

# Meeting medical needs in mainstream education

Jessica Datta, Nicola Ryder and Nicola Madge



NCB promotes the voices, interests and well-being of all children and young people across every aspect of their lives.

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# Contents

Acknowledgements .....	2
<b>Chapter 1: Introduction .....</b>	<b>7</b>
Medical needs .....	7
Inclusion: The legislative and policy framework.....	9
Links between disability, special educational needs and medical needs.....	9
Guidance for schools.....	10
The school health service.....	11
Working in partnership .....	13
School absence and education out of school .....	14
This report .....	16
<b>Chapter 2: The study methodology.....</b>	<b>17</b>
The study areas.....	17
Study area one .....	17
School inclusion .....	17
The schools.....	18
The school health service.....	18
Study area two.....	18
School inclusion .....	18
The schools.....	18
The school health service.....	19
Ethnicity within the study areas .....	19
The study schools .....	20
The school survey .....	20
Interviews with school staff.....	23
The case studies .....	23
Data analysis.....	25
Ethical issues .....	25
<b>Chapter 3: Medical needs and their impact .....</b>	<b>27</b>
Illness, medical conditions, disability and injury .....	27
A reclassification of conditions .....	28
How are medical conditions related to general health? .....	29
Is ethnicity related to medical conditions? .....	31
The impact of medical conditions on learning .....	32
The impact on mobility .....	33
The impact on friendships .....	34
Medical needs and choosing a school.....	36
Funding and inclusion.....	37
Medical needs, the school curriculum and extracurricular activities .....	37
Physical education and medical needs.....	38
Other curriculum subjects .....	39
Tests and examinations.....	40
Extracurricular activities.....	40
Time off school.....	41
Other types of impact .....	43
Families and medical needs.....	44

Schools' attitudes to and knowledge about medical needs .....	44
Key messages.....	46
<b>Chapter 4: Schools, their policies and practice .....</b>	<b>47</b>
Admissions procedures .....	47
Admissions and the physical environment.....	47
Policies on provision for students with medical needs.....	48
Disability access plans .....	49
Keeping records on students' medical needs.....	50
Gathering information .....	50
School databases .....	51
Medical needs registers.....	51
Healthcare plans.....	51
The relationship between SEN, disability and medical needs .....	52
School ethos.....	54
Key findings.....	55
<b>Chapter 5: Staff roles and responsibilities .....</b>	<b>56</b>
Providing general information and support.....	56
Seeking help.....	56
Taking responsibility .....	57
The pastoral team.....	57
The role of the school matron .....	58
The role of first aiders .....	60
Medication and its administration .....	61
How many young people need to take medication? .....	61
Supporting students at school.....	63
Consent and self-administration .....	64
How is the administration of medication organised? .....	64
Logging and monitoring .....	65
A dedicated medical room .....	65
Young people's views .....	66
Dealing with emergencies .....	67
The numbers involved .....	67
Medical emergencies or planned procedures? .....	67
Does fear of repercussion prevent school staff from acting in an emergency? .....	69
Young people and emergencies .....	69
The issue of personal care .....	70
Personal care needs.....	71
Facilities and support.....	71
Difficulties faced by students .....	71
Supporting students with personal care needs .....	72
Key findings.....	72
<b>Chapter 6: Absence from school and education out of school .....</b>	<b>74</b>
Rates of absence .....	74
Reasons for absence.....	75
Patterns of absence.....	75
Prolonged periods of absence.....	75
Recurrent absence.....	75
'Indirect' absence .....	76

The impact of absence .....	77
Falling behind .....	78
Effect on exams .....	78
The importance of education .....	79
Absence and friendships .....	79
Maintaining contact between schools and students during absence .....	79
Education during short or recurrent periods of absence .....	80
Home education.....	81
Education in hospital.....	83
Support for students following absence from school .....	84
Key findings.....	87
<b>Chapter 7: Sharing information and working together .....</b>	<b>89</b>
Information on students with medical conditions .....	89
Admission to a new school .....	89
Storing, updating and using information .....	90
Information-sharing between members of staff.....	90
The question of confidentiality .....	91
Providing a confidential 'listening ear' .....	93
The school health service.....	94
Public health .....	95
Advising and supporting students .....	95
Information and training .....	96
The school curriculum.....	96
The profile of the school health service .....	96
Community health and hospital services .....	96
Key findings.....	99
<b>Chapter 8: Knowledge of medical conditions and needs, and implications for training.....</b>	<b>100</b>
How much do school staff know about medical conditions? .....	100
What training do schools offer on medical conditions and needs? .....	101
Who provides the training? .....	102
Who should attend training sessions? .....	104
Key findings.....	104
<b>Chapter 9: Key messages .....</b>	<b>106</b>
A positive school ethos is an important factor .....	106
School policies, formal and informal.....	106
Defining and managing medical needs .....	107
Awareness of the impact of medical needs on young people.....	108
Students need someone they know and can turn to.....	108
Effective communication channels are essential .....	109
School policies are for all students .....	110
Managing school absence.....	110
Supporting schools to support students .....	111
<b>References .....</b>	<b>114</b>
<b>Appendix A: The school survey questionnaire.....</b>	<b>119</b>

**Appendix B: Medical conditions, disabilities and injuries reported by students who responded to the questionnaire ..... 123**

Sensory .....	123
Eyes.....	123
Ears .....	123
Accidents and injuries .....	123
Infections, viruses and short-term illness .....	123
Musculoskeletal conditions.....	124
Long-term medical or serious conditions.....	124
Non-medical conditions .....	126

## Chapter 1: Introduction

The past years have seen a decisive shift towards educational inclusion and the placement of children and young people with a wide range of medical needs within mainstream schools. While this approach is generally favoured, evidence suggesting that medical needs can remain 'somewhat hidden' (Lightfoot and others 2001) in mainstream education has led to some concern. This has not lessened, with recent reports on the rising rates of medical need in mainstream secondary schools relating this to medical advances and improved prognoses for children with conditions such as cancer and cystic fibrosis (National Statistics 2004), and the move away from specialist schools towards greater educational inclusion (Lightfoot and others 1999).

The purpose of this study is to look at how young people with medical needs cope in mainstream secondary schools, and to address this issue from the perspectives of young people themselves as well as from those of their parents and carers, schools and health practitioners. There is much literature on the medical needs associated with most conditions and syndromes, but far less is known about how young people with these conditions manage in mainstream education, or the degree to which their needs are met.

### Medical needs

For the purposes of this study, medical needs are conditions that, if not properly managed, could limit a young person's access to education. They might also have an impact on attainment, and could contribute to emotional or behavioural difficulties. It is recognised that students with medical conditions comprise a heterogeneous group of children and young people who may have little in common and include, for example, those with illnesses and chronic conditions (such as asthma, childhood arthritis, congenital heart disease, cystic fibrosis, diabetes, eczema, haemophilia, ME/CFS<sup>1</sup> and sickle-cell anaemia), deteriorating conditions (for example, Duchenne muscular dystrophy), injuries and the after-effects of accidents, and severe allergies, as well as those with disabilities that have associated special health needs (such as cerebral palsy and spina bifida). It is also appreciated that not all young people with certain defined conditions necessarily have medical needs at school.

Other studies and reports have suggested that a considerable proportion of young people have medical needs. The British Paediatric Association (BPA) estimated that – excluding acute illness, injuries and more routine transient illnesses – one in ten of those under the age of 15 has an illness that chronically reduces functional capacity (BPA 1995). While this estimate was supported by Erens and others (2001), Eiser (1993) put the figure nearer to 15 per cent if significant short-term illness was included. A survey carried out by the National Children's Bureau (NCB) found that 27 per cent of a sample of around 3,000 secondary school students self-reported a medical condition or disability (Madge and Franklin 2003).

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<sup>1</sup> Myalgic encephalopathy/chronic fatigue syndrome

The *Health Survey for England 2002* (DH 2002) provides information on the rates of medical conditions among young people (see Table 1.1). Respiratory conditions were most commonly reported, with 42 per cent of all reported disabilities due to asthma. The next most numerous category was skin conditions at 8 per cent.

**Table 1.1: Medical conditions among children and young people aged 0–16 years (in rates per 1000)**

Type of medical condition (ICD categories) <sup>2</sup>	Males	Females
Infectious diseases	1	1
Neoplasms and benign growths	1	1
Endocrine and metabolic disorders	5	6
Blood and related organs	3	5
Mental disorders	27	10
Nervous system	16	10
Eye complaints	10	8
Ear complaints	18	14
Heart and circulatory system	5	5
Respiratory system	123	99
Digestive system	18	14
Genito-urinary system	9	6
Skin complaints	45	43
Musculoskeletal system	16	13

Source: *Health Survey for England 2002* (DH 2000)

There is some indication that medical conditions are on the increase among young people. The *Health Survey for England 2003* (DH 2004a), for instance, reported a 9 per cent increase in the prevalence of long-term medical conditions among both boys and girls aged under 16 since 1995. This meant that 29 per cent of boys and 25 per cent of girls were reporting long-term conditions; 11 per cent and 9 per cent, respectively, reported limiting long-standing illness. No increase was found in the rates of acute illness, which remained at 10 per cent for boys and 14 per cent for girls. Other studies have suggested that the incidence of asthma among the young is on the increase (for example, Gupta and Strachan 2004). These figures provide good grounds for developing policies that support access to education for these young people.

It must also be noted that young people may suffer from more than one medical condition and that it is common for those with a disability or learning difficulties to also be affected by a medical condition.

<sup>2</sup> ICD categories as in the: *International Classification of Diseases and Related Health Problems* (10th Revision) World Health Organization, Geneva, 1992.

## **Inclusion: The legislative and policy framework**

The Special Educational Needs and Disability Act 2001 (SENDA) strengthened special educational needs (SEN) legislation and extended the scope of the Disability Discrimination Act 1995 (DDA) (Stobbs, 2001a and b). In relation to SEN, it reinforced the rights of students to attend mainstream schools unless incompatible with either parental wishes or the efficient education of other children and young people. In reference to disability, the SENDA importantly extended the scope of the 1995 DDA to education. Extended services to schools provided by youth services, voluntary agencies or private companies are also covered by the DDA. A range of guidance from the Disability Rights Commission (DRC) and the Department for Education and Skills (DfES) supported the implementation of the new duties. This guidance has been followed more recently by the development of practical resources to help schools implement these duties (DfES/DRC 2006).

The Disability Discrimination Act 2005 introduced a new duty on the public sector to promote disability equality. This new duty complements existing duties under the DDA and specifically requires schools to produce a Disability Equality Scheme. In producing such a scheme, the school must: involve disabled people (including disabled children and young people) and any other key stakeholders such as staff, parents and community groups; gather and make use of data which is relevant to the scheme; produce a three-year action plan; clarify how the impact of the action plan will be assessed; report annually on progress in promoting disability equality.

## **Links between disability, special educational needs and medical needs**

Special educational needs and disability are relatively independent concepts in terms of legislation and guidance. The important distinction for the purposes of this report is that the definition of SEN does not include many students with health needs – unless they also have educational needs. This does not mean, however, that many students who have SEN do not also have health needs. The definition of those with a ‘disability’, according to the DDA, does include students with a wide range of health needs – when the effect of their condition has a long-term and substantial effect on their ability to carry out normal, everyday activities. The DDA provides a useful definition of disability (see box below) and this is also explained in the accompanying guidance (HM Government 2002).

### ***Disability as defined by the Disability Discrimination Act 1995***

A person has a disability if he or she has a physical or mental impairment that has a substantial and long-term effect on his or her ability to carry out normal day-to-day activities.

The definition is broad and includes those with a wide range of impairments – including learning disabilities, dyslexia, diabetes and epilepsy – where the effect of the impairment on the student’s ability to carry out normal day-to-day activities is adverse, substantial and long term.

The functional definition employed by the DDA means medical conditions are recognised as disabilities only if they have specified impacts on everyday functioning. The *Disability Discrimination Act: Code of practice for schools* (DRC2002) outlines these impacts as relating to: mobility; manual dexterity; physical coordination; continence; ability to lift, carry or otherwise move everyday objects; speech, hearing or eyesight; memory or ability to concentrate, learn or understand; or perception of risk of physical danger. More recently, the Disability Discrimination Act 2005 established that individuals with conditions such as cancer, multiple sclerosis and HIV are considered disabled from the time when they know that they have the condition rather than from when the condition begins to interfere with their daily activities.

When SENDA extended the DDA to cover education, it introduced two key duties for schools which affect students with medical conditions. These are the 'less favourable treatment duty' and the 'reasonable adjustments duty'. It is unlawful for schools to discriminate against disabled pupils. Discrimination occurs if a school treats a disabled pupil or prospective student 'less favourably' than another for a reason related to their disability and without justification. It is also deemed discriminatory if a school fails, without justification, to make 'reasonable adjustments' to avoid placing disabled students at a substantial disadvantage.

## Guidance for schools

In response to long-standing concerns about the support of, and responsibility for, young people with medical needs, the DfES and Department of Health (DH) jointly published the good practice guidance *Supporting Pupils with Medical Needs* (DEE/DH 1996) and the accompanying circular (DEE 1996). The good practice guide was intended to help schools to draw up policies on managing medication and to establish effective systems for supporting individuals with medical needs. The guidance addressed issues of: medication; responsibilities; the formulation of policies and procedures; the development of individual healthcare plans; the gathering of background information on what it identifies as 'common conditions causing concern at school' such as asthma, epilepsy, diabetes and anaphylaxis. The circular set these issues in the context of current policy and practice, including SEN, health and safety, and restrictions on holding and administering medication.

The guidance and its implementation attracted considerable criticism. The Health Committee report (House of Commons Health Committee 1997), for instance, was critical of its use of vague terminology and the lack of clarification regarding roles and responsibilities. Criticism also focused on the coverage of medication. Specifically, the National Association of Headteachers reported that teachers were being asked to perform specialist and invasive procedures that they felt should be undertaken by parents – a view that was opposed by parent groups and voluntary associations. It was also claimed that schools generated problems for students who were self-medicating, by confiscating medication and equipment such as asthma inhalers, and the report expressed serious concern about the liability of school staff in the case of emergency procedures. The Health Committee report called for clear guidelines outlining responsibilities for medication, recommending the encouragement of self-administration, as well as the training of teachers to provide the same level of support as parents. It also suggested that the government provide much clearer guidelines outlining the legal position and indemnity of school staff.

More recent reports have also criticised the distribution and effectiveness of the guidance. Lightfoot and others (2001), for instance, found that most teachers in their study recognised the need for clear protocols to support students with medical needs, but were unaware of the guidance. They point out that, although available to schools on request, it was distributed only to local education authorities (LEAs). Other investigations found that, even if schools were aware of the guidance, they may not have been following it. Costello and others (2004), for example, found that the management of medicines in schools was 'far from ideal' and that government guidance was rarely implemented. These authors argued for improved standards in terms of local policy, which usually governed schools' medical procedures, and more consistency in the management of medicines. In their investigation of epilepsy support in secondary schools, Dunkley and others (2003) found that, although 10 of the 14 participating schools were aware of the guidance, only half were using it for reference. Similarly, in a study of primary school headteachers, Nash (1999) found that fewer than half had read the guidance and only about a third knew whether other staff were aware of it. The need to develop school policies that outline procedures and clarify responsibilities was identified by Mencap (2001) as key to the effective support of students with medical needs, because a lack of effective policies has been shown to lead to poor support (Bury and others 1997).

Models of good practice on school procedures to be used in the event of a medical emergency were provided in both the 1996 and 2005 guidance. *Managing Medicines in Schools and Early Years Settings* (DfES 2005) states that schools should have arrangements for dealing with emergency situations as part of general risk management procedures. Again, the use of healthcare plans is strongly advocated, particularly in outlining the responsibilities of school staff in the event of an emergency. The new guidance suggests that thought also be given to training school support staff – such as lunchtime supervisors – as teaching staff may not be responsible for students at all times of the day.

The 2005 guidance provides advice on medicines policies, roles and responsibilities, and healthcare plans, as well as a legal framework for schools and local authorities in the management of medicines in schools and early years settings. The impact of this latest guidance remains to be seen. It offers some clarification of roles and responsibilities, and places a greater emphasis on training. Dissemination of the guidance has again been limited to LEAs, which raises the question of whether it will reach the audience for which it is primarily designed. In addition, its specific focus on managing medicines may mean that the needs of students with non-medicine-related needs may be overlooked. However, the publication of *Including Me* (Carlin 2005), a handbook for staff managing complex health needs in schools and early years settings, provides useful guidance, practical advice, examples, checklists and case studies.

## The school health service

Health authorities are required by statute to provide health services for children and young people and, while there is little legislation outlining what this provision should include, DH has published several documents that aim to clarify the responsibilities of the school health services. *Saving Lives: Our healthier nation* (DH 1999a) and *Making a Difference* (DH 1999b) both outline a child-centred public health role for nurses, with a focus on improving health and tackling inequality. The publication of

*School Nurse: Practice development resource pack* (DfES/DH 2006b), which updates previous policy, is in line with the White Paper *Choosing Health* (DH 2004b) and the *National Service Framework for Children, Young People and Maternity Services* (DH 2004c).

Although these documents provide details of the scope of the school nurses' remit, they offer little about what can be expected in terms of specific provision, apart from noting that they should be based on local need. There is mention of the role that school nurses should play in supporting young people with medical needs, but these statements remain vague and open to interpretation. Nurses are encouraged to take an advisory and training role in relation to this group rather than provide hands-on support.

