

Supporting a child with a disfigurement: a teacher's guide

Introduction

1 DISFIGUREMENT – SOME FACTS

One in 500 children has a facial difference, mark or scar which significantly affects their ability to lead an ordinary life¹. One in 100 has a noticeable facial or other feature.

A child or young person can have a facial disfigurement for many reasons:

- born with a condition, e.g. birth mark, cleft lip, Apert's, Moebius
- traumatic injury, e.g. a burn or dog bite
- illness – disfigurement resulting from the illness itself or its treatment, e.g. cancer
- condition develops during childhood, e.g. psoriasis

Some conditions are permanent and relatively stable, e.g. loss of an eye, facial paralysis. Others change over time, e.g. eczema, vitiligo, acne.

Medical treatment can include:

- surgery to graft or remove bone or other tissue, e.g. to repair a cleft palate or help a burn to heal
- laser treatment, e.g. to reduce birthmark,
- ongoing management, e.g. eczema, burn scars.

Surgery and other treatments can make conditions less conspicuous but complete transformations are rare. For many conditions no effective treatment is available.

It might seem that children with the most severe disfigurements will be the most seriously adversely affected, but research shows that this is not so². A pupil may be seriously affected by her³ unusual, changed or changing appearance, even though it does not look so very bad to you or others. This may be because reactions to a minor disfigurement are less consistent, whereas responses to a major disfigurement are more predictable⁴.

Research also shows that dislike of a child with a facial disfigurement increases with age: older children tend to be less accepting.⁵

Disfigurements of the face or hands are particularly noticeable, but other parts of the body will also be on show at times. Summer clothes, swimming and getting changed for sport can trigger curiosity or staring, even from good friends and familiar classmates. Conditions such as cerebral palsy or scoliosis, affecting a child's posture or movement, may also trigger staring and curiosity in others.

¹ Based on OPCS(1988) Report 1, The prevalence of disability among adults, HMSO.

² Findings summarised in *The Full Picture*, A *Changing Faces* publication.

³ Through out these *Guides* we alternate between he and she and use either to refer to both boys and girls.

⁴ Macgregor (1990) Facial disfigurement: problems and management of social interaction and implications for mental health, *Aesthetic Plastic Surgery*, 14(4).

⁵ Richardson (1970) quoted in Bull,R. & Rumsey,N.(1988) *The Social Psychology of Facial Appearance*, Springer-Verlag, New York Inc.

Even though others may not consciously intend to treat a person differently or less favourably when they have a facial disfigurement, almost all people do, especially upon first meeting them.⁶

2 HOW DISFIGUREMENT AFFECTS PEOPLE

Whatever the cause and the apparent severity of a child's disfigurement, a variety of difficulties are experienced:

- out and about in public places such as supermarkets or on public transport – other people look and stare, pass comment, ask questions, or give advice. Having an illness, injury or condition that affects the way you look deprives you of the ordinary social anonymity we all take for granted when we go out.
- meeting new people – the noticeable feature is distracting, particularly if the eyes-nose-mouth 'communication triangle' is affected. New people are apt to be either over-focused on the unusual feature or to determinedly ignore it – in either case it is hard to 'act natural'.
- underachievement in education and working life – because of (1) lowered self-esteem due to unfulfilling social interactions because of reactions to disfigurement outlined above; (2) lowered expectations because of a prevailing social myth that a child with a facial disfigurement doesn't have much of a future; (3) discrimination throughout society in favour of people with conventionally 'attractive' facial features.

3 WHY DOES THIS HAPPEN?

The usual first 'lesson' most of us learn about disfigurement will have taken place when we were quite small and saw someone who looked unlike anyone we'd ever seen before. As young children do, we immediately asked whichever grown-up was with us, "Why is that man's face like that?" This kind of question invariably brings a stern response – "Sshhh! It's rude to stare!" The outcome, over time, is that while disfigurement is invariably associated with reactions such as surprise, concern, and curiosity, there is also a strong general rule – a taboo – against asking or talking about it.

At the same time human beings have an enormous capacity for noticing and remembering faces, identifying likenesses and recognising people we haven't seen for ages. *Appearance* matters to us – we don't look and react as we do to a new and unusual face because we're rude (although some reactions are excessive and unnecessary), but simply because we're human.

