

GUIDE 2. WORKING WITH PARENTS/CARERS AND SIBLINGS

1 UNDERSTANDING FAMILY ISSUES AROUND VISIBLE DIFFERENCE

When a young person who has a visible difference transfers to secondary school, parents/carers 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 child looks.

Feelings of blame or guilt

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

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

The mark, scar or condition which affects their child may have entailed numerous and/or painful medical procedures or there may be no effective treatment available for the visible difference.

The reactions of other people

The family's wider network of relatives, friends and neighbours may have been affected by the young person's visible difference.

There may have been difficult incidents where complete strangers reacted with surprise, concern or unkindness towards the young person's unusual appearance.

There may have been bullying or ostracism because of the way the young person 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 young person's future

Myths and stereotypes about visible difference may make parents/carers very anxious about their child's future.

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

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

2 SHARING INFORMATION

To meet the requirements of the Equality Act, it is essential that schools create opportunities for parents/carers and for students 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 student will not be disadvantaged because of their visible difference. There are useful CPD resources for teachers and school staff called [A World of Difference](#) which can be used before the child starts school or during their time at school.

An important part of encouraging the sharing of information will be developing the parents/carers and their child's trust that any 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 student with a visible difference can include details of all professionals who have been or are currently involved. This will help you refer parents/carers to the appropriate professional if a specific concern arises.

If the parents find it difficult to talk about their child's visible difference 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 secondary school](#) and [Having something to say](#)). Or you need any help, you can call [Changing Faces](#) for advice and support.

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 young person'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/carers know about good sources of information, advice and support:

- For concerns about visible difference, other people's reactions to a young person, and the social and psychological well-being of a young person who has a condition, illness or injury that affects the way they look, contact [Changing Faces](#).
- For more information about the condition or illness that affects the child, and about support groups for different illnesses and conditions, go to [Contact](#).

Local support may also be available from within the community for young children and young people with or without special educational needs and disabilities, and for other family members including parents/carers. 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 student who has a visible difference 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 their siblings are managing too, even if they attend other schools.

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

Be prepared to liaise with staff at the school attended by your student'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 visible difference. (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 student without a visible difference, for your student and the parents/carers 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 young people. Find out how these services are accessed – including advocacy and interpreter services.