awful to look like you... you're so brave to go out there and do what you do.' The reality is, it can be hard because of people's reactions to my appearance, but I am not brave or a superhero – this is part of my life.'

People with disfigurements are often viewed as 'different', outside of the normal – or even nasty.

'The name I hated most was Scarface – worse than Thicker.'

'When I go to hospital, the surgeon refers to my condition as a defect, an abnormality – not knowing how that makes me feel as a person. I realise surgery is important but I am a person not just a condition.'

'I get fed up by the portrayals of frightening villains in films as being disfigured – in the Bond movies, for example. These images must influence people's beliefs and opinions about me.'



People with disfigurements are thought to need cosmetic surgery and there is a belief that this will make them happy. It's up to them to be 'fixed' by a surgeon.

'I'm tired of all the attention that is given to cosmetic surgery or the airbrushed images in magazines. This puts a lot of pressure on people like me. Firstly people expect me to go and have surgery to fix my face. Secondly they think if you look good, you are more valuable. I'm judged as odd and a less valuable part of society.'

What is face equality?

We know that people who have disfigurements can and do lead successful and fulfilled lives – but public attitudes, assumptions and discrimination make it extremely hard for them to do so.

Face equality is about being treated fairly and equally irrespective of facial appearance.

It is about creating a society in which everyone is valued for the unique contribution that they can make to society.

In a world with face equality

Everyone will be treated fairly and equally whatever their facial appearance.

- Health and social care professionals will develop services that treat patients with disfigurements as having psychological and social as well as medical needs.

- The education system will ensure that all staff are adequately trained to develop a culture and practice of inclusion for pupils with disfigurements, eliminating facial prejudice and discrimination.



- Employers in the private, public and voluntary sectors will create a culture and practice of face equality for people with disfigurements as employees and customers, removing facial prejudice and discrimination.
- The media, advertisers and the film industry will adopt more factual and unbiased portrayals of people with disfigurements, actively avoiding language and imagery that creates prejudice.
- Politicians and policy-makers will ensure that facial prejudice and discrimination are effectively outlawed by improving anti-discrimination law and promoting best practice.

People with disfigurements should be judged fairly without prejudice, and treated without discrimination. This is why we have created the *face equality* campaign.

We are calling on you to *stand out and show your support for face equality*.

Everyone can play an important role in bringing about face equality. Whether you are a teacher, employer, journalist, health professional, parent or just happen to be out and about.

You can make the difference. You can help us champion this important equality issue. To find out what you can do, go to www.changingfaces.org.uk



The charity *Changing Faces* was founded in 1992 by James Partridge, OBE, who was injured in a car fire when he was 18 years old. The work of *Changing Faces* complements medicine and surgery by addressing the psychological and social challenges posed by disfigurement.

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This leaflet is also available in plain text and on CD



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EDUCATION



Disfigurement in schools

One in every 500 children/young people in the UK has a significant facial disfigurement – two in every major school.

Common causes are:

- birth conditions like birthmarks, cleft lip and palates, cranio-facial syndromes
- a traumatic injury like a burn, scars from an accident or dog bite
- an illness such as cancer or as a result of surgical treatment for it
- skin conditions like eczema, acne or vitiligo.

Changing Faces believes that teachers and educationalists need to understand that all pupils and students with disfiguring conditions are vulnerable to 'facial prejudice' and 'facial discrimination'. However, many pupils do have positive experiences at school and this is due mainly to the culture that the school creates.

The Disability Discrimination Act 1995 – later amended to include schools – established disfigurement as a disability, and makes it unlawful to discriminate against a pupil with a disfigurement. However hundreds of parents and young people have contacted *Changing Faces* reporting difficulties at school.

The reasons for change

There are several unconscious prejudices which can disadvantage children and young people with disfigurements at school: for example, because other pupils and teachers may believe that 'good looks' are essential to success, they may inadvertently assume low expectations and can be patronising or overly sympathetic.

Similarly, if they associate disfigurement with low IQ, pupils can be treated unfairly.

Worst of all, other children can be very cruel if one of their peers looks unusual. Children with disfigurements often experience staring, name-calling and other forms of bullying.

Changing Faces carried out a small-scale survey in January 2008 of how young people with disfigurements viewed their school experience and sought comments from our young people's website (www.iface.org.uk). Both confirmed that problems persist.

'People tease me at school and I don't know what to do about it.'

'At break time I still get the occasional comments and whispers and so on from younger kids that don't even know me. It's well horrible. Like today, this boy proper laughed at me and stared right into my face, he was like leaning across my shoulder to look. That proper made me annoyed and upset the whole of the day.'

