

7–11 years. Supporting a child with a disfigurement: a teacher's guide

Guide 1. Starting junior school

When preparing for the arrival of a child who has an unusual appearance, all staff will need information about how looking different affects both adults and children as well as some practical 'do's and don'ts' for dealing with reactions such as staring, making comments and asking questions. Ideally these preparations should be undertaken well before the new pupil joins your school.

The child will probably have had a settled period in infant school where everyone has become used to the way she looks. The staff there will be an important source of information about how the child has managed and how the new challenges might most effectively be approached.

Arrange to meet the child and her family at an early stage. (See the *Guide on Working with parents and siblings*.) Ask what the family calls their child's condition, injury or illness and how they describe it. Some families may need to spend some time and thought on this.

Also ask parents how they deal with other people's reactions to the way their child looks because families cope in different ways:

- giving positive answers to other people's questions
- reacting with hostility to strangers' reactions to their child's disfigured appearance
- ignoring the unwanted attention their child receives
- protecting their child from staring and curiosity by avoiding situations such as playgrounds and supermarkets
- using different approaches at different times.

It will also be very useful to make contact at an early stage with other professionals who may be involved. Request and read all the assessments and reports about this new child to help you identify and meet all the needs she may have, and ensure good ongoing support. Also, if difficulties do arise at a later stage, you will be well placed to share your concerns and seek additional input if required. See the *Guide on Working collaboratively with other professionals*.

1 LOOKING AND BEING LOOKED AT

Both children and adults who look different often experience staring, questions and comments, especially from people who haven't met them before. Most of us find it unpleasant to be stared at or pestered with questions, for whatever reason. But when your school has a new pupil who has a condition, injury or illness that affects the way they look, it is going to be important to handle the other children's reactions positively.

It is important not to prohibit staring and curiosity. Making friends begins with looking and being looked at. The other children are likely to look carefully, perhaps with surprise and interest. They usually ask questions – of the child herself, of another child, or of a nearby member of staff. If these expressions of interest are discouraged the child who looks different is at risk of finding it harder in the long run to make friends.

2 LOOKING AT YOUR OWN FEELINGS AND BELIEFS

Anyone encountering a person who has a disfigurement can experience many different reactions. This is especially so when it is a child who has a condition, injury or illness which affects the way they look. But with all the demands teachers meet every day, you may not have time to pause and fully register your own reactions when you meet the new child who has a disfigurement.

Find time to check yourself out. You may feel embarrassed, shocked, upset, angry, vulnerable, repulsed, or touched with pity by a child whose appearance is unusual. Recognising your own feelings and beliefs about appearance and disfigurement will help you to support the child better.

...about appearance

How important is appearance for you? What does a person's outward appearance say about them? How are you affected by people's appearance?

Try and notice other aspects of people as well as their physical appearance. What about their character, their attitudes, energy, sensitivity, imagination or humour?

...about disfigurement

What are your assumptions or beliefs about disfigurement? Throughout history and across many cultures, beauty has often been linked to goodness, virtue and happy endings, disfigurement to badness, sin and punishment. What do *you* think? What are your hopes and fears for this young child, both now and in the future?

There are in fact many people with disfigurements leading full lives, with careers, families, and all the usual ups and downs. They have developed the social skills and strategies, and built up the self-esteem to respond effectively each time they encounter someone who stares or doesn't know where to look.

3 LINKING WITH PREVIOUS TEACHERS WHO KNOW THE CHILD

As the child's teacher you need fuller answers to the questions below so that you can prepare effectively for her visits and eventual start at your school. Arrange to observe the child in her current class *and at playtime*. Talk to her current teacher about how she experiences school, including the social environment school provides. The focus of any information about your new pupil's disfigurement needs to be *the child* rather than the disfigurement:

- Who is this child? What has happened to her face (or hands etc)?
- How does this affect her? (Speech? Breathing? Swallowing? Hearing? Sight? Sensitivity to heat or cold? Fine motor skills?)
- How does she manage?
- Is her condition stable or will it / could it alter? If so, would the alteration be gradual or sudden?
- Does she have any ongoing treatment, or is any medical treatment planned?
- How is school attendance affected (or may be affected in future?)

- What about her personality, strengths and abilities? What resources does she herself bring to the challenge of disfigurement?
- How well does she engage socially with other children?... and with adults she knows well?
- How does she respond when people she does not know well look at her and comment or ask a question? Does she have an answer of her own, or does she let others speak for her? ...Sometimes? Always?
- What form of words have been used by staff to respond to other people's expressions of curiosity or concern?