In the absence of a free flow of questions and answers when someone looks unusual, our imagination tends to step in. Common myths about disfigurement include

- imagining that someone who looks like that cannot have a happy, fulfilling life
- imagining that plastic surgery can make it go away
- imagining that appearance doesn't matter because it's the inside that counts.

⁶ Kleck and Strenta (1980) quoted in Bull, R. & Rumsey, N. (1988), as above.

Myths like these make it much harder to meet and get to know a child or young person with a disfigurement. For more about unravelling the myths and misconceptions about disfigurement, see the *Changing Faces* booklet, *Facing Changes*.

4. DISFIGUREMENT – A SOCIAL CHALLENGE

The most commonly expressed concerns of children and young people are

- other people's embarrassment
- reactions, including staring, comments and questions about their appearance
- teasing, name-calling and ostracism.

It is not the disfigurement which creates barriers but people's responses to disfigurement.⁷ This is a very important research finding because it opens up the possibility of devising social interventions which enable barriers to be overcome.

On one side, the child or young person with the facial difference can learn to deal positively with other people's preoccupation with or avoidance of their appearance. This is best achieved if they learn to take the initiative by saying something to acknowledge the reaction of surprise or curiosity and enable others to 'see' them as the ordinary person they are. This takes time and practice - see the *Guide on Having something to say*.

On the other side, we can all learn something more socially useful than "It's rude to stare." Particularly in our media-dominated and style-conscious culture, we can all benefit from learning to see the 'whole person' – seeing how people look but without judgement and combining what we see by way of appearance with what we discover by making eye-contact, perhaps with a smile, and exchanging a few words. The *Guide on Working inclusively with groups* outlines learning activities to help children and young people to develop their powers of perception, expression and communication in the important areas of appearance, personality and difference.

As well as being the place where children and young people come to learn, early years settings, schools, and colleges provide ideal *social* environments for addressing the challenge of disfigurement. This series of guides will enable you to:

- address everyone's real reactions of surprise, concern and curiosity
- teach the child or young person you are working with to acquire a better understanding of other people's reactions to the way they look and learn a range of special social skills which deal with these reactions.

In this way everyone can learn to face disfigurement more confidently.

5 DISFIGUREMENT AND THE LAW

Part IV of the Disability Discrimination Act 1995, as amended by the Special Educational Needs and Disability Act 2001 establishes disfigurement as a disability. As with many people who are considered to be disabled by the Government and the Disability Rights

⁷ Findings summarised in *The Psychology of Facial Disfigurement*, a *Changing Faces* publication

Commission, children and young people with disfigurements may not consider themselves to have a disability. However, the legislation still applies. A person is considered to be disabled (and covered by the legislation) if they have a disability or long-term illness that has an impact on their day-to-day life, and this includes disfigurement.

What this means for early years settings, schools and colleges is that it is unlawful to discriminate against a pupil with a disfigurement in respect of -

- Admissions
- Education and associated services, covering all aspects of school life
- Exclusions

A pupil with a disfigurement can be discriminated against -

- if the child receives **less favourable treatment** at school than other children because of his or her disfigurement
- if the school has **failed to make a reasonable adjustment** to ensure that the child is not at a substantial disadvantage compared with other pupils, because of his or her disfigurement

A child or young person with a disfigurement might be at a substantial disadvantage if, for instance, his experience at school provided less opportunities or facilitated less progress than other pupils, or entailed indignity or discomfort or required more effort than was the case for other children.

The legislation requires education providers to think ahead, and keep their policies, preparations and provision under review. Early years settings, schools and colleges have an **anticipatory duty** towards all pupils and potential pupils with disfigurement (who may not see themselves as disabled, as explained above, and who may not think of their visible difference as a disfigurement).

The Disability Rights Commission *Code of Practice for Schools* explains the law and its requirements clearly with many examples. This can be obtained from

DRC Helpline, Freepost, MIN 02164, Stratford Upon Avon, CV37 9BR, tel 08457 622 633 text phone 08457 622 644 email enquiry@drc-gb.org website www.drc-gb.org

To help you in your work with a child or young person who has a disfigurement, and with all the children or young people you work with, use the guidance for your part of the UK.