One parent said of her daughter, **'She only recently moved to secondary school – all has been ok but she endured four years of bullying at junior school. This has led her to not mixing well with her peers and whilst she enjoys school and engages fully in**

all aspects, I feel she is still isolated – or ostracised – by other girls her age.'

Getting it right

Schools that get it right do so because:

- Teaching staff display positive attitudes and behaviours towards pupils with disfigurements – and have high expectations about their future.
- The school creates a culture of inclusion for all students.
- The school is well-equipped with information, skills and resources to handle the challenges of disfigurement with confidence.
- The curriculum contains strong lessons on Citizenship and follows the Social and Emotional Aspects of Learning (SEAL) programme – making the link with subjects covered within those lessons with issues relating to disfigurement.

Changing Faces has been at the forefront in developing effective resources and interventions to enable this to happen. Please see our Teachers' Guides available for download on our website, www.changingfaces.org.uk. However, there is still much to be done.

Many schools need a long-term strategy in relation to supporting pupils with disfigurements and enabling other students to interact and relate to them in a confident and positive way. In doing so, they can provide a robust foundation for their pupils to prepare them in their future roles as employers, teachers, parents and citizens.

For further information go to www.changingfaces.org.uk

What you can do

Stand out. Show your support for face equality

Changing Faces calls on the education system to ensure that all staff are adequately trained to develop a culture and practice of inclusion for pupils with disfigurements, eliminating facial prejudice and discrimination.

We call on the Department for Children, Schools and Families, and those departments at devolved and local levels, schools, colleges and universities to adopt three key principles for education for pupils with disfigurements:

1. Become familiar with the causes and effects of disfiguring conditions

All teaching professionals should be informed about the causes and effects of disfigurement and should be trained to stamp out bullying, teasing and prejudice in the classroom.

2. Adopt positive thinking about people with disfigurements

Schools should test out their own attitudes towards disfigurement and develop more inclusive thinking and behaviour – and should commit to Face Equality Weeks.

3. Adopt new ways of behaving when you meet someone with a disfigurement

Schools should make sure that staff are adequately trained to identify and address the psychological and social welfare needs of their pupils/students within their personal development curriculum (eg: with access to psychological and social support).

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EMPLOYMENT AND CUSTOMER SERVICE



Disfigurement in the workplace

Every day, employers and providers of customer services in companies and organisations across the UK are likely to come across people with disfigurements.

One in 111 people has a significant disfigurement to their face from birth, accidental scarring, cancer surgery, skin conditions and facial paralysis. Many others have disfigurements to their hands and bodies. Despite surgical advances, a disfigurement can rarely be removed.

The present Disability Discrimination Act (1995) makes it illegal to discriminate against someone with a severe disfigurement. However, despite this law, many people with disfigurements have told *Changing Faces* that too often they are made to feel undervalued, abnormal and 'different' in the workplace. As customers, they often receive a less than welcoming reception.

A public attitude survey of 1,000 people conducted in January 2008 showed that 90% of the general public find it hard to apply positive qualities to people with disfigurements. Particularly pertinent to employers, is that people with disfigurements are judged as being less socially skilled and less likely to succeed than the general population. The survey also showed that such attitudes were unwitting: people were generally unaware that they held such beliefs.

Such general attitudes about disfigurement, if transferred into the workplace can result in discrimination in the recruitment, retention, management and career prospects of people with disfigurements. Furthermore, they can influence the way that people who have disfigurements are treated as customers and clients.

The reasons for change

There are several unconscious prejudices which can disadvantage people with disfigurements at work. For example, because line managers or recruitment staff may consider that 'good looks' to be essential to the success of their organisation, they may believe that it would not be a

good idea to have them on the front desk. Similarly, if people associate disfigurement with low expectations, employees can be treated unfairly.

Worst of all are workplaces that allow harassment, name-calling, ridicule and ostracism.

In January 2008 *Changing Faces* conducted a small-scale survey of people's experiences in the workplace. Comments included:

'I was disappointed not to get the post but there was no way of proving that the scarring was the reason. I was well qualified and had the right experience for the job.'

'I heard comments made at interviews and questions were inappropriately asked that other candidates would not be asked. I knew I had not got the post as soon as they asked the questions they did.'

'Discrimination seemed to be subtle, but got worse after I was 40. In today's

world, perfect facial features seem to count more than intelligence, hard work, qualifications and interpersonal skills.'

