

3 – 6 years. Supporting a child with a disfigurement: a teacher's guide

Guide 5. Having something to say

A very young child may appear to be unaware of their unusual appearance. However, sooner or later, they will encounter other children who notice and are curious. Children can be very forthright with their curiosity and will ask direct questions such as “What’s that on your face?” A child may touch another child’s unusual feature, or even try to rub or pull off a mark on another child’s face.

Adults’ reactions to children’s curiosity are crucial to the way the children come to feel about disfigurement – in others or in themselves. Many adults will subscribe to the commonly held belief that personal remarks are extremely rude and that a visible difference should never be noticed or discussed.

As it is not nice to be stared at, adults often tell children not to stare. But children often avoid staring by turning away from the child who looks different. The child with a disfigurement will then find it harder to play socially and make friends.

All the research into the social experiences of people with disfigurement indicates that it is more helpful to tolerate some initial curiosity, even if it looks like ‘staring’, and to say something very brief about the way they look.

1 MODELLING EFFECTIVE RESPONSES

Children learn much from watching and experiencing what other people do. As influential adults, you and your colleagues will help a child who has a disfigurement simply by responding effectively to expressions of curiosity and concern about a child’s unusual appearance. Then when the child himself is ready to respond to other people’s reactions, he will know how to do this.

To make a positive and effective response, this is what a child needs to learn:

1. Recognise that surprise and curiosity are normal reactions and not expressions of deliberate unkindness
2. Respond with just enough information and reassurance to enable the other person to settle their thoughts
3. Having mentioned the disfigurement, move the attention on to something else.

The child you are supporting will gradually understand that when he meets new people there will be concern and curiosity. Rather than being annoyed or daunted by this, he can deal positively with a potentially awkward situation. The age at which a child is able to do this will vary. All children need the watchful support and modelled interventions of the adults around them.

Modelling good social responses to curiosity about disfigurement is useful even when a child who has a facial difference does not seem to be aware of reactions to their unusual

appearance. Having no response prepared leaves a child at risk of reacting anxiously, defensively or with annoyance – leading to unsatisfactory social interactions.

2 DECIDING WHAT TO SAY

The exact form of words that everyone will use needs to be discussed with parents. Find out if the child already uses a specific form of words to describe his unusual feature, for example 'It's my birthmark'.

If not, you will need to work with the parents to find words and phrases that feel comfortable. This calls for sensitivity and respect. There may be painful issues for parents about what has happened to their child, or concerns about diagnosis and medical language. Parents' cultural background may also have a bearing on what they want to say.

It can be helpful to draw up a list of all the things you and the parents can think of that you might say, and then pick out the ones which seem to work best. Here are some examples which may be helpful to get started (taken from the *Guide on Starting School*).

- That's just the way Chloe's face is.
- Danny has a scar. He was hurt but he is OK now.
- Muna has one ear like yours and one folded-up ear.
- Jess has had a pink mark on her face since she was a baby.
- You can't catch it.
- When it gets sore we put cream on it.
- Kieran has a big eye and a small eye.

If you and the parents can arrive at two or three options, it will then be very useful to see if the child has a preference. You or a parent need to ask what he would like to say if someone asked him about the way he looks. Then give him the options you have arrived at together. He might like to have some time to try out different responses before choosing. You could play out a situation together like a 'pretend' game.

At first it is best if everyone uses the same simple form of words, both in and out of school. Over time a more extensive range of responses will develop depending on the social situation.

3 MOVING THE CONVERSATION ON

This is a key social skill to model as part of 'having something to say'. When you model it you will be helping everyone to be more comfortable with difference. Later, when the child is ready to start speaking for himself, he will be able to avoid too much attention to his unusual appearance while showing something positive about himself as a person.

Children with disfigurements find the following kinds of follow-ons particularly useful.

1. Showing an interest in the child who asked

Teacher: "That's just the way Craig's skull is. Is your skull smooth as a ball all over or can you feel any little ups and downs?" (Run your fingers over your own forehead and scalp too!)

Child: “It’s a scar from when a dog bit me. Have you ever had a bad cut or a big bruise?”

2. Maintaining conversation but changing the subject

Teacher: “Jamie was in a fire but he’s okay now. Let’s wipe the tables, shall we?”

Child: “It’s called a birthmark – I always had it. Do you want play footie with us?”

3. Ending the conversation

Teacher: “Naomi has eczema. It makes her skin very dry and sore. You can’t catch it. Do you want to get your coat and go out to play?”

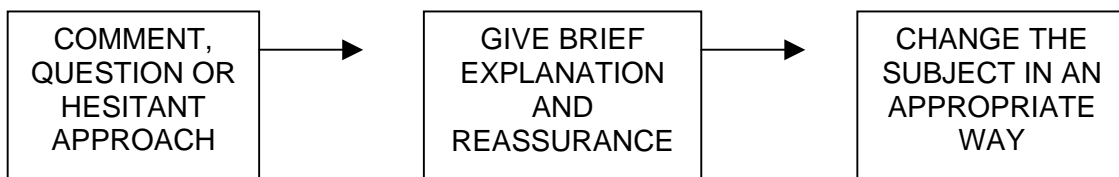
Child: “It’s just the way my head is. My Mum’s waiting for me – see ya.”

Learning and rehearsing in a ‘safe’ situation, e.g. role-play, can help the child gain confidence in using planned responses. Children can be helped to do this by using toys or puppets to try out interactions.

If or when the child who looks different is able to give their own response to comments or questions about the way he looks, notice how his interactions develop. Some children are much more socially fluent than others and you will be able to judge how much help your pupil needs with his ‘scripts’.

4 GETTING EVERYONE INVOLVED

All the adults in your playgroup, nursery or school need to be prepared to ‘model’ the process of taking the initiative, giving a brief explanation wherever the situation requires it, and moving the conversation on to something else. This information can be presented to staff as part of a meeting, preferably before the new child joins you. Staff will need to know what to look out for, how to respond, and how to move the conversation on.



It can be helpful if the parents of the other children can learn about this too so that they know what to say if their child saves up their questions until after school. As mentioned before, parents may (wrongly) want to tell their child that it’s rude to talk about it.

Josie - a case study
 Josie started school at the age of four – following her two older brothers. She had a large portwine birthmark mark over her face and was happy to tell people that she was born with the mark and it was called a birthmark. Her family gave her plenty of support and she was well accepted in her local community.

The staff at Josie’s infant school were prepared to use agreed ways of talking about Josie’s birthmark when the subject arose naturally. What they did not expect was the

reaction of some of the parents and older children who did not know Josie. The staring and comments at the school gates upset Josie's brothers very much and resulted in arguments with some older children.

Members of staff met to discuss the problem and decided to supervise the infant school gate. They were careful to monitor reactions to Josie's face and to respond when necessary with a simple explanation followed by a change of subject.

The class teachers of the older children taught lessons in which they included issues of differences of appearance and the anxiety that all children commonly feel when they are made aware of some aspect of their own appearance. They did not talk about Josie in her absence but they did talk about differences such as having red hair, being unusually tall or having scars following an accident. There were no further incidents and Josie settled happily into school life.

5 CONSIDERING SIBLINGS

A young child may have a brother or sister who gets comments and questions about their sibling's difference. They can learn to deal with curiosity, concern and comments by using the techniques of prepared responses described above. For more information about how a child's disfigurement can affect brothers and sisters, see the *Guide on Working with parents and siblings*.