

7-11 GUIDE 2. WORKING WITH PARENTS, CARERS AND SIBLINGS

1 UNDERSTANDING FAMILY ISSUES AROUND A CHILD'S DISFIGUREMENT

When a child who has a disfigurement transfers to junior school, parents often have concerns about their 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/carers may blame themselves, especially if their child'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 reactions of other people

The parents'/carers' wider network of relatives, friends and neighbours may have been affected by what has happened to their child. There may have been difficult incidents where complete strangers reacted with surprise, concern or unkindness towards their child's unusual appearance.

Practical concerns

If the child has had many visits to hospitals, or long journeys to specialist centres and overnight stays, siblings may have been cared for by relatives or neighbours.

There may have been (or still be ongoing) hugely stressful difficulties with breathing, feeding and/or sleeping.

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/carers very anxious about their child's future.

Medical interventions may be needed over many years or medical treatment may not entirely achieve the hoped-for results. Parents may face intense hopes, fears and disappointments. If the child's condition does not yet have a diagnosis parents may find it even harder to think about their child's future.

2 SHARING INFORMATION

As the child's teacher you will want to make sure you create opportunities for parents/carers and for children 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 child will not be disadvantaged because of their visible difference.

Any information that is shared must be handled sensitively and show regard for the General Data Protection Regulation (GDPR). An important part of encouraging the sharing of information will be developing parents' trust. This is more likely to happen if you are welcoming and willing to explore possibilities for the child in your junior setting. It will be useful if your records of a child with a visible difference can include details of other professionals who have been or are currently involved with the child. This will help you refer parents to the appropriate professional if a specific concern arises.

Parents/carers may not know that when a child can be referred for assessment for extra educational provision, if this is thought to be beneficial. If you have any concerns it is important to speak with

the person responsible for coordinating support for children with special educational needs and disabilities.

If the parents/carers find it difficult to talk about their child's visible difference or do not want to consider using social strategies (see the [Guide on Having something to say](#)) when other people stare or ask questions; you can suggest that they may want to contact Changing Faces for advice and support.

3 ENSURING APPROPRIATE SUPPORT FOR PARENTS

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

Be ready to let parents/carers know about good sources of information, advice and support. If parents/carers don't ask about additional support, don't assume they wouldn't welcome it – it could be that they have low expectations or little hope.

- For concerns about visible difference, other people's reactions to a child, and the social and psychological well-being of a child 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 <https://contact.org.uk/>

Much more locally, support may be available from within the community for children with various special needs or with none, and for other family members including parents. This can sometimes be harder to track down but your local authority and 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 and social well-being of a child 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 child you are working with, but it may be appropriate to consider how this child's siblings are managing too, even if they attend another setting or a school nearby.

The brothers and sisters of a child with a visible difference 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/carers from time to time how their other children deal with curiosity or unkindness about their child who looks different.

Be prepared to liaise with staff at the school attended by your pupil's siblings. This may well be the school which the child you are working with will attend when they are older. There are several points which the teachers of siblings may need to be made aware of:

- Siblings can find it helpful to learn special social skills for dealing with the reactions of other children to their sibling's visible difference. (See the *Guide on Having something to say*)
- Brothers and sisters may have more than usual contact with hospital and medical problems or they may have been left with friends or relations while their sibling was away in hospital with their parents.

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- 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

- 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.