Getting it right

Employers that get it right, do so because their directors, managers and staff display and model positive behaviour towards people with disfigurements. The organisation creates a culture of inclusion for all. And it is well-equipped with information, skills and resources to be able to handle the challenges of disfigurement in a confident and positive way.

Changing Faces has been at the forefront in developing effective resources and interventions to enable this to happen. Please see our Employers' Guides available for download on our website, www.changingfaces.org.uk

'You have to work twice as hard to prove you are better than a person without a disfigurement. I do feel I have to prove myself sometimes at these conferences, meeting etc. But then, somebody has to break certain mindsets and it happens to be me in this situation.'

In order to make the reasonable adjustments required by the law, it is important that employers are aware of their own attitudes and knowledge in relation to disfigurement and introduce practical measures to eliminate facial prejudice and discrimination within their organisations.

For further information go to www.changingfaces.org.uk

What you can do

Stand out. Show your support for face equality

Changing Faces calls on employers in the private, public and voluntary sectors to create a culture and practice of face equality for people with disfigurements as employees and customers, stamping out facial prejudice and discrimination.

We call on all the Department for Work and Pensions and for Business Enterprise and Regulatory Reform, and those departments at devolved and local levels, to ensure that facial discrimination is outlawed in employment.

Employers should adopt three goals in employing and serving people with disfigurements:

1. Become familiar with the causes and effects of disfiguring conditions

Staff should be trained and informed to develop policies and procedures which avoid facial prejudice and discrimination in recruitment, retention, career advancement, management and customer service.

2. Adopt the positive in your thinking about people with disfigurements

The culture and ethos throughout all organisations should promote the inclusion of people with disfigurements.

3. Adopt new ways of behaving when you meet someone with a disfigurement

Organisations should ensure that their recruitment, interviewers and customer-facing staff receive face equality training so that people with disfigurements are recruited, retained and served, equally and fairly.

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HEALTH AND SOCIAL CARE



Disfigurement in health and social care

Every year, over 415,000 people in the UK are born with or acquire a disfiguring condition to their face, hands or body – from birth, accident, cancer surgery, skin and eye conditions, from facial paralysis and from medical accidents such as mistakes in cosmetic procedures.

Most will come into contact with the NHS – at a GP clinic, A&E or specialist hospital service.

Many medical specialties provide services for them but the focus is often on medical interventions without consideration of the psychological and social implications.

Changing Faces believes that health and social care professionals and policy-makers need to understand that all patients with disfiguring conditions and their families are vulnerable to ‘facial prejudice’ and ‘facial discrimination’ in society.

The NHS and social services need to recognise this so they can develop appropriate services to prevent and/or treat the psychological and social problems that can result.

The reasons for change

People with disfigurements can feel extremely self-conscious and may find it difficult to talk about their feelings. Public reactions to their appearance can make them feel even worse. They can face staring, intrusive questions, ridicule, name-calling, bullying and exclusion. Some people can be blatantly discriminatory, refusing them work or good customer service.

In addition, the prevailing assumptions about what life is like for someone with a disfigurement can undermine a patient’s self-esteem. For example, because many people believe that ‘good looks’ are essential to success in today’s society, the patient and family may inadvertently apply this to themselves – and experience low expectations from others too.

The role of medicine and health care

Modern reconstructive surgery and medical treatments can be very effective in making some disfigurements less noticeable, but a disfigurement can rarely be removed completely.

Research shows that psychological and social problems are common after a disfigurement usually affecting a person's (and family's) self-esteem and self-confidence. These can include a fear of public places, low expectations, difficulty in making friends and forming relationships and finding jobs and in extreme cases, suicide. Importantly, research also shows that the distress caused by a disfigurement is not determined by its severity, so all patients with disfiguring conditions, even those which seem 'minor', need to be considered vulnerable.

Yet despite this evidence, disfigurement is still predominantly seen as a medical issue, with far too little attention being given to its psychological and social impact.

Getting it right

Changing Faces believes that many of the psychological and social problems experienced by patients after a disfiguring condition can be traced

back to the challenge of living in a society which has negative attitudes towards disfigurement.

Health and social care professionals need to design services that can both prevent patients experiencing these problems and can identify and treat them should they be experienced. A radical re-think is needed to ensure the effective rehabilitation of people with disfigurements – just as has started to happen in services for children with cleft lips and palates.

Professionals using medical jargon with their patients to describe their conditions ('defects', 'abnormalities', 'deformities') can reinforce patients' negative beliefs about their appearance.

Similarly, over-emphasis on the ability of surgery to 'fix' a disfigurement can result in unrealistic expectations about surgery; depression is common when such expectations are not met.

