

NEW WRITING

If it's not everyone, it's not inclusion:

When a child is vulnerable to being seen as different because of disfigurement, everyone needs to be involved in promoting inclusion at school

By Jane Frances



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facial disfigurement – creating inclusive school communities was published by RoutledgeFalmer in 2004. She is pursuing part-time PhD studies researching more deeply some key issues at the interface between special and mainstream provision in our schools.

Summary

At *Changing Faces* we work with children and young people who have conditions, injuries or illness that affect the way they look, and with their families and their schools. If we want schools and life after school to become more and more accessible and inclusive then schools have a vital job to do in enabling *everyone* to be

more comfortable and confident around disfigurement and disability.

Changing Faces is the leading UK-based charity working for and on behalf of people of all ages, and their families, affected by disfigurement, however caused. As well as working directly with children and their families, *Changing Faces* provides training and consultancy for education and health professionals, campaigning for social change, and also has a strong research base including close links to the Centre for Appearance Research at the University of the West of England. *Changing Faces* is committed to enabling everyone to face disfigurement with confidence.

At *Changing Faces* we work with children and young people who have conditions, injuries or illness that affect the way they look, and with their families and their schools. This includes children who are born with conditions such as cleft lip and palate or Crouzon's, which affect the bone formation of their head and face, or birthmarks which affect the appearance of the

skin and may affect blood vessel development too. Other children develop skin conditions such as eczema which affects the skin's ability to keep itself moist and flexible, or vitiligo which affects skin pigmentation. Yet other children are affected by scarring from burn injuries or dog bites.

Disfigurement is recognised as a disability in legislation, and children whose disfiguring condition, injury or illness entails medical and/or sensory needs, for example, must have these effectively addressed at school. But another vital category of needs – *everyone's* psychological and social needs associated with disfigurement – can be harder to address.

The infrequency of facial disfigurement is part of the problem. One in 500 children has a blemish, mark or scar which significantly affects their ability to lead an ordinary life. One in 100 has a noticeable facial or other feature. (OPCS, 1988) It can be difficult to acquire the experience and expertise needed to give effective support.

Meanwhile everyone is taught that it is rude to stare, and even ruder to talk about it, and possibly that '*It's the inside that counts*'. But it is so much more complicated than that.

Language and vocabulary

Some people find the word *disfigurement* too drastic or perhaps judgemental-seeming. Interestingly, much research over many decades into the impact of appearance among adults as well as children, routinely distinguishes between *attractive* and *disfigured* people.

By carefully widening and varying our vocabulary (e.g. *facial difference, visible difference*) the child who has a condition, injury or illness that affects the way they look, can gradually work out their own way of talking about their appearance.

Being matter-of-fact with such words as *scar, mark, lumps and bumps, missing ear, shape, texture, size, colour, fused fingers*, makes it possible to avoid both judgement and euphemism. Kindly meant alternatives can tend to create or endorse a sense of taboo, '*This thing is unmentionable*.' So, contrary to the prevailing lesson that it is rude to talk about it, it is in fact important (though perhaps at first uncomfortable) to talk about a child's

disfigurement – but never about *a disfigured child*.

Describing someone as *a disfigured person* can make it hard for other aspects of their identity to signify. *A person with a disfigurement* is more spacious. A pupil with burn scars might be a talented musician or basketball player, a thoughtful and generous member of class...

School and disfigurement

To enjoy and do well at school our young clients and their school staff need effective strategies for dealing with staring and questions, comments and teasing. Children and young people also need to be able to make friends.

About half of the responses so far to our *School Experiences Questionnaire* (Changing Faces, 2008) describe '*bad experiences*', ranging from, '*just name-calling/teasing mostly*' through '*pointing and laughing*' and '*pointing and shouting*', to being often bullied both verbally and physically. School can be a hard place to be.

But more respondents than not are also saying positive things about school and almost two thirds link feeling safe at school to being with friends. '*Friends make me feel mentally and physically healthy and safe, and make me enjoy school more than the school itself.*'

Vital as it is not to be teased or bullied, it is also essential to create pro-social environments in our schools, and to support pupils, so that they can make friends.

Research before intervention

For children and young people at school it is other people's reactions and responses to the way they look (Macgregor, 1990) which can become a significant barrier to wellbeing and achievement at school. Reactions here and now in this classroom or along this corridor are important, but it also important to be aware of the cumulative effect on the individual of unwanted attention, awkwardness, avoidance, comments, stares, double-takes and ridicule in many situations both in and out of school – and perhaps happening since infancy.

To address the social and psychological challenge of disfigurement effectively in school we must begin with a good look at some significant research findings. Only through greater awareness and understanding of the

psychological and social forces which tend to operate around disfigurement can we effectively support individual children whose appearance is affected, and enable their peer community and all school staff to become comfortable around disfigurement.

Many research findings are counter-intuitive:

- The apparent severity of a disfigurement is no guide to its impact on the person who has it (Mcgregor, 1990). A child may be seriously affected by a disfigurement that does not look so very noticeable to you or me.
- Among children, dislike of children with facial disfigurements increases with age (Richardson, 1970).
- Even though we may not consciously intend to treat a person differently or less favourably when they have a facial disfigurement, almost all of us do, especially upon first meeting (Kleck and Strenta, 1980).
- The things we think will help (such as prohibiting classmates from staring) may not in fact be helpful, and the things we think we should not do (especially talking about it in an ad hoc conversational way) may turn out to be the most effective (Frances, 2004).
- Teaching mainstream pupils about the disabilities which affect some pupils can reduce the amount of social interaction between mainstream and disabled pupils (Vandell and George, 1981).

