

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

Guide 3. Working collaboratively with other professionals

Medical needs vary greatly for children with disfiguring illnesses, injuries and conditions. Equally, a child with a disfigurement may or may not have special educational needs. Other professionals will be involved if he has:

- medical needs associated with his disfiguring injury, illness or condition
- an additional disability or special educational needs – which may or may not be associated with the illness, injury or condition that affects the way he looks

Rachel aged 4 had a birthmark on her face. This was removed by surgery and the scar healed well and is gradually fading.

Joe aged 6 was born with a cleft lip and palate. He had surgery as an infant and has periodic surgery to improve his bite. Following surgical treatments he needs speech therapy to help him to readjust to the changed shape of his mouth.

Sophie aged 3 has eczema and needs to have cream applied regularly and to have her skin protected from the sun.

Michael aged 5 has Crouzon's syndrome. He has regular clinic appointments and monitoring of his hearing problems. He has had facial surgery, which considerably altered his appearance and required a long period of extra care and readjustment.

Some children see an interdisciplinary team of professionals at a specialist hospital centre e.g. a Cleft Team usually includes surgeon, specialist nurse, speech and language therapist, child psychologist. They are all based at the same centre and they will all see the child and his parents during a hospital visit or a hospital stay.

Other children may see health professionals at different hospitals or in their home area, depending on their individual medical needs. If there are other needs, professionals from other disciplines may be involved too. This can range from just one or two to a large number of different professionals - educational psychologist, community paediatrician, outreach nurse, occupational therapist, speech and language therapist, physiotherapist, social worker, educational welfare officer, child psychologist or specialist nurse from the Child and Adolescent Mental Health Service.

The professionals involved may not meet together except, in some cases, for an annual review meeting. Good communications and collaborative working will ensure the best outcomes for the child.

- Ensure that a named person in your early years setting or infant school is on everyone's file so that you receive a copy of all assessments, reports and other communications regarding the child.

- Include parents as full collaborative partners. Always let parents know when you hear (or don't hear) from other professionals and practitioners involved. Always ask if parents have received copies of reports and other communications etc.
- Where appropriate, be prepared to invite other professionals to meet and assess the child in your early years setting or infant school. It may help the child not to have to meet new people in unfamiliar settings.
- Be sure to keep an ongoing record of the child's achievements and positive experiences as well as concerns and other observations, to help with preparing assessments and reports when these are required.

1 ABSENCE FROM EARLY YEARS OR INFANT SCHOOL

Hospital settings where children stay in for treatment usually have a play specialist and care is taken to provide play and learning opportunities. However, hospital environments and medical treatments inevitably provide children with very different experiences from those available in early years and infants settings and at home:

- Much more contact with adults who are working to restore, maintain or improve specific aspects of the child's health
- Far less contact with children, often including less contact with siblings and other family members
- Painful or frightening medical procedures
- Restriction of movement during treatment and recovery eg treatment of serious burns may immobilise a child for many weeks
- Restriction of functioning during treatment and recovery eg feeding through tube to stomach following surgery to face, mouth, jaw or throat.

At home afterwards:

- Parents may be required to continue with procedures eg tube feeding, dressing changes, physiotherapy exercises
- Strength and stamina may be reduced following hospitalisation
- Activity and play may continue to be restricted for a time.

When a young child spends time away from his early years setting or infant class, it may not seem that he is missing much 'schoolwork' as is often the concern for older children. However, play and other activities among children are crucial to good social development.

A child with a disfiguring condition, injury or illness may seriously miss out on vital social foundations due to prolonged or repeated stays in hospital or the accumulated effect of days spent in clinics with outpatient appointments. The social experiences in early years become all the more important, even if – in fact *especially if* – the child seems reluctant because he is more used to being with adults rather than children of his own age.

2 CHANGED APPEARANCE

An injury, illness or medical treatment may noticeably alter a child's appearance.

- A head injury for example, or burns can change facial features or skin colour and texture, and can affect the mobility of the face. The child may be required to wear special pressure garments at all times, sometimes including a face-mask, to control and manage the growth of new skin.
- Illness and treatment can affect appearance – hair loss following chemotherapy; darkening of birthmark following laser treatment; loss of fingers or toes following meningitis and other serious infections.
- Some conditions require a series of surgical or medical treatments. A cleft palate, for example, may need a series of surgical repairs as the child grows. The way the child's voice sounds can be affected as well as their appearance.

Children are often thought to be resilient, but don't assume that this is so. Early years workers and infant school staff are well placed to make good observations of a child's emotional and behavioural patterns. If there are concerns about a child's emotional or behavioural development seek an assessment from the school nurse or Child and Adolescent Mental Health Service. They can identify conditions such as Post Traumatic Stress Disorder and Clinical Depression so that, if necessary, early intervention can be made.

3 RETURNING TO EARLY YEARS OR INFANT SCHOOL

It is important that children who have had medical treatment return to normal life as soon as possible although a child may, at first, be able to manage only an hour or two at a time back in their early years setting or infant class. Good contact with the parents and the medical and other professionals concerned and being flexible will help with smooth re-integration.

The child may also have new or different needs following a stay in hospital:

- Medical needs - seek advice and support regarding staffing, medication, special equipment, specialist treatment e.g. physiotherapy. For example burn injuries or severe eczema can lead to extreme sensitivity to warmth or to touch.
- Practical needs – a child with facial differences may find eating difficult and need more time or other arrangements at meal times. Also, after a period of hospitalisation, a child may have lowered strength or stamina and need help with some tasks and activities.
- Learning needs – trauma and hospitalisation may be followed by a period of regression: the child can no longer do some of the things he could do before and may behave in ways which seem 'younger' or inappropriate. It is important to allow him time to recover from this set-back.
- Emotional and social needs - as with learning needs, above, a child who has spent some time in hospital may lose ground in terms of social and psychological development. It will be important to identify and assess his new and perhaps

temporary needs in order to modify the demands made of him and provide appropriate support. See the *Guide on Practical support with social skills*.

- Physical needs – physical activities are often of prime importance for children who have been physically constrained for long periods by illness, injury or medical treatment. If stamina is limited, extra rest during the day may be more beneficial than reducing participation in physical activities.