Lightfoot and Bines (1997) identified four key roles of the school nurse – safeguarding students' health and welfare, providing family support, acting as a confidante and promoting health – and these roles are still under consideration. In the last few years it has been suggested that school nurses could provide a wide range of services that fit with the government aims of promoting healthy eating, reducing teenage pregnancy and providing drug education. DeBell and Jackson (2000), for example, offer some clarification on what school nurses should and could offer. They argue that school nurses should have special responsibility for four areas of health in relation to those of school age: health promotion; child and adolescent mental health; chronic and complex health needs; the care of vulnerable students. Students with medical needs are included in this strategy and are seen as a key part of the health remit of the school. The report states that school nurses 'play a pivotal role in providing support and advice for children and young people with chronic health needs'.

In practice, however, school nurses are a scarce resource, with only 2,500 serving 20,000 schools (Carson 2004). Although the availability of a school nursing service varies from one local education authority to another, large caseloads in most areas mean that it is not possible for a school nurse to offer one-to-one support to a student with a medical condition. One study found that students did not see the service as a potential source of support because they did not have access to a nurse when they wanted it, and rarely had contact with a school doctor (Lightfoot and others 1999). As they were unlikely to have had the opportunity to build a relationship with a school nurse, they were unlikely to approach her for advice or support and were more likely to turn to a sympathetic teacher. In another study, just under one third of secondary school students reported contact with a school nurse, although most commonly this was only for immunisation (Madge and Franklin 2003). Hall (1999) argues that the caseload of school nurses means that they are unable to provide extensive nursing care, and that the role of the school health service is mainly about liaison with GPs, community nurses and paediatricians.

*Choosing Health: Making healthy choices easier* (DH 2004b), the public health White Paper, has proposed an increase in the number of school nurses to ensure that there is a nurse available in every 'cluster' of schools. The nurses' role will be expanded with the introduction of *The National Service Framework for Children, Young People and Maternity Services* (DH 2004c). However, funding identified for the purpose of implementing the *Choosing Health* agenda was not 'ring fenced' and, in many areas, has been used to offset overspending by Primary Care Trusts

(PCTs). School nurses are likely have a wide remit – to promote good health across the school population, to contribute to sex and drug education, to offer services to vulnerable students to protect them from harm, and to play a part in extended schools (Carson 2004). *The Chief Nursing Officer's Review* (DH 2004d) seems to be in agreement, arguing for bringing 'nursing and public health expertise to integrated services and initiatives for children and young people'.

Innovative programmes have already been introduced in some areas with the support of the National Healthy Schools programme (DfES/DH 2005). One group of nurses in Manchester, for example, provided teachers with advice on recognising and treating the symptoms of asthma. Three schools provided after-school music lessons that combined lessons in wind and brass instruments with asthma education from the school nurse. This not only increased students' self-confidence and provided them with a new skill, it also improved the health of those taking part.

## Working in partnership

Working in partnerships across disciplines has been stressed as the most effective way to provide 'joined up' services. Kurtz and Thornes (2000) argue that the complexity of young people's wide and diverse health needs, and the effectiveness of approaches to meet them, indicate the need for a closely integrated multidisciplinary and interagency response. Mukherjee and others (2000) discuss how good communication between local health and school staff is important for ensuring that students receive the health-related support they need to get the most from school life. Nonetheless, there is considerable evidence to suggest that effective partnership working does not always happen. Berry and Dawkins (2000), for example, found that health and education authorities commonly fail to work together at a local level to meet the health needs of students. Kurtz and Thornes (2000) further reported that teachers described an apparent lack of communication between health service personnel, which could result in a student not being seen for a long period and then being seen by two practitioners on the same day. Issues that can impede successful partnership working are a lack of communication and information exchange, an uncertainty about responsibilities and poorly planned interventions (Dyson and others 1998). In some cases, parents take the role of coordinator themselves, acting as a conduit between service providers. Mukherjee and others (2002) outline barriers to effective communication as described by both school and health staff. Teachers described confusion about professional roles and responsibilities, and a lack of information from consultants, while health staff were concerned about confidentiality. Both described how staff from different agencies failed to perceive each other as partners. The authors recommend the joint development of a more systematic approach to communication.

The Ofsted (2005) report on *Managing Challenging Behaviour* looked at the support schools get from other services to manage students' difficult behaviour. It found that only half of the schools studied had established satisfactory relationships with an appropriate range of services, and that links with health services were undeveloped in at least a third of the schools. In the other schools, procedures for working with external professionals were not clear and information was not shared effectively. The report also criticises local authorities' coordination of multi-agency work, citing many instances where professionals from different organisations have failed to provide appropriate advice and action. It concludes that support from social services

departments to schools is inadequate; although links are good in early years settings where education and social services are funded and run jointly, and where common procedures and information are shared.

Poor inter-agency working can have direct repercussions for families. This is clearly illustrated by a study of parental experiences of services for children in need of long-term ventilation (Margolan and others 2004), where delays occurred in returning to school after hospitalisation because of difficulties in recruiting and training carers. Disputes between health and education services about funding and management of carers added to these delays. In one of her case studies, Seymour (2004) mentions the time wasted while waiting for decisions to be made by professionals in different services, and the importance of joint working and joint funding in making suitable arrangements for individual children and young people.

Recent policy on extended schools suggests that schools might, in future, provide health and other services on site. A trial of nurse-led clinics for adolescents with asthma, located in secondary schools, found that such clinics can reach a high proportion of adolescents even though they do not necessarily result in a measurable improvement in outcome (Salisbury and others 2002). Another example of good practice demonstrated how specialist diabetes nurses can work with the school health service, schools and the LEA to provide training on diabetes to school staff, protocols for sharing information and care pathways for all students with diabetes (Farthing and Sadler 2004).

## **School absence and education out of school**

It has been estimated that, each year, there are some 100,000 school students (DfES 2001) who require education outside school because of illness or injury. The number of young people with medical needs actually absent at any one time, however, is likely to be much higher: this figure does not include those absent from school for recurrent periods or periods shorter than the requisite 15 consecutive days before home tuition is arranged.

Recurrent or prolonged absence from school can compound the difficulties faced by those with medical needs. Reports have suggested that increased absence from school, related to illness, may account for the discrepancies between the academic achievement of children and young people with medical needs and their healthier peers (Fowler and others 1985). In addition, studies refer to the negative effect school absence can have on peer relationships. Absence can, for instance, result in isolation (Lightfoot and others 1999); preoccupation with the social world of school; a disruptive effect on friendships (Bolton 1997); a dread of losing contact with friends (Closs and Norris 1997); limitations on participation with school life (Lightfoot and others 2001).

Understandably, continuing with education has been found to be very important for students with medical needs, and Lightfoot and others (1999) reported the attempts young people made to prioritise education. These included employing strategies to keep up with their school work, such as using lunch breaks and free periods to work, focusing on particular subjects and getting notes written up for them. Young people participating in Closs and Norris's research (1999) reported experiencing frustration if they fell behind in their school work because of absence.

Students who miss a certain amount of school are automatically entitled to education out of school. *The Education of Sick Children* (DEE/DH 1994) was published in response to the new duty of LEAs, given to them by the 1993 Education Act, to provide education for children and young people unable to attend school through illness or injury. The guidance received fierce criticism for its failure to stipulate standards for the quality and quantity of this education, leaving children and young people vulnerable to inadequate provision (Closs 2000). There was also criticism of the suggestion that home tuition should be arranged only after a student had been absent for four consecutive weeks (Bolton 1997). In response to such criticism, and following extensive consultation, the DfES (2001) published *Access to Education for Children and Young People with Medical Needs*. This aimed to minimise the disruption to mainstream schooling as far as possible, with LEAs providing flexible provision via home tuition, hospital teaching or an integrated home–hospital service. The statutory guidance outlined the minimum national standards for education other than at school. These standards included the following:

- Alternative teaching to be arranged for those without access to education for 15 consecutive school days.
- Alternative teaching to be arranged for those with prolonged or repeated absence on the first day of each episode of non-attendance.
- Education offered to be comparable in terms of curriculum and quality for a minimum of five hours a week.
- Hours of education offered each week should increase as necessary in order to enable the child or young person to keep up with his or her education.

In addition to this, LEAs and schools were directed to develop policies for education other than at school to be coordinated by a named member of staff. LEAs should ensure that students receiving home or hospital tuition have personalised education plans (PEPs) and individual reintegration plans for their return to school. The guidance also emphasised the need for more interagency work and clearer referral procedures.

Despite the improvements following the 1994 document, the new statutory guidance is seen to have failings in a number of areas (Ofsted 2003). At school level, the policies and procedures outlined in the guidance are rarely initiated, and schools take little responsibility for continuing the education of students outside of the school environment, a criticism also raised by Seymour (2004). PEPs are used only rarely, despite being an essential element for the continuation of education (ACE 2003). Finally, LEAs were not found to provide adequate clarification regarding roles and responsibilities.

According to Farrell and Harris (2003), the key to ensuring effective provision for children and young people unable to attend school for medical reasons lies in five factors: mainstream ownership of (that is, schools accepting responsibility for, and maintaining a high profile during) alternative education; effective partnership and collaboration; ensuring a flexible approach, tailored to individual cases; the responsiveness of LEAs and the home hospital tuition service to need; clarity about roles and responsibilities.

## **This report**

The rest of this report explores issues for students with medical needs in mainstream education and is based on a survey of over 6,500 young people attending 17 schools in two English local authorities; and on case studies with 19 young people, their families and professionals both from schools and health services.

Chapter 2 outlines the research methodology, and Chapter 3 sets the scene by describing the young people, their medical needs and some of the ways in which their conditions have had an impact on their lives. Chapter 4 turns to look at schools and their policies for students with medical needs; staff roles and responsibilities in this area are discussed in Chapter 5. Absences from school are described and discussed in Chapter 6, together with an outline of ways in which students are able to continue with their education when not well enough to attend their own school. The information collected on students, and how it is distributed and used, and interagency working, provide the focus for Chapter 7, while Chapter 8 discusses implications for training. Key messages and conclusions are documented in Chapter 9.

*Every effort has been made to ensure that this report refers to the most up-to-date legislation and guidance published at the time of writing (summer 2006). However, this is a rapidly changing policy area and it is not possible, therefore, to guarantee that all relevant developments have been mentioned.*

## Chapter 2: The study methodology

Our research was carried out in two localities that differed in size, geographical setting, population, ethnic diversity, and policy and practice in relation to the inclusion of students in mainstream schools. There were two main stages. First, a school survey was conducted with over 6,500 school students to provide a representative picture of student health within the study areas as well as an estimate of the proportion of young people who consider they have a medical condition of some kind. And, second, a series of face-to-face interviews was undertaken to gain more detail on the characteristics and circumstances of students with medical conditions, and the ways in which their medical needs were, and were not, being met. These included discussions with school staff as well as case studies focusing on young people and their families.

### The study areas

The following two study areas in the south east of England were selected as research sites.

#### *Study area one*

The first study area is an outer London borough with a population of over 270,000 people, of whom nearly a quarter are under 19. It is characterised by marked cultural and ethnic diversity, having the second highest proportion of minority ethnic residents of all local authorities in Britain. Over one quarter of the population is Asian, nearly one in five is black, and the majority of the 13,800 secondary school students in the borough are from black and minority ethnic families. According to the most recent Joint Area Review of children's services in 2006, between 7 and 8 per cent of the population are classed as refugees and asylum seekers. The number of students from families with refugee status make up a large minority of students in some schools. Nearly three-quarters of the young people in the schools are from ethnic minorities and over 130 languages are spoken. The borough is also geographically and economically diverse, with relatively wealthy suburban areas in the north and high levels of disadvantage in some of the urban wards in the south. Nearly one third of school students in the borough are eligible for free school meals.

#### **School inclusion**

According to a 2003 Ofsted inspection report, the local education authority's strategy for special educational needs has improved over recent years and it now has a satisfactory policy for SEN and inclusive education. The 2006 Joint Area Review reported that a group of headteachers described the authority as going 'above and beyond' in its work to support inclusion. Provision has been enhanced by the addition of special units attached to schools to support students with particular conditions. Partnership working by the authority with local health agencies is praised by Ofsted. However, at the time of the inspection, the role of special schools was not clear and this lack of clarity was seen as reducing the potential for more effective partnership working between specialist provision and mainstream schools.

### **The schools**

At the time of writing, there are 14 secondary schools in the borough, of which eight are foundation schools, four are voluntary-aided, one is a community school and one is a city academy. Three of the 14 secondary schools in the borough had joined the National Healthy Schools programme and, of these two, had achieved Healthy Schools status.

### **The school health service**

At the time of writing there were 28 school nurses attached to PCTs in the local authority plus school nursing assistants. School nurse caseloads were between 1,600 and 3,000 students per nurse. Surveillance is carried out as children start school and then is more targeted to those who are identified as vulnerable. The school nursing service was in the process of developing a public health practitioner role in relation to issues such as domestic violence, teenage pregnancy, smoking, drugs, black and ethnic minority issues, special needs and child protection. Life-threatening conditions are more likely to be dealt with by the community children's nursing team than by school nurses.

### ***Study area two***

The second study area, a shire county, is relatively prosperous, although with some areas of deprivation. It has a large population of just over one million people, of whom 21 per cent are under 16 years old, and includes large urban conurbations as well as sparsely populated rural areas. According to the 2004 Pupil Level Annual Schools Census, 9.7 per cent of secondary school students are eligible for free school meals.

### **School inclusion**

Education and social services for children and young people were merged into one integrated service in 2001, with the joint aims of providing a unified casework system, developing local preventative strategies, and facilitating partnership working across different services and professions. The authority's plan for school organisation states that students' needs will be provided for in mainstream settings whenever possible and appropriate. However, the intention is also to continue to maintain a special school sector, which provides directly for those with the most significant and complex needs, and also plays an increasingly important role in the work of mainstream schools. Children's services place an emphasis on early assessment to ensure that needs are met for children in their first years. Physical access to schools has been improved in recent years and a number of mainstream secondary schools now have enhanced provision for wheelchair users.

### **The schools**

There are 76 mainstream secondary schools in the county of which, at the time of writing, 44 are community schools, 16 foundation, 15 voluntary-aided and one voluntary-controlled. Of these schools, 23 have been awarded specialist status. There are also 26 special schools catering for students with a wide range of needs, and a specialist teaching unit based in a hospital. In addition, the authority offers a home and hospital education service to students whose education is disrupted due

to illness. At the time of writing, 20 secondary schools had joined the National Healthy Schools programme and eight of these had achieved Healthy Schools status.

### The school health service

A school health team of advisers and community nurses is based in local health clinics and employed by primary health trusts. Members of this team are assigned to schools in local areas. Caseloads are large, however, and school nurses may not provide services to individual students who have medical needs. Some schools employ a 'matron' who is available on site to support students with health needs. In some schools, the matron role is carried out by a qualified nurse while, in others, she had received first aid training but was not professionally qualified.

### Ethnicity within the study areas

Study area one was selected because of its large black and minority ethnic population. The table below (Table 2.1) shows census data on the ethnicity of residents in the two areas. It shows that the majority of the population of study area one is not 'White' and that there is a large Indian community as well as an ethnically diverse population in general. Simplified categories are employed in Table 2.2 to highlight differences between the study areas.

**Table 2.1: Ethnicity of residents in the two study areas (percentages)**

	Study area one	Study area two
White British	29.2	88.8
White Irish	7	1.7
White Other	9.1	3.2
White & Black Caribbean	1	0.4
White & Black African	0.7	0.1
White & Asian	1	0.4
other mixed	1.1	0.3
Indian	18.5	1.6
Pakistani	4	0.7
Bangladeshi	0.4	0.3
Other Asian	4.8	0.4
Black Caribbean	10.5	0.6
Black African	7.8	0.5
Other Black	1.6	0.1
Chinese	1.1	0.5
other ethnic group	2.3	0.3
Total	100.1	99.9

Totals do not sum to 100 because of rounding.

Source: Office for National Statistics (2003)

**Table 2.2: Ethnicity of residents in the two study areas, using simplified categories (percentages)**

	Study area one	Study area two
White	45.3	93.7
Mixed	3.7	1.2
Asian	27.7	3
Black	19.9	1.2
other	3.4	0.8
Total	100	99.9

Totals do not sum to 100 because of rounding.

Source: Office for National Statistics (2003)

## The study schools

All 14 secondary schools in study area one were invited to participate in the study and six agreed. One of these six administered the school survey to students but did not take part in policy interviews or case studies. In study area two, 19 randomly selected schools were initially approached to take part and, of these, seven agreed. To increase the number, a further six schools were selected at random from study area two and four of these agreed to participate. A summary of the study schools is provided in Table 2.3.

**Table 2.3: Types of schools in the study areas**

	Study area one	Study area two
School type		
Community		5
Foundation	5	3
Voluntary aided	1	3
Mixed	4	8
Girls only	1	2
Boys only	1	1
Specialist status	4	7

The number of students with special educational needs at the study schools varied widely. In one selective grammar school, for example, there were no students with statements and only 0.5 per cent had special educational needs. In the school with the largest number of students with special education needs, 5.4 per cent had statements and an additional 49.3 per cent had special educational needs but no statement. Academic attainment as measured by GCSE results also varied widely across the participating schools.