Perhaps other research findings are more in line with what our common sense might lead us to suppose:

- Making friends begins with looking, so prohibiting staring – which is a kind of looking – risks isolating a child who is vulnerable to being seen as different (Bronfenbrenner, 1979).
- Self-esteem (and increased capacity to achieve at school) is linked to access to positive social interactions every day (Bull and Rumsey, 1988).
- Factors for successful acceptance of minority group members in classroom settings are (i) equal status within the

situation (ii) common goals (iii) situations requiring or promoting interdependence (iv) authority support (David, 2007).

- Through their effect on teacher expectations, beliefs about disfigurement will crucially influence the pupil's wellbeing and outcomes at school (Rosenthal, 1968).

Feelings and mindsets

What happens inside a person upon first seeing or meeting someone who has a facial disfigurement? We become briefly unlike our usual selves, unsure, suddenly hesitating or over-doing our greeting. Or we may find ourselves staring at someone quite unknown to us in the crowd.

Social biology suggests a visceral response may be at work here, originating in the amygdala – a group of neurons deep in the brain. The amygdala is involved in the primary emotions of fear, disgust, anger and, in some lists, parental love. When a response occurs, it is not just an emotion but a set of body-rooted survival mechanisms that have evolved to turn us away from the strange in case it represents danger, and propel us towards things that may be of benefit to us.

Anyone with a disfigurement is regrettably familiar with being on the receiving end of this perhaps fleeting, but nonetheless real, visceral response. In the absence of a clear understanding of other people's reactions, one may feel unacceptable, unwanted (Gilbert, 2002). Sensitivity increases with each new encounter with this awkward response from others.

More widely, certain myths, often not spoken aloud, affect the mindset we bring to disfigurement (Langlois, 1995):

- People with disfigurements are scary, are somehow not okay.
- A child who looks like that cannot look forward to a good life.
- Anyone who looks like that must be very brave.
- Modern medicine, cosmetic surgery, etc. can sort it out.

These myths, often barely conscious, must be undone because teacher expectations have an important effect on a child's experiences and achievements at school.

In spite of prevalent stereotypical representations in the media and the huge emphasis everywhere on airbrushed beauty, there is in fact no connection between appearance and moral character.

Many people with disfigurements live fulfilled lives with careers and families and all the usual ups and downs. They may have to learn strategies for ignoring or overcoming certain kinds of reactions from other people, but that is because having a disfigurement does not stop you being an ordinary person (Clarke, 1998).

Many children and their families seek medical and surgical intervention to remove or treat their disfigurement and, undoubtedly, the best medical treatment to address appearance as well as function is always desirable. However, there are limits to what can be achieved and for most people affected facial disfigurements are lifelong.

To recap, there is always a risk that responses to disfigurement will be influenced by both visceral responses to the unknown – to some archaic 'danger' – and by dubious mindsets about what disfigurement 'means' or how to 'fix it'. To undo all of this requires a degree of internal frankness as well as time, space and thought.

Meanwhile, the tendency to stare, at least initially, may not be rude so much as simply human.

Planning for change

It is especially important for school staff to recognise and understand their own response to disfigurement in order to engage effectively with all their pupils concerning appearance and difference, and thereby to support the child better and influence the inclusiveness of the school's social environment.

Reactions to disfigurement are best tackled through understanding and, certainly within school, communicating. This is most straightforward at the beginning of children's school experiences, when there are fewer negative experiences to be undone. The following exchange illustrates how this might be done:

Pupil with disfigurement: *They're staring at me. Please stop them staring.*

Teacher: *I think maybe they haven't met anyone before who has a birthmark like your birthmark. I wonder if they're rather interested. What do you think you could tell them about your birthmark?*

Pupil: *I was born with my special mark.*

Teacher: *Shall we try saying that and then ask them to play?*

Among older pupils, accumulated hurt, insecurity, and lowered self-esteem, as well as heightened sensitivity to appearance, can make it a much bigger task to turn the situation around. However, this big task comprises a number of specific tasks:

- Identifying a member of staff in each school with an interest in pastoral and self-esteem aspects of school experience, who would like to develop further specialist expertise.
- Ensuring whole-school involvement in inclusion because most children and young people have anxieties around how they look, whether or not they have a disfigurement (Lovegrove, 2002). A curriculum which facilitates inclusion would ideally begin with self-image, self-belief and awareness around appearance and difference and would provide opportunities to explore all manner of appearance-related teasing and put-downs and how to address them. This means ensuring the curriculum provides plenty of opportunities to consider and discuss stereotyping and lack of positive role-models in the media and the wider culture – which necessarily form a backdrop for everything that happens in school.
- Considering running an Inset (in-service training) session geared towards staff wellbeing ahead of taking it out to all pupils.
- Adopting a constructive response to support a pupil with a disfigurement in which all staff, guided by the specialist member of staff, help to settle other people's uneasy reactions to visible

difference.

- Putting in place when required a personal programme of psychological support and repair for the child, addressing such aspects as self-perception, self-expression and self-esteem. When he or she is ready, start to experiment with pro-social strategies for managing unwanted attention, i.e. responses such as 'I was in a fire, but I'm okay now. Have you ever had an accident?' which invite a connection rather than more conventional (and understandable) responses such as telling someone who is staring that they are being rude.

Action and outcomes

These innovative tasks need not be hugely expensive and are seriously doable, in parallel, over time. If we want schools and life after school to become more and more accessible and inclusive then schools have a vital job to do in enabling *everyone* to be more comfortable and confident around disfigurement and disability.

Useful publications

Supporting a child with a disfigurement: a teachers guide. Free download from www.changingfaces.org.uk

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