

7-11 years. Supporting a child with a disfigurement: a teacher's guide

Guide 3. Working collaboratively with other professionals

A pupil who has a disfigurement may or may not have special educational needs. Other professionals will be involved if she has:

- medical needs associated with her 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 she looks.

Medical needs vary greatly for children with disfiguring illnesses, injuries and conditions. There may be no medical needs - perhaps following a completely successful treatment earlier in the child's life or because no treatment is available. Alternatively, the child may need medical interventions which lead to frequent or lengthy absences from school. If a pupil's medical needs are inadequately supported, this can have a significant impact on her capacity to enjoy and achieve at school and on her long-term outcomes educationally and socially.

When a pupil goes away to hospital, concerns often focus on keeping up with schoolwork. However, for good long-term social development children need plenty of opportunities to play and socialise together. Children develop their capacity to make and keep friends and to achieve positive social interactions of all kinds through play and other social experiences over many years. A child's social well-being underpins her capacity to achieve her educational potential.

A child who has missed out on such early years experiences as accepting and resisting each other's overtures¹ – grabbing and sharing in the sandpit – may find peer relationships difficult at junior school. This is often the case for a child with a disfigurement, due to a combination of other people's reactions to their unusual appearance and prolonged or repeated stays in hospital or outpatient appointments.

1 WORKING WITH OTHER PROFESSIONALS AND PARENTS

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 her 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 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, e.g. an educational psychologist, community paediatrician, outreach nurse, occupational therapist, speech and language therapist, physiotherapist,

¹ Rubin, K.H. and Wilkinson, M. (1995) 'Peer rejection and socialisation in childhood', in R.Eder (ed.) *Craniofacial Anomalies: Psychological Perspectives*, New York: Springer-Verlag, p168.

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 help to ensure the best outcomes for your pupil.

- Ensure that a named person, the SENCO perhaps, in your school is known to all the other professionals involved so that you receive a copy of all assessments, reports and other communications.
- Include parents as full collaborative partners. Always let parents know when you hear (or don't hear) from other professionals and practitioners involved, and ask if parents have received copies of reports and other communications.
- Where appropriate, be prepared to invite other professionals to meet and assess the child in your 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.

2 ABSENCE FROM SCHOOL FOR MEDICAL REASONS

Hospital settings where children stay in for treatment usually have a play specialist and sometimes a hospital school with teachers. Care is taken to provide play and learning opportunities but hospital environments and medical treatments inevitably entail very different experiences from those available in school and at home. These include:

- 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, e.g. treatment of serious burns may immobilise a child for many weeks
- Restriction of functioning during treatment and recovery, e.g. feeding through tube to stomach following surgery to face, mouth, jaw or throat

At home afterwards:

- Parents may be required to continue with procedures, e.g. tube feeding, dressing changes, physiotherapy exercises
- Strength and stamina may be reduced following hospitalisation
- A range of activities may continue to be restricted for a time.

When a pupil spends time away from school there is often concern about the learning and schoolwork she is missing. However, 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 child's social links with her peer group become all the more important, even if – in fact *especially if* – she seems reluctant because they are more used to being with adults.

There are several things you can do to help ensure the child's well-being, both educationally and socially:

- Nominate a teacher, perhaps the SENCO, to establish and maintain contact with other educational services such as the Hospital School or Home Tuition Service.
- Provide the hospital school or hospital teacher with information about the child's educational progress and targets and any learning difficulties they may have. This should include regular updates about what the child's class is covering in school. Continuity in content and teaching methods will ease re-integration later.
- Nominate a teacher, perhaps your pupil's class teacher, to establish and maintain links between the absent pupil and her classmates so that her sense of belonging in the school is not lost. Most pupils enjoy sending each other texts, e-mails, letters and cards.
- Maintain records of topics and learning covered by the pupil's class while she is absent to help with identifying priorities for 'catching up' later.
- Maintain meaningful contact with parents – such as sending school information and newsletters home, perhaps with a covering note asking about their child's progress.
- If the child spends some time recovering at home, it will be important to maintain the links set out above, and also to liaise with a home tutor or send some schoolwork home.
- If your pupil spends some time recovering at home, explore the possibility of arranging for classmates to visit her.

3 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 appearance.

Children are often thought to be resilient, but don't assume that this is so. School staff are well placed to make good observations of a pupil's emotional and behavioural patterns. If there are concerns about her behaviour or her emotional well-being 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.

4 RETURNING TO SCHOOL

It is important that children who have had medical treatment return to normal life as soon as possible. Good contact with parents and medical or other professionals can help with smooth re-integration but you will also need to be flexible as a child may, at first, be able to manage only an hour or two at a time back at school.

Your pupil 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. Burn injuries or severe eczema, for example can cause extreme sensitivity to heat or to touch.
- **Practical needs** Your pupil may find eating difficult and need more time or other arrangements at meal times. She may also have lowered stamina and need help with some activities.
- **Learning needs** Trauma and hospitalisation may be followed by a period of regression; your pupil can no longer do some of the things she could do before and may behave in ways which seem 'younger' or inappropriate. It is important to allow her time to recover from this set-back.
- **Psychosocial needs** As with learning needs, a child who has spent some time in hospital may lose ground in her social and psychological development. It is important to identify and assess her new, perhaps temporary, needs in order to modify the demands made of her 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 of time. If stamina is limited, consider varying arrangements for activities such as PE and swimming as extra rest during the school day may be more beneficial than reducing participation in physical activities.