## The school survey

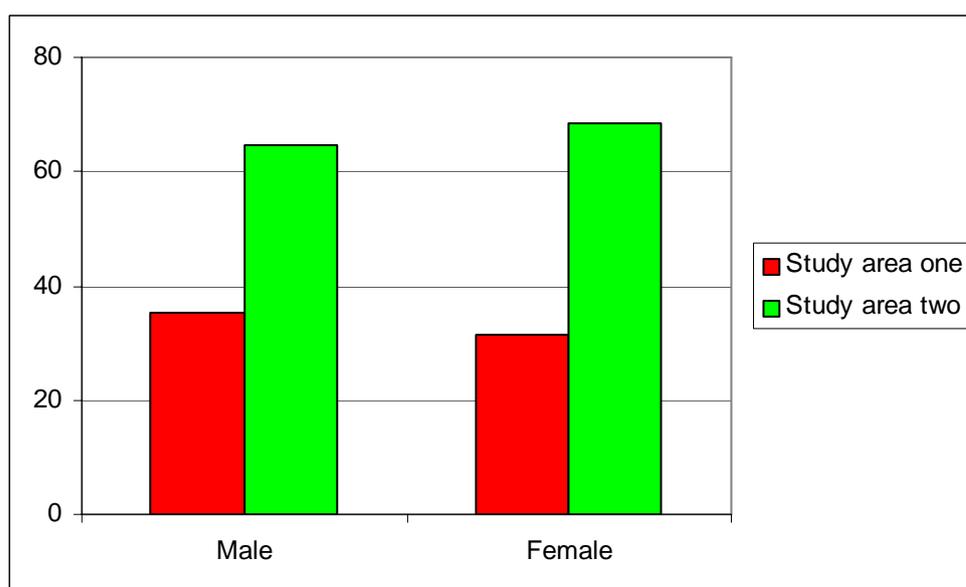
A self-report survey questionnaire entitled 'Your health at school' was developed and piloted with students outside the study areas, and included questions on: health and medical conditions; their impact on school life; views on school responses to

medical conditions and needs. All students in Years 8, 9 and 10 of participating schools were asked to complete the questionnaire. These year groups were chosen because most of these students would have attended the school for at least one year and would not be studying for public examinations. School staff administered the survey during the school day. Parents were given the opportunity to refuse consent for their children's participation but it was not possible for researchers to ascertain how many parents did refuse. Students were given a sealable envelope for the completed questionnaire to ensure that their responses remained confidential. The school survey questionnaire is presented in Appendix A.

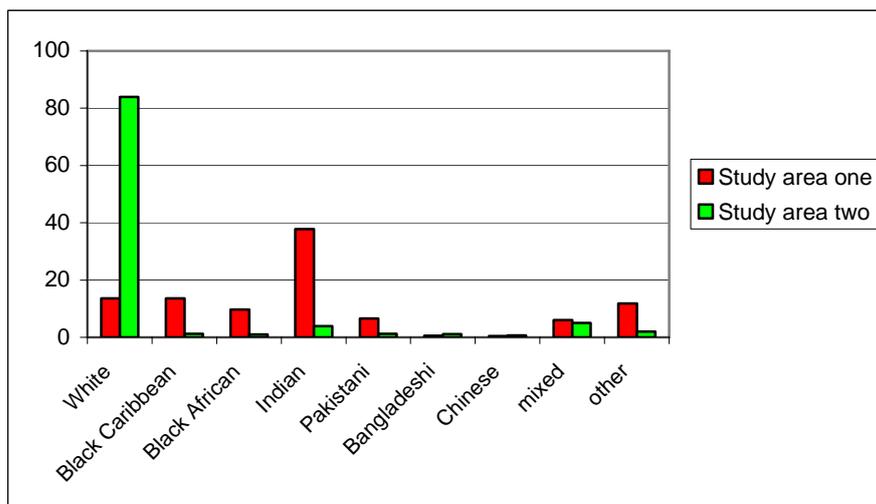
A total of 6,579 students at the study schools completed the questionnaire, approximately one-third of whom were from study area one and two-thirds from study area two. These proportions reflected the larger number of participating schools in the second study area. There were, in addition, more girls than boys due to the fact that there were three 'girls only' schools but two 'boys only' schools in the overall sample.

The questionnaires were administered during the school day by teachers and it was not possible for the research team to determine the survey's response rate. Teachers were asked to complete and return paperwork on the numbers of students absent from school on the day of administration, those whose parents did not want them to take part in the survey and those students who were unwilling to participate, but the documentation received was incomplete. It was decided that it would not be possible to collect accurate information on response after the questionnaire had been administered. However, reports from school staff indicate that, of those classes and tutor groups that took part, the response rate was high.

**Figure 2.1: Sex of students who completed the questionnaire by study area (percentages)**

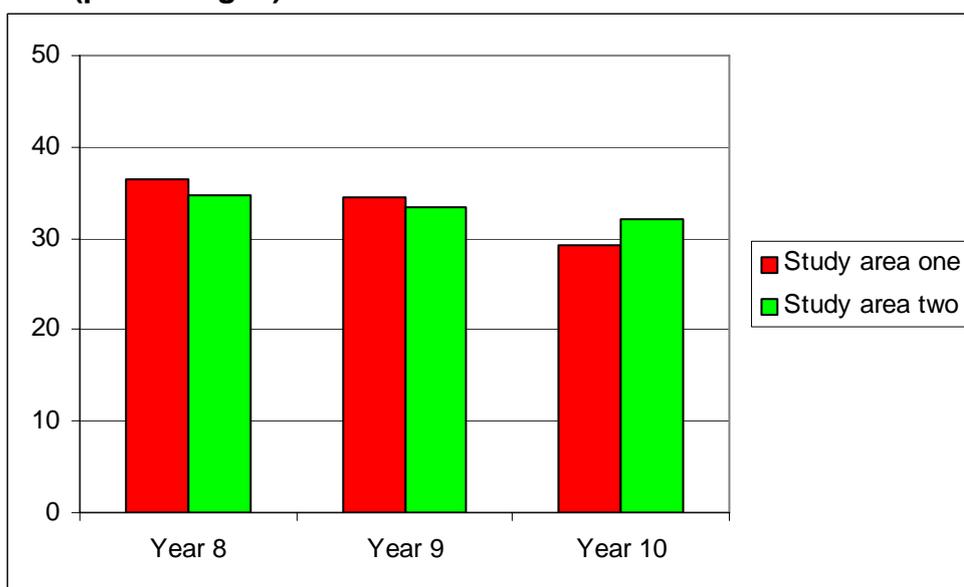


**Figure 2.2: Ethnicity of students who completed the questionnaire by study area (percentages)**



Students were asked to describe their ethnicity. Respondents included students from a wide range of ethnic backgrounds. As noted above, the majority of students in study area two (86 per cent) were from minority ethnic families but, overall, just over 60 per cent of respondents described themselves as 'White'. The categories shown in the table above are based on classifications of 'write-in' answers to a question about ethnicity suggested by National Statistics (2003). The 'other ethnic group' category includes 344 students who offered a wide range of descriptions including Sri Lankan, Iraqi, Iranian, Japanese, Filipino, Latin American, Arab, Vietnamese, Afghani and Moroccan.

**Figure 2.3: Year group of students who completed the questionnaire by study area (percentages)**



Students aged 12 to 15, from Years 8, 9 and 10, completed the survey. Roughly one third of respondents were in each year group (see Figure 2.3).

## Interviews with school staff

To investigate school policies and procedures in relation to students with medical needs, interviews were carried out with at least one member of staff at each study school. Researchers asked the contact person at each participating school to suggest a particular member of staff, knowledgeable about the school's policy and practice in the area of enquiry, to be interviewed for the study. Schools suggested a range of different members of staff including headteachers, deputy headteachers, SENCOs, school matrons, office staff and first aiders. This variation may reflect how particular schools respond to taking part in research projects as well as the seniority of staff charged with responsibility for students with medical needs.

**Table 2.4: Role of school staff who participated in interviews to discuss policy**

Headteacher	4
Deputy headteacher	5
SENCO	3
School matron	3
Head of year	1
Head of student services	1
Bursar	1
First aider	1
Member of welfare support team	1

Most interviews were carried out with individuals but in three cases there was more than one respondent present. These interviews provided data about: the prevalence of medical conditions; written policies; staff roles and responsibilities; information sharing and confidentiality; arrangements for administering medicines and dealing with emergencies; staff training; links with health services; absences from school; links with home and hospital tuition services. In some cases, respondents said that the study had prompted them to consider or reconsider their policy and practice as it became clear that the school did not have written policies or that procedures could be improved.

## The case studies

The initial recruitment of young people for case studies took place through schools. With the help of a school nurse or SENCO, suitable students with medical needs were approached and asked whether they would be prepared to take part. They were given written information about what was involved so they could discuss it with their parents, and those who were willing to participate opted in to the study by returning a completed form to researchers who then made contact by phone.

The aim of the case studies was to provide a more detailed picture, than was possible from the survey, of issues facing students with medical needs and how these were met by school and health staff. Where possible, the 'multi-perspective' case studies (Poursanidou and others 2003) involved interviews with young people, a parent or parents, a teacher and a healthcare professional. Discussion topics included the impact of a medical condition on school life, the process of starting secondary school, managing the condition at school, the extent to which information about the condition was shared with peers and staff, absence from school and any

experience of home and hospital tuition. The interview schedules were piloted with four young people and their parents who were outside the study areas.

As noted above, the recruitment of young people was initially restricted to students in Years 8, 9 and 10. However, because of difficulties in making contact with potential participants, and in order to increase the sample, the sampling frame was subsequently widened to include those in Years 7 and 11. As it still proved difficult to recruit enough participants, we also approached local community health services and self-help groups and asked them to pass information to suitable young people with whom they were in contact. One young person with type 1 diabetes and another infected by HIV were successfully recruited in this way. One of these attended one of the study schools and the other did not divulge which school she attended.

There were 19 case studies in total, of which 7 were from study area one and 12 from study area two. Of the subjects, 9 were male and 10 female; they ranged in age from 11 to 16 years old. Ten described themselves as 'White', three as of mixed heritage, three as 'Black African', two as 'Indian' and one as 'Black Caribbean'. The study area, sex, age, ethnicity and medical conditions of these students are shown in Tables 2.5 and 2.6 below.

**Table 2.5: Case study participants**

<b>Study area</b>	<b>Sex</b>	<b>Ethnicity</b>	<b>Age</b>
Study area one	Male	White	12
Study area one	Female	Black Caribbean	15
Study area one	Female	mixed heritage	13
Study area one	Male	Black African	16
Study area one	Male	Indian	12
Study area one	Female	Black African	16
Study area one	Female	Black African	13
Study area two	Male	White	11
Study area two	Male	White	14
Study area two	Male	White	13
Study area two	Female	White	13
Study area two	Female	White	14
Study area two	Female	mixed heritage	14
Study area two	Male	Indian	14
Study area two	Male	White	13
Study area two	Male	mixed heritage	15
Study area two	Female	White	14
Study area two	Male	White	14
Study area two	Female	White	15

**Table 2.6: Medical conditions presented by case study subjects**

Anaphylaxis	2
Asthma	3
Congenital muscular dystrophy	1
Curvature of the spine	1
Cystic fibrosis	1
Diabetes (type 1)	4
Eczema	2
Epilepsy	2
Friedreich's ataxia	1
Haemophilia	1
Hay fever	3
HIV+	1
Sickle-cell anaemia	1
Spina bifida	1
Stoma	1
<b>Total</b>	<b>25</b>

There are a larger number of medical conditions listed in Table 2.6 than young people interviewed, because six reported having more than one condition.

Interviews were conducted with all 19 young people and, apart from one, were carried out by a member of the research team at the young person's home. In 13 cases, parents were not present at interviews and in six they were. The young person affected with HIV was recruited via a local youth organisation and, for reasons of confidentiality, the interview was carried out by a member of that organisation's staff and parents were not interviewed. Interviews were carried out with 18 parents. The majority of interviews were carried out with mothers (16) and the remainder with both parents (2).

In all, 10 members of school staff were interviewed. These included three SENCOs, two school matrons, three form tutors, one school nurse and one learning support assistant. The school nurse was not strictly a member of school staff but was the person suggested by the young person and her mother as best placed to talk about health needs at school. One of the school matrons acted as an informant for three case studies. Eight health professionals were interviewed and included six specialist nurses (for diabetes, for example), one community nurse and one occupational therapist. One of the specialist nurses provided information relating to two of the young people.

## Data analysis

Survey data were analysed using the SPSS software programme. Interviews were tape recorded and transcribed and analysed thematically. The NVivo software programme was used for the analysis of qualitative data.

## Ethical issues

Researchers at the National Children's Bureau adhere to NCB's own Guidelines for Research that include a statement of ethical research practice and to the Data

Protection Act 1998. We also work to the British Sociological Association's Statement of Ethical Practice. Approval was sought and granted by a Multi-centre Research Ethics Committee (MREC); two Local Research Ethics Committees (LREC) were informed.

## Chapter 3: Medical needs and their impact

This chapter draws on the findings of the school survey conducted with over 6,500 young people, as well as case study interviews carried out face-to-face with 19 young people and their parents to discuss the medical needs of secondary school students. It examines whether students consider that they have medical conditions or disabilities, or have experienced accidents and injuries, and outlines the nature of their conditions and their health more generally. What impact do medical conditions have on young people at school, and what do they think about other people's knowledge of, and attitudes towards, their conditions?

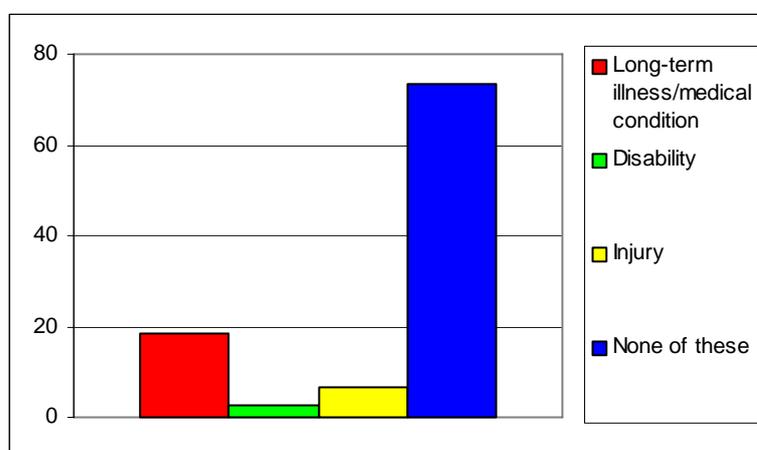
Other chapters look in more detail at the special issues surrounding medication, emergency treatment, personal care within the school setting and arrangements for students with repeated absence or spells in hospital.

### Illness, medical conditions, disability and injury

All students who took part in the school survey were asked whether they had 'a long-term illness or medical condition', 'a disability', 'an injury' or 'none of these'. Overall, 18.7 per cent (N = 1,218) reported a long-term illness or medical condition, 2.8 per cent (N = 182) a disability and 6.5 per cent (N = 425) an injury (Figure 3.1).

Some students reported having more than one of these conditions: 81 students with a long-term illness or medical condition also reported a disability (23), an injury (51) or both (7), and two students reported both a disability and an injury. Overall, 26.6 per cent of students who answered the question mentioned a condition of some kind and the remaining 73.4 per cent said they had none of these. These figures are in line with Madge and Franklin's (2003) finding that 27 per cent of a sample of almost 3,000 students at six state-maintained, co-educational, comprehensive secondary schools, self-reported a medical problem or disability of some kind.

**Figure 3.1: Self-reported long-term illness or medical condition, disabilities and injuries (percentages)**

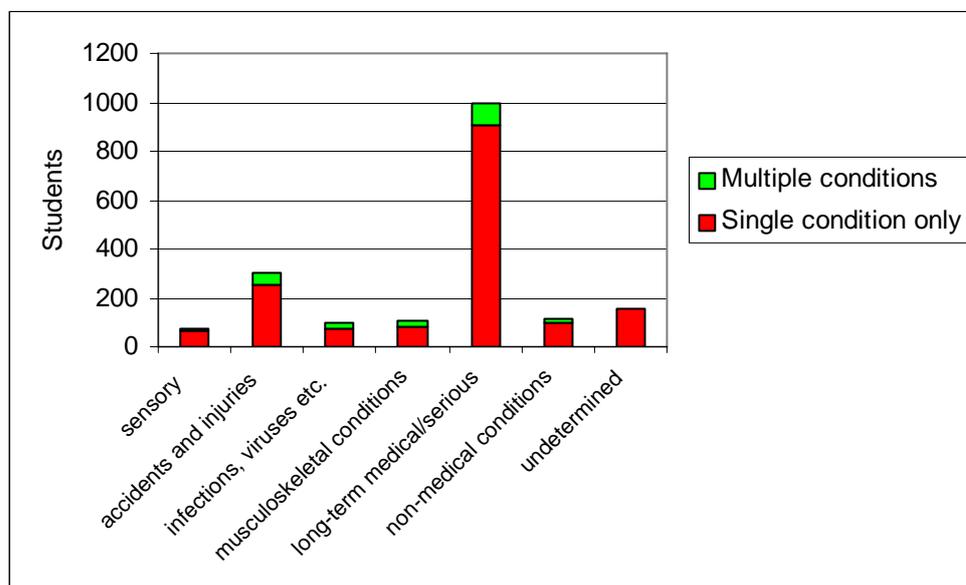


Students were asked to provide details of their medical condition, injury or disability. The most commonly mentioned conditions were: asthma (9.8 per cent of the overall sample), nose bleeds (5.4 per cent), anaemia/iron deficiency (5.3 per cent), accidents and injuries (5.0 per cent), hay fever (5.0 per cent), cystic fibrosis (5.0 per cent), sickle-cell anaemia (3.2 per cent), mental health concern (3.1 per cent), skin disorders (3.0 per cent) and allergies (2.8 per cent). The full list of conditions mentioned is given in Appendix B.

## A reclassification of conditions

It was apparent from the descriptions respondents gave of their illnesses, conditions, disabilities and injuries that, first, there was considerable overlap across categories and, second, that some fell outside our broad-based definition of physical complaints. Although it was not always easy to determine the nature and severity of conditions from the accounts young people gave, these were, as far as possible, reclassified under six main headings: sensory; accidents and injuries; infections, viruses and short-term illness; musculoskeletal conditions; long-term medical or serious conditions; non-medical conditions. Over one hundred students indicated a condition but did not say what it was: these were classified as 'undetermined'. The proportions of the overall sample that fell within these overlapping categories are shown in Figure 3.2.

