

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

## **Guide 2. Working with parents and siblings**

### **1 UNDERSTANDING FAMILY ISSUES AROUND A CHILD'S DISFIGUREMENT**

When it is time for their child to start early years or infants, parents whose child has a disfigurement 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 disfigurement was caused by fire, dog bite or other traumatic event.

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' 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, the family's other children 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 very anxious about their child's future. (See *Changing Faces* booklet *Facing Changes*.)

Medical interventions may be needed over many years or medical treatment may not entirely achieve the hoped for results. Parents must 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 her future.

## 2 SHARING INFORMATION

Information is a crucial part of meeting the Disability Discrimination Act duties. As an early years teacher you will want to make sure you create opportunities for parents 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 her disfigurement.

An important part of encouraging the sharing of information will be developing parents' trust that information they share will be handled sensitively. This is more likely to happen if you are welcoming and willing to explore possibilities for the child in your early years or infant setting. It will be useful if your records of a child with disfigurement 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 when a specific concern arises.

Parents may not know that when a child has a significant impairment they may be referred for assessment for extra educational provision. Early Years Action or Early Years Action Plus ensure additional support is identified within the nursery setting or by more specialist help such as the Early Years Area SENCO or an Educational Psychologist.

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 *Guide on 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*.

## 3 ENSURING APPROPRIATE SUPPORT FOR PARENTS

Families range from those who have had good, informed support to those who have been coping alone with little idea where to go for advice, information and support.

Be ready to let parents know about good sources of information, advice and support. If parents 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 disfigurement, other people's reactions to a child's unusual appearance, 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 *Contact a Family*, 209-211 City Road, London EC1V 1JN, tel 020 7608 8700, e-mail [info@cafamily.org.uk](mailto:info@cafamily.org.uk) website [www.cafamily.org.uk](http://www.cafamily.org.uk). Freephone for parents and families (Mon-Fri 10am-4pm) 0808 808 3555

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 Early Years Area SENCO should be able to help. It can also be useful to find out what kinds of clubs and groups are run at local community centres and religious centres in your area.

## 4 DON'T FORGET THE SIBLINGS

The educational and social well-being of a child 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 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 early years setting or a school nearby.

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 early years setting or infant school together you will become aware of this. If not, ask the parents from time to time how their other children deal with curiosity or unkindness about their son or daughter who looks different.

Be prepared to liaise with staff at the school attended by your pupil's brother or sister. This may well be the school which the child you are working with will attend when she is 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 brother 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 problems 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

- 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.