

11-16 years. Supporting a child with a disfigurement: a teacher's guide

Guide 2. Working with parents and siblings

1 UNDERSTANDING FAMILY ISSUES AROUND DISFIGUREMENT

When a young person who has a disfigurement transfers to secondary school, parents often have concerns about her social acceptance and happiness. They may also have sensitive or painful concerns about the condition, injury or illness that affects the way their daughter looks.

Feelings of blame or guilt

Parents may blame themselves, especially if their daughter's disfigurement was caused by fire, dog bite or other traumatic incident.

These feelings may also arise where a child is born with a disfiguring condition, especially if the condition has a genetic component.

The condition, injury or illness which affects their daughter may have entailed numerous and/or painful medical procedures or there may be no effective treatment available for the illness or condition that affects her appearance.

The reactions of other people

The parents' wider network of relatives, friends and neighbours may have been affected by what has happened to their daughter.

There may have been difficult incidents where complete strangers reacted with surprise, concern or unkindness towards her unusual appearance.

There may have been bullying or ostracism because of the way their daughter looks.

Practical concerns

If the young person has had many visits to hospitals, or long journeys to specialist centres and overnight stays, the family's other children may have been cared for by relatives or neighbours.

There may have been, or still be, great difficulty in getting enough information or support.

Anxieties about their child's future

Myths and stereotypes about disfigurement may make parents very anxious about their child's future. (See *Changing Faces* booklet *Facing Changes*.)

Medical interventions may lie ahead or medical treatment may not have achieved the hoped for results. Parents must face intense hopes, fears and disappointments.

If the child's condition does not have a specific diagnosis parents may find it even harder to think about their child's future.

2 SHARING INFORMATION

To meet the Disability Discrimination Act duties, it is essential that schools create opportunities for parents and for pupils themselves to share information about possible and actual barriers and difficulties. Then preparations and adjustments can be made such as staff training, so that the pupil will not be disadvantaged because of her disfigurement.

An important part of encouraging the sharing of information will be developing the parents' and their son or daughter's trust that information they share will be handled sensitively. This is more likely to happen if school staff are welcoming and willing to explore possibilities for the young person's education and well-being at your school.

It will be useful if your records of a pupil with disfigurement can include details of all professionals who have been or are currently involved. This will help you refer parents to the appropriate professional when a specific concern arises.

If the parents find it difficult to talk about their child's unusual appearance or do not want to consider using social strategies such as 'Having something to say' when other people stare or ask, (see the *Guides on Starting senior school* and *Having something to say*), or if they have firm views which seem difficult to put into action, it could be useful at this point to contact the School Specialist at *Changing Faces*. The contact details are given at the end of this *Guide*.

3 ENSURING APPROPRIATE SUPPORT FOR PARENTS

Outside school, families range from those who have a good, informed network of supportive friends and professionals, to those who find themselves coping alone. The child's experience of previous schooling will have helped to shape parents understanding of what kind of support, if any, their child may need, and what kind of support is available.

If parents don't ask about additional support, this may not mean that they are managing well – it could be that they have low expectations or little hope. Be ready to let parents know about good sources of information, advice and support:

- For concerns about looking different, other people's reactions to unusual appearance, and the social and psychological well-being of a child or young person who has a condition, illness or injury that affects the way they look, contact *Changing Faces*. Contact details are at the end of this *Guide*.
- For more information about the condition or illness that affects the child, and about support groups for different illnesses and conditions, go to:
Contact a Family, 209-211 City Road, London EC1V 1JN, tel 020 7608 8700
 e-mail info@cafamily.org.uk website www.cafamily.org.uk
 Freephone for parents and families (Mon-Fri 10am-4pm) 0808 808 3555

Local support may also be available from within the community for children and young people with or without special needs and for other family members including parents. This can sometimes be harder to track down but your local authority, community centres and

religious centres in your area should have information about what kinds of clubs and groups are available locally.

4 DON'T FORGET THE SIBLINGS

The educational, emotional and social well-being of a pupil who has a disfigurement will in part be shaped by the well-being of the family as a whole. Your concerns will centre on the young person in your school but it may be appropriate to consider how her siblings are managing too, even if they attend other schools.

The brothers and sisters of a child who looks unusual are often subject to comments and questions and possibly to teasing and name-calling about their family member who looks different. If the siblings attend your school you will become aware of this. If not, ask the parents from time to time how their other children deal with curiosity and possibly unkindness about the family member who looks different.

Be prepared to liaise with staff at the school attended by your pupil's brother or sister. There are several points which the teachers of siblings may need to be aware of:

- Siblings can find it helpful to learn special social skills for dealing with the reactions of other children to their brother's or sister's unusual appearance. (See the *Guide on Having Something to Say*.)
- Brothers and sisters may have more than usual contact with hospital and medical settings or they may have been left with friends or relations while their sibling was away in hospital with their parents.
- Siblings may feel very responsible for the well-being and happiness of a brother or sister at school or they may feel a responsibility is being placed upon them which they do not want or cannot manage.
- Siblings need to be involved and allowed to express their feelings and opinions.

5 BUILDING GOOD SCHOOL-FAMILY LINKS

- Create opportunities, sooner and more frequently than you might for a pupil without a disfigurement, for your pupil and the parents to explore and consider education, training and employment options beyond school.
- Be flexible and sensitive to changing situations.
- Always share information about progress in learning and social development.
- Be clear and consistent about policies on access and inclusion.
- Find out about local groups and services that are available to support families and children. Find out how these services are accessed – including advocacy and interpreter services.