Figure 3.2: Students and their reclassified conditions



A long-term illness or medical condition was most frequently indicated. Accidents and injuries were the next most commonly mentioned and sensory conditions were the least numerous. A number of students mentioned only non-medical conditions; although they did not meet the original requirement of the investigation, these have been retained within the study population both because the students in question felt they did have a medical condition and because they comprise a useful comparison group. Most of the analyses that follow are based on those who reported only a single category of condition.

The full list of these reclassified categories is presented in Appendix B. The 'sensory' category included a range of conditions relating to vision and hearing, some of which were more detailed and specific than others. Details provided on 'accidents and injuries' sometimes mentioned the cause of the injury (for example, a car accident or skiing accident), sometimes the type of injury (such as a pulled muscle or broken bones) and sometimes the site of an injury (for example, the leg, head, rib or wrist). It was not always clear from what the young people reported how long 'infections, viruses and sickness' lasted and whether or not such conditions were recurrent. The descriptions provided within this category ranged from colds, flu, a virus, fever, stomach pains, travel sickness and food poisoning, to more serious conditions such as meningitis, tuberculosis and appendicitis. Cases of benign or suspected tumours were also included in this category. A wide range of musculoskeletal conditions was also mentioned and, again, it was not always easy to judge their severity. Long-term medical and serious conditions, which comprised the largest category, included a wide selection of illnesses of varying degrees of severity. This category included chronic conditions such as diabetes, asthma, coeliac disease and cystic fibrosis, as well as cancer and leukaemia and conditions that cause disabilities such as Friedreich's ataxia and spina bifida. Non-medical conditions reported by respondents included eating disorders, attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD) and depression.

There was some overlap between categories, with six students falling within three categories and 100 falling within two. Numerically, overlap was most noticeable for long-term medical/serious conditions and accidents and injuries: a total of 39 young people reported conditions in both these categories.

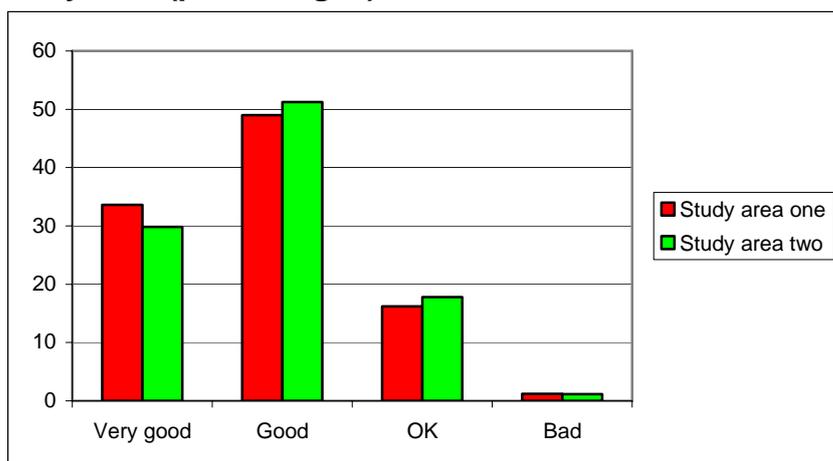
The proportions of males and females reporting some type of medical condition were very similar at 27.5 and 26 per cent respectively. There were, however, some differences in their distribution across the health categories. The greatest contrasts were found for accidents and injuries (4 per cent of females but 5.5 per cent of males fell within this category); long-term medical/serious conditions (13.9 per cent of males compared with 16.2 per cent of females); and non-medical conditions (1.2 per cent of females but 2.4 per cent of males). Also, particularly noticeable were the far greater number of males (4.9 per cent in contrast with 1.9 per cent of females) who did not describe their condition and were classified within the undetermined category.

## **How are medical conditions related to general health?**

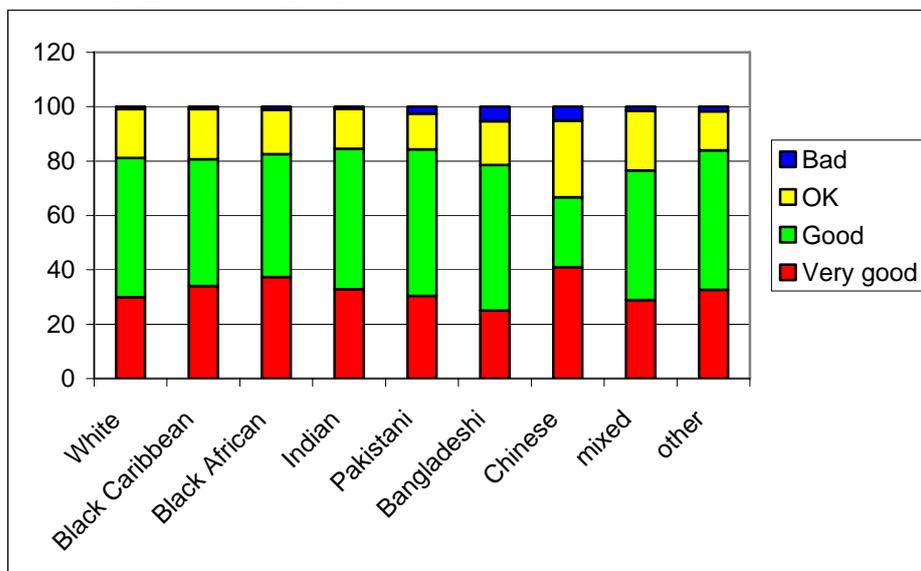
Students were also asked how they would describe their general health. Overall, almost one in three (31.1 per cent) reported it was 'very good', half (50.5 per cent) that it was 'good', almost one in six (17.3 per cent) that it was 'OK', and a small number (1.2 per cent) that it was 'bad'. Boys were somewhat more likely than girls to say their health was very good, while girls were more likely to say it was good.

As shown in Figure 3.3, health status was similar across the two study areas, with just over 80 per cent of respondents reporting that their general health was 'good' or 'very good'.

**Figure 3.3 Health status of students who completed the questionnaire in each study area (percentages)**



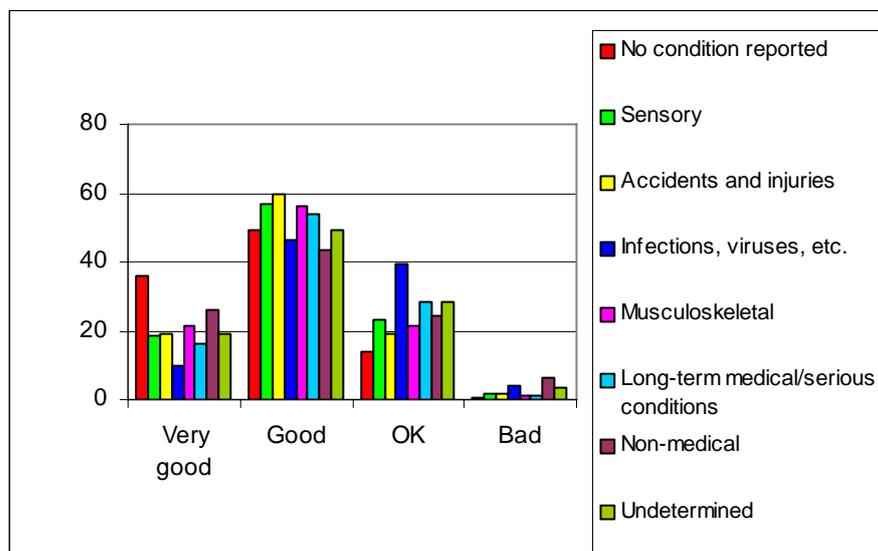
**Figure 3.4: Health status of students who completed the questionnaire by ethnicity (percentages)**



As Figure 3.4 shows, there was some difference in reported health status by students of different ethnicity, but, because of small numbers in some of the categories, these cannot be relied on. Chinese students, for example, were more likely than those in other groups to report that their health was 'very good' or 'OK' but there were only 39 Chinese students in the sample. Similarly, Bangladeshi students were more likely than those in other groups to report having 'bad' health but there were only 56 students overall who described themselves as Bangladeshi.

Not surprisingly, students who reported having medical conditions of some kind were less likely than those who did not to say their health was very good.

Figure 3.5: Medical conditions (single categories only) reported by students who completed the questionnaire and general health (percentages)



## Is ethnicity related to medical conditions?

As outlined in Chapter 2, the populations in the two study areas were markedly different in terms of ethnicity. While 296 young people in study area one classified themselves as 'White' and 1,882 gave some other description, the comparable numbers in study area two were 3,624 and 695. This means that breakdown by black and minority ethnic group is possible only in study area one, and that there are severe limitations on what can be said about ethnicity and the differences between the two areas.

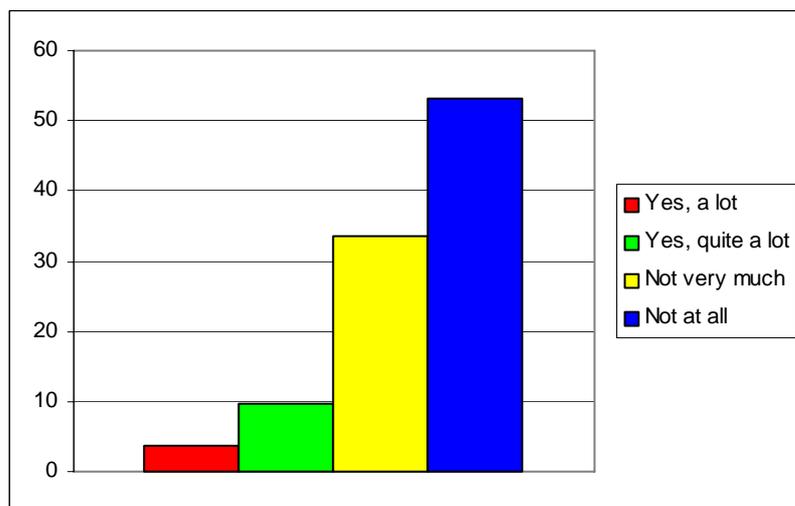
All the same, some possible differences in medical needs could be attributed to different ethnic groups in study area one, but not in study area two. More specifically, 18.8 per cent and 23.9 per cent of those from 'White' and 'other ethnicity' groups respectively reported a medical need, disability or injury in the first area; as compared with 27.9 per cent and 26.6 per cent in the second. Looking at the findings from study area one in more detail, some differences between different ethnicity groups emerged. Although numbers were small, long-term medical and serious conditions were most likely to be reported by Black Caribbean students (23.6 per cent), followed by those who described themselves as of mixed heritage (22.7 per cent), Other Black (21.1 per cent), Bangladeshi (18.2 per cent) and White (16.6 per cent). Also, the highest rates of sensory disorders were recorded by Black African and mixed heritage groups (1.8 and 1.9 per cent respectively compared with an average of 0.7 per cent), the highest rates of accidents and injuries by the Bangladeshi group (10 per cent compared with an average of 3.4 per cent), and the highest rates of musculoskeletal disorders by those from Black Caribbean backgrounds (2.1 per cent compared with an average of 0.6 per cent). Those who described themselves as White were most likely to report non-medical conditions (2.8 per cent compared to an average of 0.7 per cent).

Overall, just over three-quarters of students (75.5 per cent) in study area one reported that they had no long-term illness or medical condition, disability or injury. Those most likely to give this response were, in order, from Chinese (90 per cent), 'something else' (79.8 per cent), Indian (79.2 per cent), Pakistani (78.9 per cent), and Black African (75.4 per cent) backgrounds. However, as noted above, there are small numbers in some of the categories and the findings are therefore not reliable.

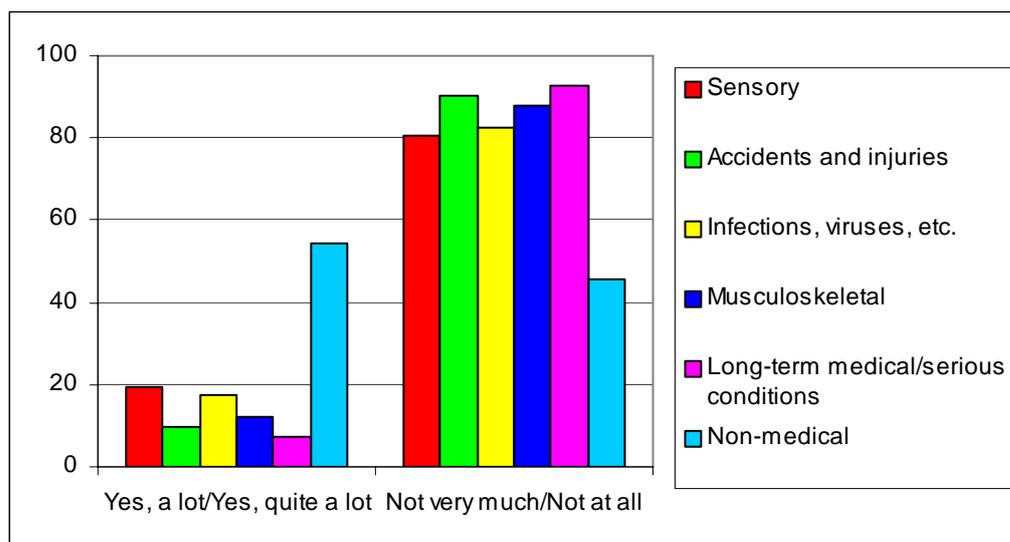
## The impact of medical conditions on learning

Students who reported that they had a 'a long-term illness or medical condition', 'a disability' or 'an injury' were asked whether it had had an effect on their learning and were given response choices of 'Yes, a lot', 'Yes, quite a lot', 'Not very much' or 'Not at all'. As can be seen from Figure 3.6, just over half (53 per cent) of young people said their condition did not have an impact on their learning at school. Nonetheless, nearly half did note some effect. Interestingly, these were much the most likely to be students with non-medical conditions. It is also interesting to note that groups with long-term illnesses or medical conditions appeared to be least affected in this respect. Figure 3.7 shows the effect of particular conditions in more detail.

**Figure 3.6: The impact on learning of having a medical condition, disability or injury (percentages)**



**Figure 3.7: Medical conditions (single categories only) and their impact on learning (percentages)**



The young people and parents in the case studies tended to support this impression. Few directly suggested that their own, or their child's, educational progress had been hindered by a medical condition. They might nonetheless acknowledge the effect of a condition and stress how they, or their children, were doing well academically despite health problems. Some pointed to ways in which school work might suffer. Disturbed nights, being tired at school and, for those with diabetes, having high or low blood sugar levels, were examples mentioned as detrimental to school learning.

### The impact on mobility

Students were asked to indicate whether or not their condition had an impact on their mobility. The results of the school survey (Figure 3.8) suggest that it had minimal impact for most, although a significant impact for a minority. Those who had had accidents or injuries were most likely, and those who reported sensory problems, least likely, to be affected.

Some of the difficulties the young people were reported as follows:

Yeah, I can't really run very well and do all the athletic things.

(Girl with asthma)

Sometimes walking, and sometimes going to school because of the chairs and just walking up and down school with your bag and everything. Sometimes I daren't go to school because of this. Maybe Wednesdays I might not go because the two days have been so stressful for me, especially certain weeks when my back is really playing up. More recently now than before, because when I had the second operation I was all right, but now because of the screw, it seems to be bothering me more. So walking and stuff like that.

(Girl with curvature of the spine)

For a girl with spina bifida, the problem was described as follows:

I can't walk long distances and have to use a wheelchair if there is far to go.

Another girl, who has asthma, described how it affected her:

Well I quite like doing netball but I can't do it for that long because I get tired really easily. And I can't do swimming very well either, and I quite enjoy that. So when I do swim, I would say I was quite a good swimmer, but I'm not because I can't catch up with everybody else, 'cause of my asthma, so I get tired. So halfway down the pool I get really tired.

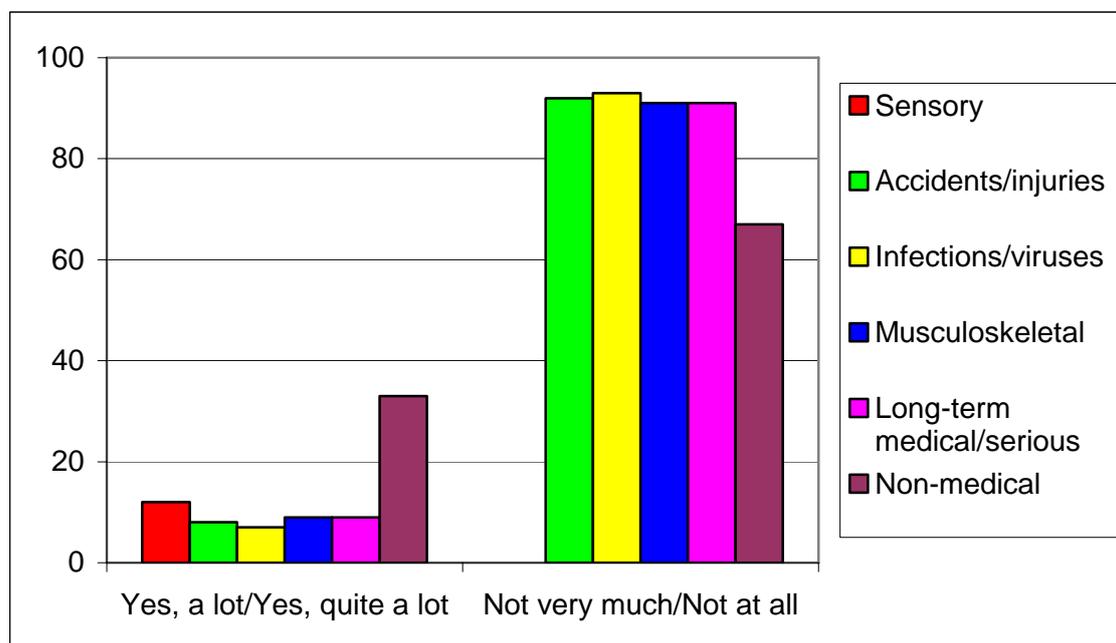
Figure 3.8: Medical conditions (single categories only) and their impact on mobility (percentages)



## The impact on friendships

Fewer than one in 10 students in most categories said that their condition had made a lot or quite a lot of difference to their friendships. Interestingly, however, one third with non-medical conditions suggested that it had. Those with dyslexia or ADHD were more likely than others to report having their friendships affected, but numbers in these categories were small.