4 PREPARING STAFF FOR THE NEW CHALLENGE

All the staff at your school, including parents who help, will have an important part to play in ensuring that everyone becomes comfortable and confident about disfigurement.

Sharing information

...about the child

Carefully plan a brief information session, perhaps as part of a more general staff meeting, before the new pupil makes her first visit from the feeder school. From your meeting with parents and your discussions with the new pupil's current teacher and other professionals involved, you will have information about the new pupil and the condition, injury or illness that affects the way she looks. Prepare information for colleagues in collaboration with the parents so that no information is passed on without their full consent, using words acceptable to the family.

Through your usual pre-admission meeting(s) with the new child and your skills of observation and assessment, you will also have information to be shared with colleagues concerning this new child's development, strengths and needs, both educationally and socially (as for any child about to join your school).

...about the social psychology of appearance and disfigurement

You will need to help colleagues develop an additional awareness and understanding of the issues associated with disfigurement. The essential consequence for anyone who has a disfigurement is the need to deal with other people's reactions to the way they look.

The new child's social, psychological and educational development will be affected (and may already have been affected) by her experience of staring, comments and questions. She is now going to have to face the reactions of everyone at her new school – yourself, your colleagues and all the other children and their parents. Ensuring that all staff understand what to say and do about such behaviours as staring, curiosity, commenting and asking questions will help to ensure that the new child can enjoy this new stage of her education and become socially confident.

...about common pitfalls

As well as issues around staring, there are some other well-intentioned interventions which need to be carefully checked.

- It can seem helpful to say that a child is "...just the same as everyone else," perhaps meaning that he or she needs the same learning and social experiences

as everyone else. However, you risk losing credibility with both children and adults, who can all see that something has happened to make this child look different.

- “It’s the inside that counts” is another well-meant attempt to smooth the path for a pupil with a disfigurement. Of course the inside counts, but the outside, the way we look, counts too. If you avoid referring to appearance you may create problems for the future.
- TV and magazines emphasise appearance, but even so, it is profoundly human to notice other people’s appearance and differences, especially faces. People who look different have to work *with this*, they cannot pretend it isn’t so.
- The child who looks different will know that she is being noticed all the time, and yet no one ever says a word about it. You risk undermining the experience of the child whose appearance is not to be mentioned.
- The child concerned may at times be worried or interested in what has happened to or in how she looks. If you and other adults make a rule that appearance is not to be spoken of, it will discourage the child from talking to you about this.
- On television and in books, characters are sometimes described and perhaps judged in terms of their appearance. If the child who has a disfigurement and the other children have not been allowed to talk about appearance and difference, the fictional book or film may become a substitute reality for them.

5 ANSWERING PUPILS’ QUESTIONS

You will be well aware that children constantly ask questions about everything. The questions they ask about another child’s appearance are just a part of this relentless curiosity about the world. Commonly asked questions include:

- Why is her face like that?
- What happened to his hand?
- Does it have a name?
- Does she have to go to hospital?
- Can I catch it?
- Does it hurt?
- Will it go away?

All staff will need to be briefed to deal with this inevitable curiosity. Even if the curious child does not speak their question aloud, but only looks, it will be best to treat their interest as a question. Your preparations will need to take account of whether the new pupil herself can answer other children’s questions, or whether staff members will need to do so. Staff need to be prepared with the words and phrases that have been agreed in advance through discussion with the parents and, if possible, with the new pupil too. (For more about this see the *Guide on Having something to say*.)

A short answer will satisfy most children. For example:

- That’s just the way Millie’s face is.
- John has a scar. He was hurt but he is OK now.

- Zak has one ear like yours and one folded-up ear.
- Jemma has had a pink mark on her face since she was a baby.
- It's got along medical name so it's called NF for short.
- No, you can't catch it.
- Yes, I think it does get sore. Milo has to keep putting special cream on his skin.

The really crucial thing here is to follow the short answer with something else to move the conversation on in a natural and appropriate way. If the pupil is answering for herself, she will need to have learnt and practiced doing this. If staff will be answering for her, they will need to follow on using one of the following techniques:

Switching the focus back to the pupil who asked.

EXAMPLE: "That's Jodi's birth-mark. I've got a mole on my elbow. Have you got an interesting mark somewhere?" or "Kieran has a big eye and a small eye. His eyes are brown. What colour are your eyes?"

Leading the conversational flow towards another subject.

EXAMPLE: "Natasha had to go to hospital yesterday but she was here again bright and early this morning. Would you like to help me put these books out on the tables?"

When staff answer, it will be useful if the pupil who looks different hears how the other children's questions are handled. By modelling answers in this way you can help her to learn when and how to speak up for herself, so that she can do this when she is ready. (See the *Guide on Having something to say*).