Services which are able to incorporate

the following proven approach to supporting patients with disfigurements play an important role in empowering people to lead full and active lives:

Finding out. Gaining realistic information about their condition and its treatment.

Attitude-building. Developing a positive set of beliefs about their future.

Counselling. Receiving emotional support face-to-face, by email or phone.

Exchanging. Sharing experiences with others in similar situations.

Social skills training. Learning new strategies for handling other people's reactions.

For further information go to www.changingfaces.org.uk

What you can do

Stand out. Show your support for face equality

Changing Faces calls on the Department of Health, and health departments at devolved and local levels, the NHS and all medical specialties to develop a range of new services to provide for the psychological and social needs of patients with disfigurements as well as their medical requirements.

Changing Faces calls on health and social care professionals to develop services that treat patients with disfigurements as having psychological and social, as well as medical needs.

1. Become familiar with the causes and effects of disfiguring conditions

All health and social care teams should be informed about the causes and psycho-social effects of disfigurement. They should be trained and skilled at providing patients with realistic information about possible treatments and at building their confidence to live within the prevailing culture which holds negative attitudes towards people with disfigurements.

2. Adopt the positive and avoid the negative

Health care professionals should use positive language about disfigurement – avoiding stigmatising language like 'defect' and 'deformity' in their communications with patients – in order to create an inclusive culture which treats them as people first.

3. Adopt new ways of behaving when you meet someone with a disfigurement

Health professionals should ensure that assessments and interventions to address their patients' psycho-social needs are routinely integrated into the service they receive both pre-discharge, at follow-up and as and when required by the patient and their family.

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MEDIA, ADVERTISING AND FILM



Disfigurement in the media

One in every 111 people in the UK has a significant disfigurement to their face. Disfigurement can affect anyone at any time across age, ethnicity and background.

A public attitude survey conducted in January 2008 showed that 90% of the general public find it difficult to attach positive qualities to people with disfigurements.

It showed that whilst not believing they do this, they implicitly judge people with disfigurements as being less attractive, less likely to succeed, less socially skilled and less likely to lead happy contented lives.

The scale of the bias against people with disfigurements in the UK survey was stronger than that found in similar surveys conducted in the USA on other issues such as race, sexuality, age and gender.

Every day, people who have disfigurements – and their parents, family and friends – are influenced by what the media in all its forms says about disfigurement. Press, TV, film and advertising portrayals frame how society thinks about disfigurement.

People who contact *Changing Faces* tell us that current depictions of disfigurement in the media create a distorted, uninformed and negative view of disfigurement and lead to exclusion, teasing and bullying. This can result in prejudice and discrimination.

'If programme makers had the courage to take the plunge and be more imaginative in terms of casting and writing characters, seeing people with unusual faces could just become a regular thing and not frightening at all. But the impact this would have on us would be extraordinary.'

'Wouldn't it be great to see more people with birthmarks, scars and other facial conditions in adverts doing everyday things like eating yoghurt?'

'Why do people in horror films always have some form of disfigurement? Don't they realise the impact this can have on how people see me?'

The reasons for change

In the media, disfigurement/disfiguring conditions are often described with negative words and imagery. Words – like horrifically disfigured, grotesquely scarred, ugly birthmark, misshapen head – are commonly used.

'She was horrifically disfigured in a car crash in 1999, on her way home from a party when her car was hit by a drunk driver.' *Sunday Times*, 11th December 2005.

'Face transplant for Elephant Man.' *Daily Telegraph*, 23rd January 2007.

'As he recovers – from a terrible disfigurement to the face – it became obvious that his personality has changed.' *Daily Mirror*, 21st September 2007.

Coverage of disfigurement also tends to be medicalised – people with disfigurements are often the subject of documentaries that present them

as quirks of nature, abnormal or in need of surgery. People who have disfigurements are rarely seen in soaps, game shows or as incidental characters in drama or comedy.

In film, disfigurement is often used as a device to portray evil characteristics such as Freddie Kreuger in *Nightmare on Elm Street*, and the countless villains in Bond movies and many other films. In theatre, the sad stories such as *Phantom of the Opera* reinforce the idea of lives being blighted forever by disfigurement.

People with disfigurements are not represented in mainstream advertising. Instead they tend to be subjects of charity adverts, presenting them as objects of pity, or fire prevention and drink drive adverts – with the message that if you aren't careful you will end up looking like this.

Advertisements for cosmetic surgery and the beauty industry portray

scars, blemishes and other forms of disfigurement as unsightly and to be removed.