**Figure 3.9: Medical conditions (single categories only) and their impact on friendships (percentages)**



The case studies identified two ways in which medical conditions could interfere with friendships and getting on with peers. One was in restricting activities and limiting opportunities to join in with what others were doing. And the other was if they led to embarrassment or teasing.

The first is illustrated by a young person who was HIV positive and upset at not seeing friends as often as she would have liked. Her medication made her rather weak and she had to rest a lot. Missing out on football with his friends was the main thing a boy with severe migraines regretted. And not being strong enough to join in activities with friends was what a boy with sickle-cell anaemia particularly disliked. He described it as follows:

I can't do the things my friends do. Yeah, like running, because I used to run faster than all of them, and now they run faster than me. Like they can play rough games and I can't join in. They can swing for like hours and hours and I just stay in the corner.

For some students, however, there were more embarrassing aspects. Sometimes it seemed friends did not really understand about their conditions. A boy with diabetes, for instance, said his friends think he is 'acting really weird' when he has a hypo (becomes hypoglycaemic), even though he feels normal himself. A girl with a nut allergy found the incessant explanations of why she could not eat certain foods irritating and could feel awkward when eating out with friends if the restaurant could not guarantee that their products were nut-free.

Some conditions led to even greater distress among friends. Two students, a boy and a girl, disliked going to school with eczema. The boy's mother said she thought

he was teased about the spots on his face, and the girl said she hated wearing shorts for PE and letting everyone see the eczema on her legs. Most teachers were sympathetic and let her wear tracksuit bottoms, but one was not. A boy with sickle-cell anaemia was embarrassed about being shorter than average. His mother said he found it difficult to mix with others at school and thought he did not fit in. And a boy with diabetes had, on one occasion, collapsed on the school stage in front of everyone and had been very embarrassed to go to school afterwards. His mother described the aftermath as follows:

What happened then is he withdrew and he just didn't take part in anything. He didn't want to know about the diabetes, he didn't want to know about the injections, he had no interest in it, he was really just depressed because it had taken over his life. He wouldn't go to the corner shop, he wouldn't go to friends, he just wouldn't leave the house.

It seemed that matters improved when he started using an insulin pump and was therefore able to control his diabetes more effectively.

## Medical needs and choosing a school

Medical needs were not always the prime reason given by families for choosing a particular school, although they were often taken into account. Decisions were based on academic and pastoral criteria as well as pragmatism. Some parents said they had selected a school because of its location. They wanted a school near home or one easy to get to in case their child needed to be picked up in an emergency. The length of the journey to school was critical for students who got tired easily or had impaired mobility. Other choices were based on a school's specialist status, attendance of an older sibling, academic excellence, recommendation or 'feel'. Many parents chose a school because it had the best facilities to accommodate their child. These included accessibility, resources such as hoists and lifts for wheelchair users, the availability of SEN support, a Christian ethos, a full-time matron, a lunch hour that suited a student's diabetes regimen and an experienced school nurse.

My mum chose to change me to the school that I'm in now because the nurse at the school knew a lot about HIV and I'm not the only one in the school with HIV.

(Student who is HIV positive)

In three cases parents described disappointment or anxiety about gaining a school place. One had been told that there were only two places for wheelchair users available each year at the local school designated for disabled students. Although her daughter was accepted, 'the procedure was fraught with uncertainty until you actually got the place'. Another parent explained how she had been sure her son would be offered a place at the school her older children attended, and which had a lift, but he was not and had to accept a place elsewhere. One family appealed to the local school on behalf of their daughter: she was eventually offered a place on the grounds of her medical condition.

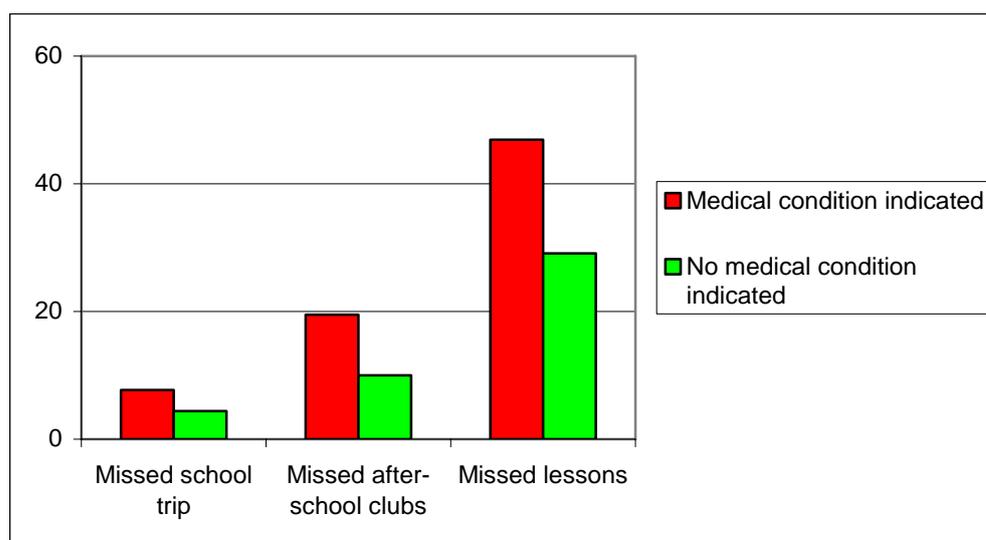
## Funding and inclusion

Although not a focus of the study, the question of accessing funds to enable students to attend particular schools was raised by a number of school staff. One issue that concerned staff was the time-consuming business of finding funds to support students resident in other boroughs. This was a particular problem for a school designated to support wheelchair users and located at the edge of two other boroughs. Fundraising from voluntary bodies was another issue and some members of staff said that finding resources was a major part of their job. Sometimes this meant making applications for grants to buy equipment not adequately funded by students' statements. Some schools had been particularly successful in this and one, for example, had been able to buy a minibus with funds from the Variety Club of Great Britain.

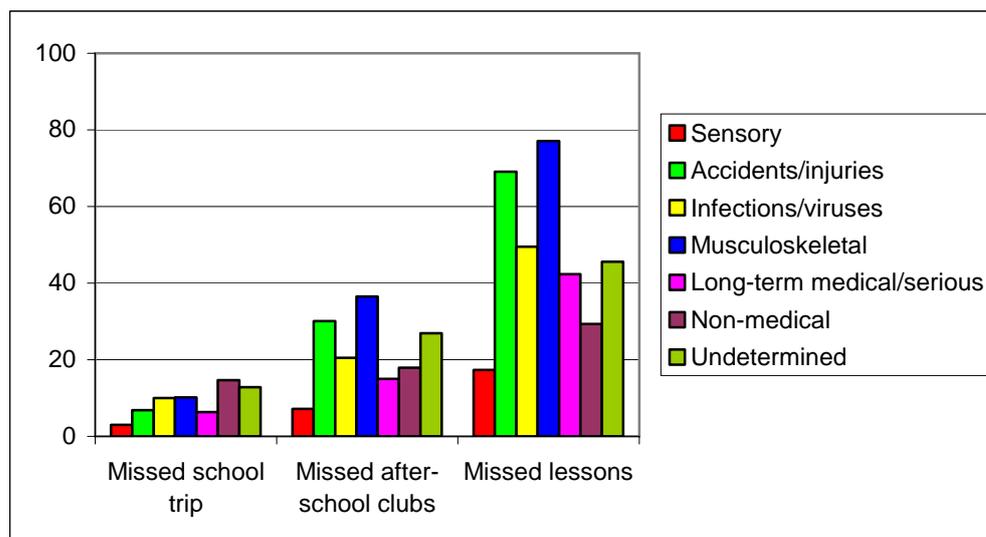
## Medical needs, the school curriculum and extracurricular activities

The school survey asked students whether, in the past 12 months, they had (even though they were at school) been unable to go on a school trip or school journey, take part in after-school clubs or activities, or attend certain lessons such as PE or science. Figure 3.10 demonstrates that students said that they had missed these things whether or not they also said they had a medical condition, but that they were more likely to have missed them if they did report a medical condition. Overall, 7.7 per cent of those with a medical condition had missed a school trip, 19.5 per cent had missed after-school clubs and 46.9 per cent had missed a school lesson. Accidents, injuries and musculoskeletal conditions were most strongly linked with missed lessons and after-school activities, while non-medical conditions showed the strongest association with missed school trips (Figure 3.11).

**Figure 3.10: Missed school trips, after-school clubs and lessons and self-reported medical conditions (percentages)**



**Figure 3.11: Missed school trips, after-school clubs and lessons and type of self-reported medical condition (percentages)**



### ***Physical education and medical needs***

Although most young people who took part in the case studies said their condition had not affected their studies, they did suggest that some curriculum subjects were more difficult to manage than others. According to the school survey, physical education (PE) presented particular problems. Almost half (46 per cent) of students reporting a medical condition, disability or injury had missed a lesson at least once because of their condition, and almost all those specifying a particular subject mentioned PE.

The case study students had a range of disorders (see Appendix B), many of which affected whether or not they felt able, safe and comfortable to take part in PE. Some, including wheelchair users and those with cystic fibrosis and spina bifida, were physically unable to participate in school PE unless it was adapted for their capabilities. Some schools arranged inclusive exercise programmes. One, for example, organised wheelchair football, popular with one girl, and provided a specialist exercise programme suitable for students with physical limitations.

We have got children who are in a wheelchair and they will do dance, they will get out of their wheelchairs to do PE, or they will stay in their wheelchairs and do PE. They do tennis, hockey or, if it's gym, they will get out of their wheelchairs. They normally have a support worker with them.

(School matron)

Some students felt unsafe doing PE and these included a boy with haemophilia, a wheelchair user whose parent was concerned about the lack of expertise among PE staff, and an HIV positive student who had regular nosebleeds. Others missed PE in certain circumstances: a student with asthma did not take part if she had forgotten

her inhaler and nor did a boy with diabetes if his blood sugar level was low. A student with epilepsy avoided cross-country runs and climbing activities. These students might watch their peers exercise, act as umpire or timekeeper, or spend time in the library catching up with homework.

Young people and parents suggested that not all schools provide a suitable range of opportunities for exercise. Some students said they became tired and out of breath when doing PE and would have preferred other types of activity. One boy with sickle-cell anaemia, for example, said that the only choice was football, which he preferred not to do because of his small stature and the fact that he tired easily. More than one student would have been happier if PE programmes had been more varied and adapted to their abilities.

Some of the PE staff are quite gruff and they don't seem to understand sometimes that a child like [daughter] would maybe like a softer PE lesson. I don't know whether there is something they could do where she'd have some exercise but it wouldn't be running round the field eight times because she can't do it.

(Parent of a student with asthma)

As already mentioned, embarrassment was another reason for preferring not to take part in PE. Ensuring that students had a private place to change, and allowing them to wear long trousers, would have avoided some students' problems.

However, many students seemed not to feel too restricted and managed to find physical activities they could take part in.

I mean, I still skate. It doesn't stop me doing that. I still play football at school and everything, so not really, apart from doing games in school. I don't do games because it's all contact sports. Instead I do music.

(Boy with haemophilia)

There's certain things at school she's not allowed to do. She's not allowed to do cross-country because if she got separated from the group she wouldn't know how to find her way back because of her memory. She's not allowed to climb the rope or the wall ladders, just in case she has an episode, and we did stop her having showers because we found out a lot of her fits would happen when she got hot, bothered and stressed out, which was nearly always while doing PE.

(Mother of a girl with epilepsy)

### ***Other curriculum subjects***

A small number of case study students said they were unable to study particular subjects (other than PE) because of their condition. Science was, after PE, and according to the school survey, the most common subject lesson missed: 7 per cent of students said they had missed it at some time on account of their condition.

There was, nonetheless, a variety of reasons given for missed lessons. Sometimes the reason was a health-related appointment but, on other occasions, it had a more direct physical cause, such as tiredness, pain, shortness of breath, writing slowly and a general inability to manage a full day's work. For example, one girl had stopped taking art lessons 'because I couldn't reach the tables' and another had problems with both art and technology because of joints which became painful when using a pen or paintbrush. In one case, a school had carried out a risk assessment for a boy with haemophilia who was using cutting tools in Resistant materials classes: it was agreed, as a result, that he could continue with the subject. Some students said they had chosen GCSE options in line with the subjects they felt they could manage best. One girl, for example, had chosen subjects that did not involve much writing and which she felt she could keep up if absent from school.

### ***Tests and examinations***

In some cases, students' said their conditions had directly affected their marks in tests and exams. Those with migraine, diabetes and asthma, for instance, described how the stress of being tested could affect them physically:

Sometimes I haven't been able to do tests because I've been high and low. There were a couple of tests that I did last week – biology, physics and maths. I did them all but I was high on the biology one so I got a rubbish mark. I forgot to take my blood test kit so I didn't know till I got home that I was high.

(Student with diabetes)

### ***Extracurricular activities***

Only one case study student – a wheelchair user – suggested that his condition had affected his participation in activities and said that he did not take part in after-school sports or school discos. Not surprisingly, case study participants found that residential trips caused more difficulties than day outings. Although several wheelchair users and others with complex health needs had not gone on residential trips, foreign exchanges and trips abroad, only one had not been able to go on a day trip. In this case, the student had diabetes and had experienced a bad hypo on a previous local outing. As a result, it had been decided that it was safer for him not to take part in future trips unless accompanied by a member of staff trained in administering glucose injections. This was not seen as an ideal solution, and the possibility of inviting one of his parents to join the trip had been considered. However, this was not seen as appropriate either, and the parent said his son ended up 'being stuck back at school with no one, basically, which isn't fair'.

Extracurricular activities commonly mean outdoor activities, which can be challenging for young people with impaired mobility. One student with muscular dystrophy had decided not to take part in a residential activity trip because she felt she could not join in with the activities and thought there was 'no point'. Her parent commented as follows:

They [the school] could have actually made an attempt to make whatever activity it was that they [the students] were going to do more inclusive.

Another student with scoliosis sometimes chose not to take part 'if it's a really active thing because I just feel that it would be too much'. One student described the preparation needed before a trip:

They always have to make sure they've got the EpiPen [a self-injection kit used for treating anaphylactic shock] with them and they have to talk to you about it before you go and make sure they've got it and the teacher has to know how to use it before you go. And as long as someone's there that knows what they're doing, then I can go.

(Student with anaphylaxis)

Arrangements for food also had to be considered beforehand. The student with anaphylaxis described the extra care necessary to avoid food containing nuts on a school camping trip, and the mother of a student with diabetes talked about the detailed planning needed to ensure her son did not have a hypo on a school outing.

It was apparent that most case study students did not miss events they liked unless it was absolutely necessary. Parents explained how they made sure their children managed to take part in school trips and other activities:

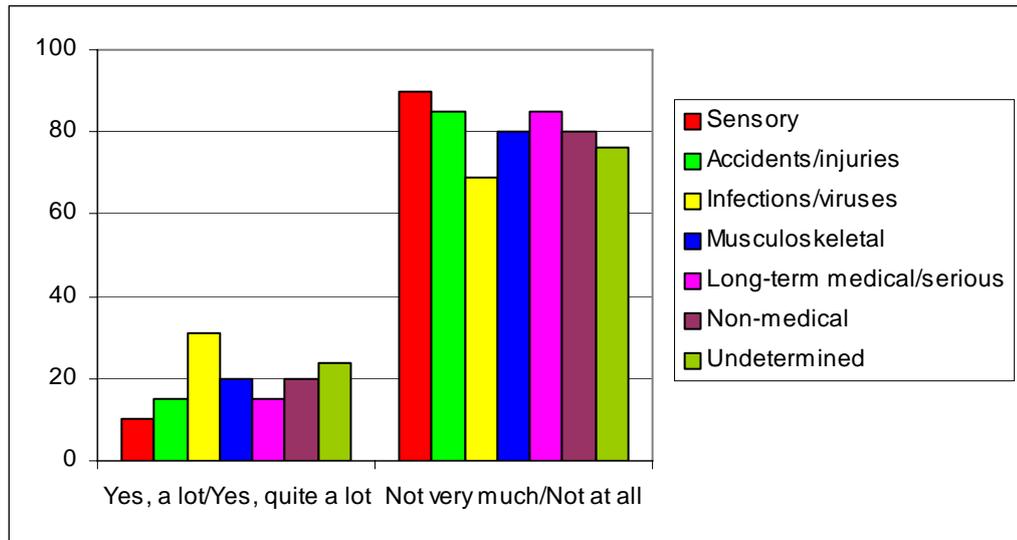
I think, always this need to carry an emergency bag around so she's always got a catheter, pads, change of underwear just in case there's a problem and having to be aware of what facilities are around. So if she goes on a field trip with school we've always got to make sure that there's some provision for her to have access to a reasonable loo and it's that kind of limitation. But otherwise we've had a go at most things.