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| <p>For England the Department for Education and Skills provides guidance under <i>Every Child Matters</i> www.everychildmatters.gov.uk</p> <p>DfES Publications, PO Box 5050, Sherwood Park, Annesley, Nottinghamshire, NG15 0DJ</p> <p>tel: 0845 60 222 60 e-mail: EveryChildMatters.MAILBOX@dfes.gsi.gov.uk</p> | <p>For Scotland the guidance is <i>Getting it right for every child</i> from</p> <p>The Scottish Executive Education Department Victoria Quay, Edinburgh, EH6 6QQ</p> <p>tel: 08457 741741, minicom: 0131 244 1829, e-mail ceu@scotland.gov.uk</p> |
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| <p>In Wales the guidance is set out in the Code of Practice National Assembly for Wales Cardiff Bay, Cardiff, CF99 1NA tel: 02920 825 111 e-mail: assembly.info@wales.gsi.gov.uk website: www.wales.gov.uk/index.htm See also Inclusion and Pupil Support consultation document at www.learning.wales.gov.uk/inclusionsupport</p> | <p>In Northern Ireland the guidance is set out in the Code of Practice and the S.E.N.Disability Order Department of Education for Northern Ireland Rathgael House, 43 Balloo Road, Bangor, Co Down, BT19 7PR tel:: 028 9127 9279 websites: deni.gov.uk and opsi.gov.uk e-mail:: mail@deni.gov.uk</p> |
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6 EDUCATION AND DISFIGUREMENT

To enable a child or young person with a disfigurement to enjoy and achieve in early years, school or college, be healthy and safe, and to be enabled to make a contribution and achieve economic well-being, you and your colleagues will need to undertake some preparation and to make some adjustments.

- Staff need a basic understanding of the basic psychological and social issues that arise for everyone when someone has a disfigurement.
- Anticipate the curiosity and the questions that children or young people will experience and prepare responses which will be socially positive for everyone.
- Carefully monitor social interactions among pupils.
- Develop interventions to discourage teasing or ostracism and facilitate positive social interactions.
- If required, create special opportunities for a child or young person who looks different to discover and practice better social interactions, including positive responses to other people's reactions to their disfigurement.
- Identify signs of low self-esteem and build good self-esteem.
- Work closely with parents and with other professionals, if involved, to ensure good care and support if required and good transitions, e.g. if the child or young person is away receiving medical treatment and then returning to school, and when moving to a new school.
- Ensure learning activities and resources enable children and young people to go beyond stereotypes around appearance, difference and disfigurement.

All these actions and adjustments are covered by the *Guides* to help you plan, prepare and provide inclusive learning experiences, both socially and academically.

7 USING THIS SET OF GUIDES

The *Guides* cover three age groups – early years, 3-6 years, junior, 7-11 years, and secondary, 11-16 years. For each age-group there are twelve guides which aim to address all the different questions and concerns that may arise when working with a child or young person who has a condition, illness or injury that affects the way they look.

1. Starting early years or school
2. Working with parents and siblings
3. Working collaboratively with other professionals
4. Working inclusively with groups
5. Having something to say
6. Building self-esteem

7. Practical support with social skills
8. Self-expression
9. Teasing, name-calling and bullying
10. Addressing speech and language difficulties
11. Choosing and using resources
12. Moving on (primary school, secondary school, college and work)

We have made the *Guides* as brief and accessible as we can so that you can find what you need without having to work through a lot of other material. Each one aims to be both informative and practical so that you can approach the challenge of disfigurement knowledgeably, sensitively and effectively.

You may also like to read the booklet, *Facing Changes*, which includes a range of personal accounts of living with disfigurement and explores some of the main social issues, myths and challenges in more detail.

If you want to extend and deepen your knowledge and understanding further, we recommend *Educating Children with Facial Disfigurement – Creating Inclusive School Communities* by Jane Frances, RoutledgeFalmer ISBN 0415280451

We hope your experience of teaching and supporting a child with a disfigurement will be enriching for you and for all the children you work with. If you require further information or advice on any aspect of appearance and visible difference or about helping a child affected by disfigurement please visit our website or contact us at our London office and ask to speak to a member of our Children and Young People Service.

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