Getting it right

Those that get it right in the media, advertising and film in relation to portrayals of disfigurement make sure that they are:

- Informed about the causes and effects of disfigurement.
- Have an open mind about the life and prospects of people with disfigurements.
- Develop films, programmes and adverts in partnerships with organisations like *Changing Faces* and people who have disfigurements themselves.

For further information go to www.changingfaces.org.uk

What you can do

Stand out. Show your support for face equality

Changing Faces calls on

- The Department of Culture, Media and Sport, and those departments at local and devolved levels, to develop policies and guidelines to ensure fairer, broader and more factual reporting and portrayals of disfigurement in media, film and advertising.
- The media, advertisers and the film industry to adopt more factual and unbiased portrayals of people with disfigurements, actively avoiding prejudicial language and imagery.

In particular, we believe:

- Journalists and editors in press and broadcasting should sign up to a voluntary code of practice (see www.changingfaces.org.uk) committing to factual and unbiased reporting of disfigurement.
- Broadcasters should commit to a broader range of portrayals of disfigurement throughout programming.
- Advertising agencies and their professional bodies like the Institute of Practitioners in Advertising should take the lead in including people with disfigurements in mainstream advertising and should put pressure on casting agencies to recruit actors with disfigurements.
- The film industry and professional bodies such as the UK Film Council should commit to showing a broader range of portrayals of disfigurement in films.

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POLICY AND LAW



Public attitudes towards disfigurement

There are hundreds of people in every ward and constituency in the UK who have unusual looks. One in every 111 has a significant disfigurement to their face. Disfigurement can affect anyone at any time across age, ethnicity and class.

Changing Faces receives many anecdotal reports from people with disfigurements that suggest they experience facial prejudice, stereotyping and discrimination which put them at a disadvantage in education, employment and in their personal and social lives.

In January 2008, *Changing Faces* commissioned Cog Research to undertake a public attitude survey to gauge public attitudes towards disfigurement. An online nationally representative survey of 1,000 people was undertaken with people over 16 years old.

The method used compared answers to conventional survey questions with an Implicit Attitude Test (IAT) to unearth attitudes people may not be aware that they have or be willing to report.

The results of the IAT test revealed that 90% of the public found it extremely difficult to associate positive qualities with people with disfigurements regarding the quality of their lives, their attractiveness, their sociability and their life prospects.

The scale of the bias against people with disfigurements in the UK survey was stronger than that found in similar surveys conducted in the USA on other issues such as race, sexuality, age and gender.

However, the key point is that the interviewees said that they did not have (or did not want to have) negative views about people with disfigurements. Much of the prejudice and discrimination that people with disfigurements face is therefore likely to be unintentional.

A new social justice campaign

A nationwide shift in public attitudes, beliefs and perception is needed.

People who have disfigurements can and do lead successful and fulfilled lives – but public attitudes, assumptions and discrimination make it extremely hard for them to do so.

The Face Equality campaign is a long-term campaign aimed at bringing about change to combat prejudice and discrimination in education, employment, in the media, film and advertising, and to transform the delivery of health and social care services.

It will aim to raise awareness and familiarity with disfigurement and transform negative attitudes.

But such efforts need to be supported by effective policies and legislation.

Politicians and policy-makers across all levels of Government need to be effectively engaged to tackle the prejudice and discrimination around disfigurement – which the leading Professor of Plastic Surgery, Gus McGrouther, once described as ‘the last bastion of discrimination in our society.’

For further information go to
www.changingfaces.org.uk

What you can do

Stand out. Show your support for face equality

Changing Faces calls on politicians and policy-makers to ensure that facial prejudice and discrimination are effectively outlawed by improving anti-discrimination law and promoting best practice.

In particular, we call on

- The Department of Health, and those departments at devolved and local levels, to develop policies and guidelines to ensure that the social and psychological needs of their patients are given as much consideration as their medical/surgical needs.
- The Department of Children, Schools and Families, and those departments at devolved and local levels, to develop policies and guidelines to ensure that schools, colleges and other educational institutions are equipped to create a culture of inclusion for children with disfigurements in education.
- The Department of Work and Pensions, and those departments at devolved and local levels, to develop policies and guidelines to ensure that facial discrimination against people with disfigurements is outlawed in employment.
- The Department of Culture, Media and Sport, and those departments at devolved and local levels, to develop policies and guidelines to ensure fairer, broader and more factual reporting and portrayals of disfigurement in media, film and advertising.
- Governments in England, Wales, Scotland and Northern Ireland to strengthen existing anti-discrimination legislation (the Disability Discrimination Act (2005)) to ensure that it outlaws facial discrimination towards people with disfigurements.

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