(Mother of a girl with spina bifida)

## Time off school

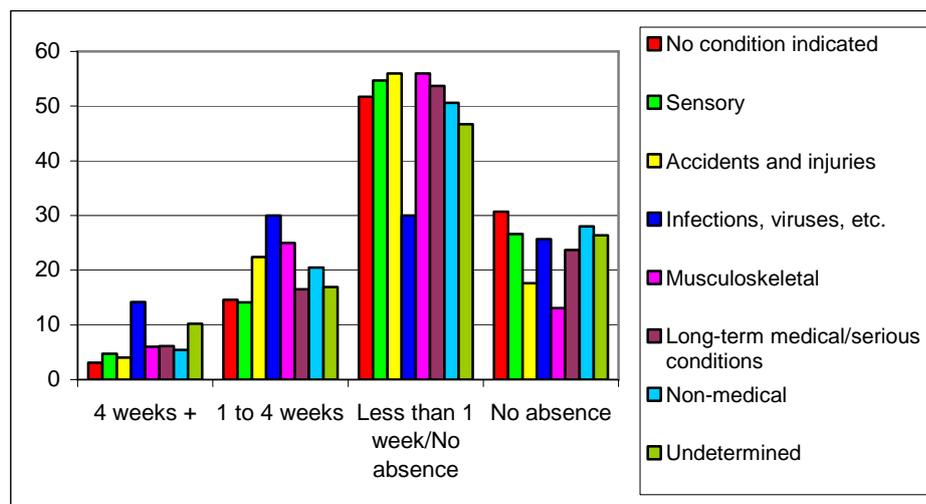
Students who participated in the school survey were asked whether their illness, medical condition, disability or injury had had an impact on their school attendance. Figure 3.12 shows that those with infections and viruses were most likely, and those with sensory difficulties least likely, to say it had. The majority of young people with medical needs did, nonetheless, suggest that their condition had not affected their school attendance very much or had not affected it at all.

**Figure 3.12: Medical conditions (single categories only) and their impact on school attendance (percentages)**



All respondents were then asked the more specific question of whether they had had time off school because of ill health within the past 12 months and, if so, for how long in total. Not surprisingly, and as indicated by Figure 3.13, those who reported a medical condition of some kind were more likely than the rest to say they had been absent from school due to ill health. About a quarter overall said they had not been absent at all, and most of the others thought they had been away from school for less than a week altogether or were not sure. Those who reported having infections and viruses were most likely to say they had been absent for longer periods.

**Figure 3.13: Absence from school according to whether or not students report medical conditions (percentages)**



The case study students all had long-term conditions and were asked about non-attendance at school because of these conditions. They or their parents mentioned

absences due to migraine – which, for one boy, had meant nearly two weeks off in one particular month – treatment for haemophilia and a series of operations for spina bifida. Sometimes the medical conditions made young people more susceptible to general illness that, in turn, meant they were absent from school. The mother of a girl with asthma spoke about her daughter:

Well, she's taken such a lot of steroids that I think it's affected her immune system. Because when she gets a cold, she gets very poorly, very quickly, and she picked up whooping cough and then she had pneumonia.

Patterns of absence were very variable for another girl with cystic fibrosis. Her mother told how it affects her:

It varies an awful lot. Her disease is so unpredictable that sometimes she will be off school for two or three days at a time, maybe at home – usually at home if it's a short spell like that. She might come home part way through the day just because her chest is feeling tight and she will come home because she can't really walk round the school and she doesn't feel comfortable in the lessons. Other times she can be in hospital and at home for part of the time for up to four weeks at a time. That is unusual but that can happen.

The mother of a boy with diabetes who also suffered from dyspraxia expressed her worries about the amount of school her son had missed:

He's missed an awful lot of school through that. Now, whether the added stress of the diabetes on top of the dyspraxia on top of social problems at school ... [played a part] ... we're not sure. It has been a big concern to us, obviously, how much school he's missed. But you do your best to make sure it's genuine and work with that. But I think we've gradually been pushing him more to go in than we were.

## Other types of impact

Most of the young people who took part in case study interviews were very open about their conditions and the impact these had. They were also happy for their parents to add further details from their perspectives. A number talked about ways, not already discussed, in which medical conditions had affected them at school. A considerable number, for example, mentioned the need for a special diet of some kind as a result of HIV, migraine, diabetes, eczema, nut allergy or cystic fibrosis. Generally this did not present unmanageable problems at school as students and their families were able to provide their own food.

More problematic were the difficulties surrounding personal care that emerged for a few students. One girl's problems arose because she regularly needed help to go to the toilet. Apparently this became a management issue and, as a result, she was excluded from school for a few days. Another student with limited bowel control always faced the possibility, and hence the worry, of an accident at school. And a boy with Friedreich's ataxia, who used a wheelchair, was unhappy and embarrassed at being taken to the toilet by a female, or unknown male, member of staff. Embarrassment, but for a different reason, was clearly felt by a girl with continence difficulties, particularly when changing to go swimming.

Some students pointed to ways in which their conditions directly affected their school work. A girl with congenital muscular dystrophy, for instance, had a contracture in the neck which meant she could not look down at things and could see them only if beyond her reach. This had important implications for lessons and tasks such as writing and reading. The impact of epilepsy on her memory could be problematic for another student.

For many others, it was just about feeling unwell and having to put up with aches, pains and discomfort while at school, or about getting used to new routines and having the confidence to look after themselves – and perhaps administer injections. Sometimes, as for a boy with severe migraines, it was simply:

... stopping me a lot from just having my own time.

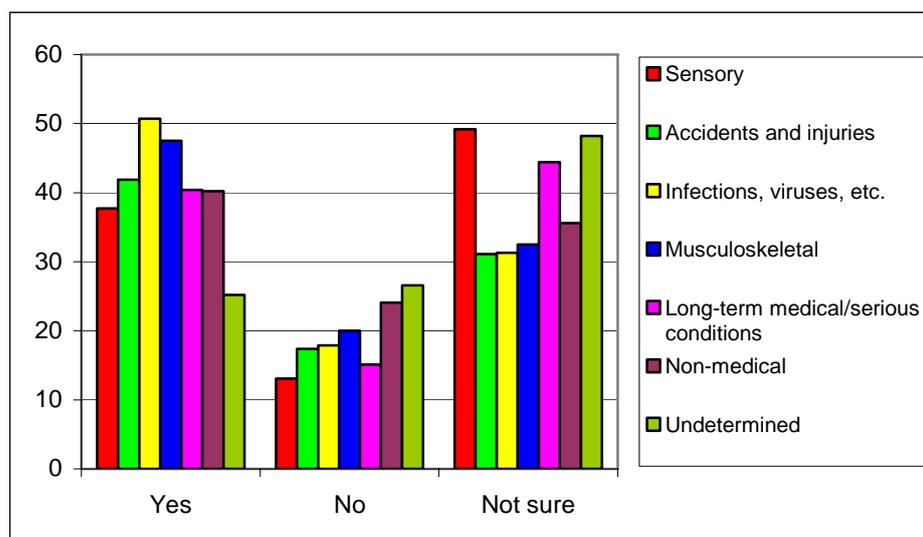
## **Families and medical needs**

The aim of this study was to investigate the extent of young people's medical needs and how these might be met at school. It did not focus on the impact a child's family might have on how schools supported – or did not support – individuals. However, interviews with young people and their parents suggested that some parents are better equipped to communicate with school staff and to negotiate with schools and children's services on behalf of their child than others who are more reticent. It seemed that parents who were not confident English speakers or who had not themselves enjoyed their time at school were less likely than others to understand the education system. Attitudes towards 'illness' and family members' expectations of their children could also affect the extent to which students took time off school. The length of time that a child had had a condition, and its seriousness, also seemed to have an impact on families' aspirations for their children.

## **Schools' attitudes to and knowledge about medical needs**

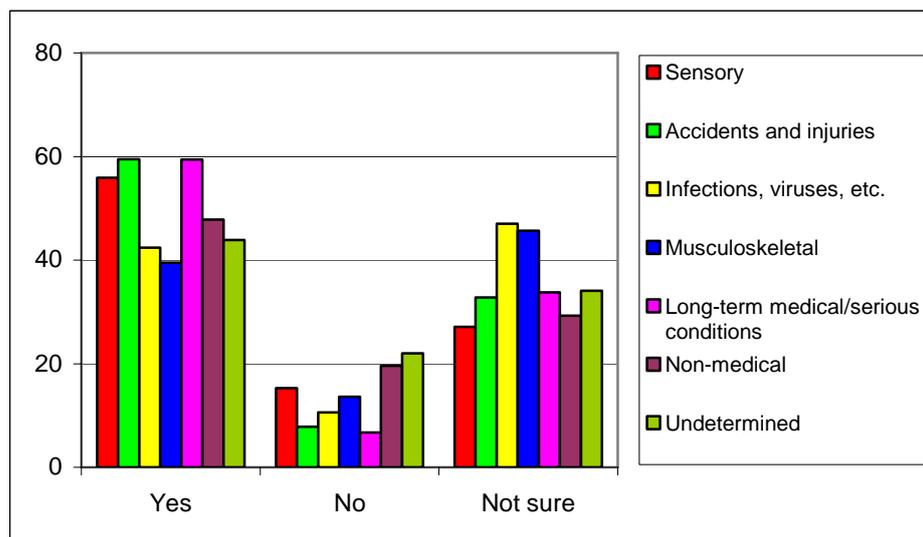
All students who responded to the student survey were asked for their views on whether or not their school was caring towards students with medical conditions, disabilities or injuries. It is interesting to find that overall only 40 per cent, whether or not they reported a medical condition themselves, thought that it was; while 15 per cent responded 'No'; and 45 per cent 'I'm not sure'. Figure 3.14 shows the proportions holding this view according to the nature of their own conditions.

**Figure 3.14: On the whole, is your school caring towards students who have an illness, a medical condition, a disability or an injury? (percentages)**



Students who reported having medical conditions, disabilities or injuries were also asked whether they thought their school knew enough about their condition. Figure 3.15 shows the results. It is of concern that such a large minority were 'Not sure' whether they were happy with the school's knowledge.

**Figure 3.15: If you have an illness, a medical condition, a disability or an injury, do you feel happy that the school knows enough about it? (percentages)**



Students who took part in case studies found that, on the whole, they were supported at school by staff and made friends. Arrangements had been made, for example, for them to work to a reduced timetable after surgery or to have extra support on school trips. However, some had experienced unpleasant incidents at school because of their condition and others had been made to feel 'different' or excluded. The ethos of the school, the character of the young person and, probably

most important, the nature of the condition all had an impact on how well cared for the students felt.

## Key messages

- Almost one in five students indicated that they had a long-term illness or medical condition, and about half this number again said they had a disability or an injury.
- Asthma was the most common condition and reported by almost one in 10 students.
- There were no striking sex differences in the numbers of students reporting conditions of some kind, although there were some slight differences in their patterns of conditions.
- Students with medical conditions reported less good general health than those without them. There was, however, little association between general health and the nature of medical conditions.
- Although numbers in different groups were small, there was some suggestion of association between medical conditions and students' ethnicity.
- Only a minority of students with medical conditions said their condition had an impact on their learning, mobility and friendships.
- Students with infections and viruses stood out among those with medical conditions in terms of the time they had had off school in the past year.
- All students, whether or not they had a medical condition, were at risk of missing school trips, after-school clubs and school lessons. Those with musculoskeletal conditions, and accidents and injuries, were, however, most likely to have missed clubs and lessons.
- A substantial number of students with medical conditions were not confident that their school was well informed about their condition; a majority of all students were not sure that their school was caring towards students with a medical condition, injury or disability.

## Chapter 4: Schools, their policies and practice

A considerable amount of legislation and guidance exists for schools on policy and practice to meet the needs of children and young people with medical needs. Earlier research suggests that dissemination of this guidance may be patchy, teachers may be unaware of its recommendations and school policies may be highly variable (see, for example, Wong and others 2004). This chapter examines how far the schools in our study were aware of this guidance and how far it was followed and implemented. It looks at: admissions procedures; medical needs policies; disability access plans; keeping records on students' medical needs; healthcare plans; how far medical needs are regarded as special educational needs; school ethos.

### Admissions procedures

All the study schools had clear policies for accepting new students into Year 7 in line with the *School Admissions Code of Practice* (DfES 2003). These policies reflected the status of the particular school. Foundation schools, for example, had considerable autonomy over the admission of new students, while the local authority controlled procedures for community schools. Where a school is named in a statement of SEN, the governing body of that school has a duty to admit the child concerned and, if the school is oversubscribed, admission authorities should apply criteria fairly to all prospective students. Some schools selected new students on academic ability while others took the family's religious affiliation into account. Two schools accepted a large number of disabled students because they had the appropriate facilities to support them. As noted in Chapter 2, the schools varied widely in the proportion of students with SEN and in their record of academic achievement at GCSE level.

### *Admissions and the physical environment*

Many of the study schools were built on many levels, had no lifts and presented a challenge for students with impaired mobility. Members of staff described their mixed feelings between, on the one hand, wanting to accept these students in a spirit of inclusion and, on the other, being concerned that they might not be able to cope. Three said they gave prospective students and their parents the opportunity to look around during the school day so they could be sure they were making an appropriate choice. One SENCO described the procedure:

What I've done is I've invited parents in, sometimes with the child, sometimes without the child, and I have walked them around the building. Quite fast, sometimes quite deliberately when there's a lot of movement going on and then I've just turned to the parent and said, 'do you think your child could cope with this?' So rather than say, 'no', I would say to the parent, 'do you think this is fair?' I think sometimes you have to let parents realise for themselves that this just isn't an appropriate placement.

Although this does seem a harsh introduction, staff were realistic about the possibilities of making changes to the environment and knew that, although ramps and handrails could be put in place, major structural improvements were a very long-term project. Staff at two schools said they had turned down applications from potential students who could not manage stairs, arguing that students' safety was paramount. One parent, whose daughter used a wheelchair, described how they were turned away by one of these schools:

In fact she also applied to go to [school]. We did go and see the school, we talked to the head and they flatly – I mean more or less – told us to our face to go knocking at somebody else's door. And they said there's no way we're going to cater for [daughter] being in a wheelchair.

(Parent)

Another potential student with a severe medical condition, who was not a permanent wheelchair user, was accepted at this same school after walking round and showing that she was able to get to even the more inaccessible areas. She admitted, however, that the physical environment was not ideal:

Actually my [condition] was more a reason not to go because the school has tiny narrow corridors and lots of stairs.

(Girl with spina bifida)

## **Policies on provision for students with medical needs**

Policies that outline any special provision for students with medical needs might include: those that relate to the holding of information, the administration of medicines, risk assessment, health and safety, the roles and responsibilities of staff, the use of healthcare plans, personal care arrangements, emergency procedures and the training of staff. Staff who were interviewed for the study were asked about their schools' policies and how students with medical needs were supported in practice.

Our findings very much support earlier research in demonstrating that awareness of guidance in this area is poor and school policies for students with medical needs are rare. One of the two local authorities reproduced *Supporting Pupils with Medical Needs: A good practice guide* (DEE 1996) in their health and safety guidance, but only one member of school staff mentioned this guidance.

Only one school had an active medical needs policy. This provided comprehensive guidelines, reproduced in staff handbooks, but was not made available to parents. In other schools, staff had considered policies but had decided against them for pragmatic and practical reasons.

Certain issues are addressed within other policies basically. Having looked at this, maybe we do need to have a medical policy but there are bits of things like there is first aid covered in a health and safety policy, there are various things within pastoral policies to do with medicines and how they are given out

and that sort of thing. So there are certain things but it's not pulled together in one self-contained policy.

We have policies for an awful lot of things. We tend to do this on 'just let's get on with it', you know, 'the child's here, we get on with it' ... To be honest, I think it's much more important to get on with it than to have a piece of paper.

I'm resistant to it because I see it as an administrative job that hasn't really got anything to do with looking after the kids. And the pupils here are being looked after ... We are dealing with their conditions, and to spend a couple of hours filling in care plans for each one, and even longer drawing up a policy, is not, in my mind, a useful thing to do.

Teachers often felt that a medical needs policy was not necessary. Although guidelines for supporting students with medical needs were seen as useful, there were concerns about increasing the administrative load for school staff and then ensuring that paperwork was kept up-to-date. It was also acknowledged that just having guidelines would not necessarily mean that they would be read or followed. This observation was supported by the fact that even senior LEA respondents could be unaware that guidelines were already reproduced in the LEA health and safety manual.

## **Disability access plans**

An Ofsted report (2004) looked at the progress made by schools in including students with special educational needs since the introduction of the SENDA. It found that, despite growing awareness, more than half the schools investigated had no disability access plans.

Only one respondent in the present study mentioned having a disability access plan. Nonetheless, although nobody interviewed about school policies mentioned the need to make 'reasonable adjustments' to provide for students' needs in line with SENDA (Stobbs 2001a), some had in fact done precisely that. Adjustments to the physical environment included the provision of lifts, ramps, handrails and accessible toilets. Staff described how timetables and classrooms had been rearranged to accommodate students with impaired mobility to ensure that they were able to access the curriculum.

There is just one area that cannot be [accessed] and that is the maths teaching area. To accommodate somebody with a wheelchair, we simply arrange his lesson in a room elsewhere, so that his whole group is taught in a different room.

(Deputy headteacher)

Wheelchair users are a small minority of students and some schools are specially designated to accommodate them with extra resources and equipment. One school, for example, had a 'base' with a medical room, accessible toilets, and facilities for physiotherapy and wheelchair adjustments. Schools not designed to be accessible, however, cannot be 'fixed' easily. Many are three storeys high, without lifts and with narrow corridors, and some are on split sites or based in more than one building.

Staff in 'old' schools explained how it was not possible to make them fully accessible for all students:

We've got areas that can only be reached by stairs and they're very narrow staircases ... We've looked so carefully at how to put lifts in and we can't. There are areas that we can't even ramp because the ramp would either have to be so long that a wheelchair would go out of the other end of the corridor or so steep that the classroom doors wouldn't open.

(SENCO)

We have got a toilet in every building that's been enlarged to take a wheelchair but we haven't been able to put lifts in. Our stairways are very narrow. The school is spread over five buildings and there isn't really anything we can do without very, very expensive adaptations.

(Deputy headteacher)

The physical environment caused difficulties for some students as they moved around the school. Staff mentioned the swift movement of large numbers of students between classrooms at the end of lessons as a particular problem for those with impaired mobility, those who were easily tired, and those recovering from surgery or other medical treatment.

I have to carry my inhaler round all the time with me, and just sometimes when I'm walking upstairs I get a bit tired and everybody else starts rushing and I'm sort of 'ooh'.

(Student with asthma)

Sometimes arrangements were made with classmates or friends to accompany students particularly vulnerable to being injured in busy corridors or who needed help climbing stairs. Often they would go to their next lesson a few minutes early to miss the general rush.

## **Keeping records on students' medical needs**

All study schools collected information on students' medical needs at school entry, although how this information was gathered varied. In all cases, details were recorded on the school database. How information was then used depended on the school. Five used the database for reference only, seven generated a medical needs register and four developed healthcare plans. Although information was supplied by parents, none of the schools consulted with parents or young people about what information was held and how it might be updated.

### ***Gathering information***

Information on students' medical needs was gained at the transition from primary to secondary school or when a student joined the school mid-year. In most cases, information was provided by parents via a health questionnaire asking for details of any illnesses or medical conditions, medication, emergency contacts and doctors. Four schools also obtained information from a child's feeder school, either through

school records or through the school nurse. In seven schools the medical forms were discussed with parents during transition interviews, whereas, in three others the procedure was, depending on the severity of the condition, to call parents in for interview to discuss the implications.

Parents who were interviewed for the study were asked about schools' admissions arrangements and how a school was informed about their child's condition. The three parents who had discussed the child's medical needs at a face-to-face meeting appeared most content with the level of information the school had about their child prior to his or her admission.

### ***School databases***

In most schools, a comprehensive list of the medical conditions affecting young people was compiled via the admissions and transition processes, and this information was then put onto the school database. Details on medical needs were included, regardless of severity, and school databases held information on the full spectrum of conditions from 'wears glasses' to life-threatening conditions. Improvements in information technology meant that all information about a student, from health to academic achievement and attendance, was now, generally, held on the same database.

### ***Medical needs registers***

In seven schools, information from the database was extracted to compile a medical needs register for restricted circulation to members of staff (see Chapter 7 for a further discussion of confidentiality and information sharing). The information held on these registers was variable. At the minimum, this consisted of the student's name, class and medical condition, but, in some cases, it included notes such as 'allowed to leave class early' or 'allow to eat in lessons'. Generally speaking, the medical needs database was accessed only for reference or contact details.

At first glance, there is little difference between the information held on registers and in databases, and the key distinction seems to be in the way information was accessed. The main advantage of a medical needs register was that information on students' conditions and needs was held in one place. On the whole, registers and databases were generated annually. Only one school updated records by writing to parents to ask them to record any new developments.

### ***Healthcare plans***

Individual healthcare plans are a key feature of government guidance (DfES 2005). Nonetheless, only four schools used the information they collected to generate such plans and several respondents asked if, in fact, they were required to do so.

Interestingly, all four schools using healthcare plans employed a full-time school matron who took responsibility for collating and updating them. How these plans were produced varied between schools. In two, the plans were informal and consisted of a file of information maintained by the school matron. In both, however, there were plans to standardise the documents and develop templates. In the other two schools, the school matrons had developed templates in line with formats suggested in the 1996 guidance (DEE/DH 1996). In all cases, the information held

covered the medical condition, treatment, medication or special provision, emergency contacts and, in some cases, contact details of health professionals. Three of the schools produced plans for all students with chronic or acute medical conditions but, in the fourth school, plans were generated only for students with 'complex conditions or disabilities', which did not cover conditions such as diabetes or asthma.

One of the recommendations of the more recent guidance (DfES 2005) for healthcare plans is that parents and students be involved in how they are drawn up. Only one school asked parents to document details such as contact numbers, medication, symptoms and emergency procedures. Parents and young people in the other three schools using healthcare plans were unaware that such a plan even existed.

Although parental awareness of healthcare plans was low, parents did express an interest in the development of such plans. They were particularly interested in the use of medical needs registers and healthcare plans as a means of information sharing and communication. There was general consensus that plans would be useful in this respect.

Schools that employed school matrons did not always use healthcare plans but they were more likely to do so and, even in those that did not, matrons did have procedures in place relating to medication and information sharing which were beneficial for students at the school. More discussion of the role of the school matron can be found in Chapter 5.

#### **One school's medical needs policy – an example of good practice**

This school had an overarching policy covering students with medical needs, which was developed and monitored by the school matron. The document was set out simply and clearly written. It explicitly applied to all members of teaching and support staff, listing their responsibilities under the policy, and set out general principles such as students' right to confidentiality. The roles of the matron and of first aiders were also described.

The policy covered the documentation relating to students with medical conditions, including permission forms, emergency contact details, healthcare plans, arrangements for updating records, detailed arrangements for storing and administering medication, and procedures for responding to emergencies. Training was also covered.

### **The relationship between SEN, disability and medical needs**

School staff did not generally associate medical needs with special educational needs unless these were related to physical disabilities. Despite this, the study witnessed reports of students' medical needs having a detrimental effect on their education. Some school staff suggested that recognition of a medical need as a SEN might aid communication and awareness:

It [medical need] is imbedded in the special education needs policy. In that, if we felt or the parents felt that the medical condition was significant enough for us to know about, because it might impact on their learning, then that would be dealt with ... The tutor or year head, or the special education needs department, might need to become involved.

(Deputy headteacher)

I mean, she is on our register [but] it's probably made no difference at all ... The only way it is, is that when we have a parents' evening, all staff have to make a comment on any girls that are on that register and their progress. So she'd get picked up there, but ... I mean, there's never been any massive educational issue with her, because she does, generally, keep up with the work.

(Headteacher)

Several school staff reported that medical needs were covered by the school's overarching SEN policy, even though they acknowledged that this would cover only learning difficulties arising from a medical need. This observation is supported by findings from the case studies. Of the 19 young people taking part, five had current statements of SEN. For three of the five, the statement was issued for a physical disability. In two of these three cases, the statement provided funding for a full-time member of support staff to enable the young person to access education and, in the third, it covered physical adaptations to the school environment (and had previously included support staff for personal care needs). The remaining two students' statements were not related to their medical condition, although one parent commented that her son's educational problems arose because he had missed a great deal of schooling when younger. Schools identified four further students who had learning difficulties that did not necessitate a statement but required school action or school action plus. Two had chronic conditions and the SENCOs had included them on the SEN register to encourage information sharing and monitoring. Although this led to little tangible support, it did mean that teachers were aware of possible problems that might arise.

Just under half of all students who identified themselves as having a medical need, injury or disability in the school survey indicated that this had a negative effect on their learning. This was particularly the case for students reporting non-medical conditions such as mental health issues, developmental disorders, and general learning difficulties. Seven students in the case studies also said that their medical condition had had an adverse effect on their schooling and provided more detail. Commonly reported effects were falling behind after time off school, dropping subjects or lessons because of difficulties keeping up, falling grades and a lack of concentration. However, these were related to the physical effects of having a medical condition and not educational needs, and so highlight the importance of schools having policies that relate to medical needs and which recognise the impact that these can have on learning.

## School ethos

A positive school ethos meant, to many school staff, inclusive policies that welcomed students with special needs. Although the majority of schools did not have a written policy on supporting students with medical needs, staff explained that individual students' circumstances would be discussed and arrangements made for them. The effectiveness of the pastoral team and the necessity for good communication both within school and with outside agencies were stressed as important for enabling inclusion.

I think we react to each child as he or she comes into Year 7 to be quite honest. We put in place what's necessary for a particular child.

(Deputy headteacher)

We do tend to treat the cases individually, so whatever needs that student has, then we put in what needs to be done about it ... We've got a very positive staff, and a lot of them will bend over backwards to help particular students.

(Headteacher)

Schools with an inclusive ethos made efforts to ensure that all students could be included in extracurricular activities. Involvement in these was seen as important, both academically and socially, and the SENCO at one school made it clear that access for all was a priority:

There's nobody left out of a visit because of a medical condition. We know that next year [student with visual impairment] will be in Year 9 and we'll be doing residential visits with Year 9, and wherever she goes that means that there will be an extra member of staff who will have to go with her and the school will have to fund that.

Another headteacher described how students with disabilities and medical conditions are included in all extracurricular activities:

They go on all our trips. We don't have any trips or outings that they can't go on, even though sometimes it's incredibly complicated, particularly when they're abroad. But we won't have one if we can't get these children on it, we just don't go. So they do everything that the other children do which is wonderful for them.

An inclusive ethos can have a positive effect on all students, whether or not they have medical needs. Staff spoke with pride about the way students supported each other, and stressed how including students with a range of conditions in mainstream education benefited the school community. Students with disabilities and medical needs were included in all aspects of school life and expected to take a full part in school activities, while able-bodied students learned to be considerate and supportive.

The fact that the ethos of the school is so inclusive means that we don't see obstructions, we just see girls who have a different situation and different needs, but they're all involved, they're all doing the same thing, they're all here

as of right. Once they're here, they're on an equal footing ... The head calls it 'family' when she's speaking publicly about it – maybe that's a little romantic and sentimental – but there is undeniably an ethos of care for other people in this school.

(Deputy headteacher)

School staff were asked if they felt their school was reactive or proactive in the way it supported students with medical needs. Responses were mixed. Many felt that, at a school level, the school was proactive in, for example, making ongoing improvements to the school environment and holding weekly interagency meetings. On the other hand, a more reactive approach was followed at an individual level, with schools often responding to novel conditions and situations. Nearly all the school staff interviewed pointed out that however well-drawn up procedures were, they could only follow them if they were informed about students' needs.

I think we're proactive in that we know we want to, and are constantly trying to, increase access in all of its manifestations. But it's an old school building and there are certain things we know we can't do. We're reactive in terms of if a child's here then we just get on with it. So I think we are both, which doesn't help your answer really but I think that's probably the truth.

(SENCO)

## Key findings

- All study schools had clear admissions policies and procedures.
- Not all schools were equally suitable for students with mobility problems, and many acknowledged that inclusive access could not easily be achieved.
- Awareness of government guidance on supporting students with medical needs was poor.
- School policies for students with medical needs were rare: some teachers had reservations about their necessity and value.
- Most of the schools in the study had disability access plans.
- All schools used the school database to record student information. They varied in whether this information was used to generate a medical needs register and/or healthcare plans.
- Medical needs were not generally regarded as special educational needs unless a physical disability was involved.
- Most schools reflected an inclusive ethos and, in principle, welcomed students with medical conditions and needs.
- Schools appeared both reactive and proactive in responding to medical needs.

## Chapter 5: Staff roles and responsibilities

Policies and procedures for the care of students with medical needs are only useful if there is a member (or members) of staff who is charged with the responsibility of putting them into practice. This should be someone who has the time and capacity to carry out this function and can ensure that colleagues also understand and accept their respective roles in supporting these students. This chapter looks at staff roles and responsibilities towards students with medical needs in four main areas: providing general information and support; medication and its administration; dealing with emergencies; the issue of personal care.

### Providing general information and support

Four principal questions were explored with young people and school staff to find out how schools provide information and support for students with medical needs. The questions asked to whom students go if they have a question or problem, how responsibility for medical needs is delegated, what role the school nurse or school matron plays in meeting medical needs, and about the contribution of first aiders and other members of the pastoral team.

#### *Seeking help*

The school survey asked students, 'Who would you go to if you felt unwell or needed help for a health matter at school?' Almost all young people who responded could identify one or more people they would approach.

Overall, six in 10 young people reported that they would go to the school health service. This was the most common response, although there were differences between the two study areas that seemed related to staffing issues: in study area one, school nurses visited schools regularly but were not based on site; in study area two, six out of the 11 schools employed a full-time school matron. In study area one, four in 10 students said they would go to the school health service as compared with seven in 10 in the second. It seemed that matrons were most likely to be seen as a source of support, although this could not be confirmed, because response codes meant that it was not possible to distinguish between preferences for talking to an on-site matron or visiting a school nurse. The second most common response was to go to the school office or reception (18 per cent), and the third was to a teacher (11 per cent). Some students, 16 per cent, suggested more than one person to whom they could turn if they were ill or needed health advice, and 7 per cent said they would talk to friends, siblings or other family members.

When asked whom they would go to if they needed help or advice at school because of illness, case study respondents were also clear about who they would approach. Often, it seemed that students had particular people in mind when they explained to whom they would turn for help or advice. They mentioned form teachers, other teachers, staff in the special needs department including learning support assistants and SENCOs, a school-based matron or the school office or reception. The person, rather than the person's role, was clearly important. Two

said, for example, that they would not go to the matron because they did not like her.

Some members of staff were seen as helpful because of their personal experience of a particular condition. A member of support staff at one school, for example, had sons who had haemophilia and was therefore well informed and able to support a student with the same condition. However, personal experience was not necessarily relevant. The mother of a boy with type 1 diabetes related how a teacher did not understand her son's condition but, because she had an elderly relative with type 2 diabetes, believed that she had some expertise and so treated him inappropriately.

### ***Taking responsibility***

Findings from interviews with school staff show that respondents in senior positions were clear about the hierarchy of responsibility in relation to caring for students. They described how the governing body develops, oversees and monitors policy, while the headteacher implements it. Pastoral responsibility for students' welfare is delegated to members of the senior management team, heads of year, form teachers and other staff, such as the SENCO and school matron.

If you had to pick one person out, on a sort of day-to-day, minute-to-minute situation, it would be Matron but ultimately responsibility, well, it's the governing body ... is delegated to me.

(Headteacher)

Less formally, other respondents outlined arrangements for pastoral care whereby responsibility for students' welfare is cascaded down through the school from senior staff to form teachers with added support from SENCOs, learning support/teaching assistants (LSA/TAs), school counsellors and learning mentors. School nurses may also play a role and, in some schools, physiotherapists provided additional treatment for particular students on site. Ideally, both pastoral and academic staff took collective responsibility for meeting the young people's medical needs. One member of school staff described how staff work together to support a young person as 'a collaborative activity'. In this case, the SENCO was charged with responsibility but worked closely with members of the pastoral team, the health and safety officer (if necessary) and the school matron.

### ***The pastoral team***

Although respondents in the majority of schools said they did not have a 'named member of staff' who was specifically responsible for students with medical needs, there was in fact someone responsible for developing policy regarding these students – often a deputy head or SENCO – as well as members of staff who took care of their needs on a day-to-day basis.

In 10 schools, heads of year were described as key to ensuring that information about a particular child's needs was shared within the school. They were alerted if a child was absent and were likely to take responsibility for coordinating support if a child became ill. They might also ensure that work is sent home or to hospital, liaise with the Educational Welfare service and, with the form teacher, instigate informal support, such as cards and visits from members of staff and fellow students.

The extent and range of the roles of particular members of staff depended on the resources available to support young people with disabilities and/or medical needs. At schools employing a matron, for example, heads of year might have responsibility for the welfare of young people in their year group, but the matron might be the person with 'first line' responsibility and to whom the young people would turn.

Within the year group, the heads of year obviously need to know who the people are that they need to have an awareness of. The form tutors obviously need to know about the medical problems in their form. The office is responsible for collating the information and they put out a list to heads of faculty of the major health problems so that people know within their teaching area.

(Deputy headteacher)

Teachers with responsibility for health and safety might also be involved in supporting students with a medical need, as might governors who sat on premises committees and could provide advice and make decisions about new or improved facilities and alterations to the environment.

Nonetheless, responsibility for meeting the needs of those students without statements of SEN and not on the SEN register was not always clear. Although the SENCO had broad responsibilities for special needs, and heads of year were required to consider all aspects of pastoral care, it seemed that students with a chronic condition would not necessarily receive individualised support. Evidence from the case studies shows that students were not always clear about who they should go to for confidential support if their school had no on-site matron.

#### **Taking responsibility – a good practice example**

At one school, the deputy head for the lower school is responsible for policy and procedures relating to medical needs as well as child protection and transition from primary school into Year 7. At this school, each department has a linked governor with responsibility for special needs who works with this deputy head.

#### ***The role of the school matron***

Six of the 11 schools in study area two employed a full-time member of staff whose role was both to support students with health problems on a day-to-day basis and to provide advice and information to staff. In most cases the 'school matron' was responsible for storing and administering medication, record keeping, managing medical emergencies, providing and/or arranging training in healthcare, and acting as a support to students who feel ill. Matrons also liaised with parents, other school staff, the school health service and professionals and agencies outside the school. Two had some administrative responsibilities but were still designated 'matron' status. In schools without a matron, a member of the administration staff qualified in first aid might undertake many similar tasks, alongside their other duties.

It seemed that the presence of a matron could make a difference to whether or not a school felt able to admit a student with complex health needs and provide the necessary support. One headteacher, for example, explained that having a matron in post gave him confidence to welcome students who might have challenging health needs.

Approximately half the matrons in study schools were qualified nurses – although one said that her qualification had lapsed – while others were qualified as first aiders. The deputy head at one school explained that, although the matron was a qualified nurse, this was not regarded as necessary for the role. The school had, in fact, attempted to ‘de-medicalise the post’ by passing responsibility for sick students to their parents. However, because of the skills of the matron and the needs of the students, the post had remained ‘resolutely a matron role’. Another first aider matron explained that, in her view, the role is not a nursing one and how, in the past, qualified nurses had left the job because they ‘hankered after going back to nursing’. She was clear that a matron had to like young people, listen to them, and liaise with others. She felt that she did not have to be a specialist herself, but she needed to have good contacts with specialists who could advise on the needs of particular students, as well as a good rapport with parents. On-site matrons are paid from a school’s own budget and not by the local Primary Care Trust or the local authority. The head at one school explained how the budget for the matron’s post came from funds allocated to the school for young people with statements of special educational needs.

Matrons act as an extra school resource, ‘mopping up’ many of the needs of school students, from the trivial to the serious, which teaching staff do not have time to deal with. Matrons described how they provide advice on a range of health and personal issues and, in some cases, situations where there may be concern for a young person’s well-being or safety. Two matrons kept a detailed log of all contacts with students and used this evidence to follow up concerns with senior staff. Another described how, after listening to students, she would refer them to the school nursing service or head of year and, with their approval, arrange an appointment for them.

It’s not just being there for the plaster for the knee. You’re there to be that extra pair of ears ... There’s a whole variety of things that I listen to – can’t judge on – but just listen.

(School matron)

Matrons also make decisions about whether and when a student should go home because of ill health, as well as when to call an ambulance. One described how teachers send students who are unwell to her to decide whether they can go back to class or go home with the agreement of the head of year and parents. Matrons have to find a balance between being seen as ‘approachable and sympathetic’ and ‘a soft touch’, in judging whether or not a student is genuinely unwell.

I probably keep them for about 10 to 15 minutes and, if they are no better, depending on what they are saying and who the child is, because some will try and swing the lead, I’ll send them home.

(School matron)

They also act as an information source for teaching staff, reminding them about the needs of particular students, providing advice and help with referrals, and organising training on particular conditions. If schools used healthcare plans, the matron was usually responsible for collating information and keeping it up to date.

Parents whose children were in regular contact with matrons were generally very positive about what they could offer, and described them as 'fantastic', 'supportive' and 'brilliant'. They appreciated the fact that there was somewhere for their child to sit or lie down and rest during the school day under supervision. Even if some of the students were not so enthusiastic, parents liked having a named person they could contact for a range of concerns, from issues surrounding medication to changes in family circumstances that might have an impact on their child at school. Parents also appreciated being contacted by the matron after an accident or to discuss a change in medication.

Matrons were not, however, universally popular. The school survey revealed that a few students were critical of a matron's unsympathetic or abrupt manner, lack of availability during lunch breaks, or the fact that she was not a qualified nurse. One boy with diabetes, who took part in the case studies, said he did not like seeing the matron, whereas his mother felt that having her there 'gave him confidence because he knew if there was a problem he could always leave the classroom and sit at matron's'.

#### **Communicating with parents – a good practice example**

One matron described how she works with parents in an informal way. She initially meets them at the school's open evening for new admissions and then offers an 'open house' if they want to talk to her – particularly if they have children in Year 7. She asks parents to 'pop in' to discuss how things are going after the first few weeks of term, and reassures them that she will contact them if she has any concerns.

#### ***The role of first aiders***

First aiders, who are trained volunteers, played an important role in many schools. In some, for example, they had responsibility for attending to emergencies and storing and administering medication. Many were office staff although some were teachers, particularly PE teachers, and, in the case of one school, a science technician and the caretaker. They were expected to know about students with ongoing medical conditions, provide cover when the matron was not available, make accident book reports, and judge when it was necessary to call an ambulance or send a student home because of illness or injury. Schools ensured that first aid qualifications were up to date and that first aiders were given the opportunity to attend training sessions in the use of Epipens, rectal diazepam and other relevant interventions and types of medication. Lists of first aiders, and where to find them, were available in the school reception or office.

There were, however, limits to the responsibility first aiders might be prepared to take on. At one school, for instance, they had been concerned about using rectal

diazepam for a student with epilepsy. The headteacher explained the dilemma. On the one hand, first aiders had been reluctant to volunteer to administer it because they 'are very conscious of being found liable and of prosecution and so forth', but on the other hand, their 'commitment to first aid' meant they also felt they 'couldn't not do something'. As the head said, 'confidence and expertise' are key to managing difficult procedures and can be provided by good quality training as well as clarity about procedures and responsibilities.

## Medication and its administration

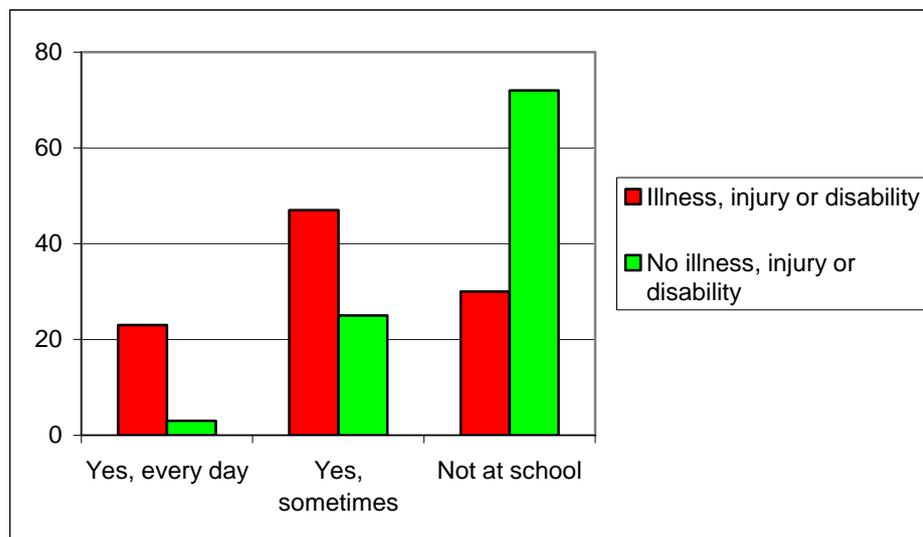
Government guidance – *Managing Medicines in Schools and Early Years Settings* (DfES 2005) – develops the points made in the 1996 guidance and states that schools should have a clear policy on the administration of medication. As already outlined, few schools in the study had developed clear school policies for students with medical needs, and here we look specifically at policy and practice in the area of medication and its administration. The following sections examine the characteristics of students taking medication at school, and the role schools play in providing support and organising its administration. Young people's views on these matters are also presented.

### ***How many young people need to take medication?***

It is estimated that around 200 million prescriptions are issued for children and young people in any one year (Costello and others 2004), and that about one in five secondary school students take some type of medication, including over-the-counter medicines, every week (Dengler and Roberts 1996). There is, however, little published information on the amount of medicines administered during the school day.

To gain some evidence on this question, the school survey asked students how often they needed to take medication and whether they needed to take it during the school day. Figure 5.1 shows that students who reported a disability, illness or injury were much more likely to say they did than the group of students who did not report any of these conditions. Five per cent of young people with a condition of some kind said they took medication at school every day and one in three said they sometimes took it at school. No student who did not report a condition said they took medication at school every day, and only eight per cent said they did so sometimes.

**Figure 5.1: Students who completed the questionnaire and take medication at school (percentages)**



Certain medical conditions were associated with a greater likelihood of taking medication at school (Table 5.1). Students with long-term medical conditions were most likely to take medication at least sometimes, and others with non-medical conditions (for example, ADHD, anxiety and/or depression) were most likely to take it regularly. Students with sensory conditions, followed by those who had suffered accidents or injuries, were least likely to take medication.

**Table 5.1: Students taking medication by category of condition (single categories only)**

Category	Number	Do you take medication at school?		
		Every day %	Sometimes %	No %
Long-term medical condition	885	6	45	49
Injury/accident	242	2	16	82
Non-medical condition	89	14	7	75
Musculoskeletal	83	1	30	69
Infection/virus	70	4	20	76
Sensory	64	2	8	90

## ***Supporting students at school***

Only one school had a policy on the distribution of medication incorporated in the overall medical needs policy available to teachers, although two others referred to medication in health and safety policies. Some schools dealt with issues of self-administration within school drugs policies.

Despite a lack of documented policy, most school staff felt that procedures were in place to support students who needed medication during the school day. All schools were willing to hold medication on the school site, although they differed in the amount of medication they were prepared to store. In one school, the deputy headteacher reported that the school refused to keep medication on site or allow students to use it at school but, when asked about specific items such as asthma inhalers, she said that these were allowed in school and would normally be kept by the child, although labelled spares would be kept in the school office. Other schools required medicines to be labelled and brought in daily by parents or older students, whereas others were happy to take weekly or even termly supplies to make things easier for parents, staff and students. All schools required parental permission to retain medication.

Our policy now is no medication at all because, I think, a couple of years ago, we were sent a circular by the LEA informing us of the dangers of administering pills and stuff to children because of allergic reaction, so, in order to protect ourselves, we now say 'no' ... If a child is not well and needs medication they need to stay home.

(Deputy headteacher)

We expect parents to (a) inform us and (b) ensure that medications are with us, with specific instructions about the dosage. Also that they supply these labelled, and that they give us a fresh supply, on a termly basis, because, as we all know, medicines can go out of date. And we also put in that policy that we will destroy things which have not been used, after a certain period, because again, you wouldn't want to give somebody something if it was out of date. So it's that kind of issue.

(School matron)

I think they just accepted that she was only going to bring in two tablets a day. It's not a question of bringing a whole pack, and it would have been pointless for her to keep going to the office saying, 'it's lunchtime, can I have my two tablets?' And so I said what we would do is we would just put the two in her lunchbox and it would be there for her, and they've gone along with it.

(School matron)

Schools also varied in their approaches to administering medication, particularly in terms of logging and monitoring distribution. Arrangements for self-administration were less clear and, often, school staff were unaware whether or not students were bringing medication to school. On the whole, school staff realised they were not required to administer medication, but were willing to supervise students giving themselves medicine, and to store this medication safely.

## ***Consent and self-administration***

All schools required written parental consent if school staff were to hold and distribute medication but not if students administered their own. Self-management of medicines is encouraged in the government guidance and not seen as problematic and, indeed, a considerable number of students taking medication, such as those using asthma inhalers, did take responsibility for themselves. At greater issue, however, is where school staff are not aware that medication is being brought into school premises. This evidently happened. In several instances, staff said that students were not allowed to carry their own medication while, at the same time, it was apparent from the case studies that they did.

Self-management of medication is advantageous in reducing pressures on staff and allowing students to have a normal school day. It also overcomes difficulties, reported by young people and parents, and particularly problematic for those with episodic conditions, that can arise if relevant staff are not available when a student needs to take medication. All the same, it is apparent that procedures need to be in place to ensure that self-administered medication is monitored. Government guidance (DfES 2005) advocates that parents give formal consent to their children carrying their own medication, so as to help keep schools informed and to overcome any possible conflict between the school's drugs policy and the requirement to support students with medical needs.

### **Managing medication: a good practice example**

One school has a documented policy, developed by the full-time matron, on managing medication, which is reproduced at the front of the school handbook. All medication is colour-coded and locked in different drawers in a cupboard in the student services office, an area easily accessible to students. Besides the school matron, all staff trained in first aid have access to the medication cupboard. Medication is held for the term and any remaining at the end of each term is destroyed. Detailed records are kept, first in a day book and then on computer, on the use of medication as well as associated accidents and incidents. These records cover all circumstances, including if a student wants a drink of water. There is a separate day sheet for students who have diabetes. Students can administer their own medication in a small first aid room.

### ***How is the administration of medication organised?***

In some cases, because of a school policy, a student's maturity, or the type of medication, it may not be appropriate for students to carry and administer their own medication. In such instances, medication is held at the school and taken in the presence of a member of staff. Schools that employed full-time matrons were likely to have better organised procedures, with medication usually stored in a locked cabinet and a detailed log kept of any taken. In schools without a matron, responsibility for dispensing medication was often delegated to administrative staff, or others in a pastoral or welfare role, who were trained in first aid and easily accessible. Some such staff were not, however, entirely happy about the situation.

Unlike school matrons, who were usually well informed about a student's background and medical condition, they sometimes felt that they lacked appropriate knowledge. Several said they were unaware of a particular student's condition and need for medication, despite taking responsibility for distributing it on a daily basis.

We have administered prescribed medicine for another child for ... I don't know if it was to do with behaviour?

(First aider)

We have had some boys who are on Ritalin and have come to take [it] ... only for us to find out later that they haven't. It just raises questions about ultimately whose responsibility it is.

(First aider)

### ***Logging and monitoring***

School staff administered medication in line with the government guidance and, in all but one school, recorded its distribution. However, only in schools with a full-time member of staff responsible for students with medical needs did it seem possible to monitor administration effectively, ensure that students take their medication and chase up those who do not. The lack of this resource raised questions about whose responsibility it should be to make sure students take their medication correctly.

The school database could be helpful in monitoring whether or not medication had been taken, but this was not a solution in itself. Again, the presence of a matron helped. One, for example, kept a medication log on the database, and used it to check if a student on medication was in school on a certain day and send a reminder to their teacher if necessary. In some schools without matrons, administrative staff used the database in this way and so reduced the pressure on staff.

### ***A dedicated medical room***

Staff and students both pointed to the need for a school to have suitable facilities for young people to administer medication. Although the Education (School Premises) Regulations (The Stationery Office 1996) requires schools to have suitable areas for medical or dental inspections, this does not extend to having a designated medical room. Indeed, medical rooms were a rarity in the schools we visited, and often the medical 'area' was a corner of the administration office. Frequently there was nowhere suitable for a student to go to rest and recover if feeling unwell. Medical rooms, where they existed, tended to be very small or had another use. One 'medical room', for example, was in fact the school nurse's office and was equipped with a desk and chair but nowhere to lie down or sit comfortably. At another school, the matron had attempted to make the medical room attractive, with posters on the wall, even though it was not much larger than a cupboard, uncomfortable and had no natural light. The headteacher at another school explained that the school's reception area had to be closed to visitors if students were injured, distressed or ill, because there was no other place where they could go to recover.

The lack of suitable and private facilities for students was of considerable concern. It seemed to be a particular limitation for students with diabetes who said they preferred to go somewhere private for their injections or to test their blood.

He had to do his injection in the dining room, eating his packed lunch in front of everyone and the girls are going, 'Ergh! that's gross.' I went in one lunch time and saw it and I didn't realise that was what was happening and I said to the head, 'This isn't on. He shouldn't be doing this in front of everyone. Why can't he go in the medical room?' and he said, 'Because we lock it at lunch times.'

(Mother of a boy with diabetes)

It is a small room and there is no real privacy if she is having intravenous antibiotics. If someone else comes in then they can see her having the treatment. She doesn't always want that to be the case when she is having blood taken.

(Mother of a girl with cystic fibrosis)

One student with a medical condition said she was more likely to go home than to visit the medical room if in pain.

Well I'd rather go home 'cause the medical room is really not nice. It's not horrible but I just don't think it's very nice.

While there is little that many schools can do to generate space for a medical area, there is a need for greater awareness of the impact that taking medication has on young people. However, needs vary from student to student. One school, for example, arranged for the medical room to be opened at lunch time so that a Year 9 student with cystic fibrosis could take her medication. She in fact said she would have preferred to use a classroom and have lunch with her friends – which was something not possible in the small medical room.

Students who completed the school survey questionnaire were asked to suggest improvements to their school to enhance the experience of students with health needs. Of the 3,828 students who responded to this question, 12 per cent thought that facilities should be improved. Many of these specifically mentioned the provision of a larger and better-equipped medical room.

### ***Young people's views***

On the whole, taking medication at school was something that young people would prefer not to have to do. Not only could it be time consuming, it also interfered with socialising or extracurricular activities. A student with diabetes, for example, said he did not feel he got enough time during the school's short lunch break to take his insulin, eat lunch and see his friends. Several others told how waiting to pick up medication during the lunch hour meant they were always at the back of the lunch queue. Another commented that collecting tablets from the school office drew attention to her condition, which she preferred not to make an issue of. School offices were often open plan and it was hard to ensure privacy in them.

Five of the 19 young people who took part in the case studies said they would refuse to take medication or undertake treatment at school, regardless of procedures or facilities. In the main, this was because they did not want to draw attention to their condition. One student with diabetes changed the timings of his insulin injections so that he did not have to undertake the procedure at school. In such cases, students were acting against the advice of healthcare staff. It seems such situations might have been overcome if acceptable plans and procedures had been established when the students first joined the school.

I take a lot of tablets. I need to take them early in the morning and late at night, so when I get to school my friends didn't know I was taking any medication.

(Student who is HIV positive)

Generally, young people were much happier when given responsibility to carry their own medication. However, this could raise issues of effective communication, as one young person found out when she got into trouble with her teacher for putting cream on her eczema in class. This issue could easily have been avoided if the teacher had been informed of the student's condition and the necessary treatment.

## Dealing with emergencies

As well as administering medication, school staff also have to respond to emergency medical situations that may occur on the school premises or during school activities or trips. Many of the medical conditions experienced by young people are episodic by nature, and may require medical attention at very short notice. The following sections look at the causes and numbers of emergency or episodic incidents, the procedures schools have in place to deal with them, and the attitudes of staff and students in these instances.

### *The numbers involved*

We asked the young people taking part in the school survey if they had received any emergency treatment at school over the last 12 months. In total, 5 per cent of students reported having emergency treatment on one occasion during the past year, and a further 1 per cent reported having treatment on more than one occasion. Not surprisingly, rates were highest for those with medical conditions. Nearly 10 per cent of students who self-reported an injury, illness or disability had received emergency treatment on one occasion, with a further 3 per cent more than once; compared to only 3 per cent and 1 per cent in the group who did not. Emergency treatment most commonly followed an injury or accident, including sporting injuries, broken bones in the playground, and accidents in the classroom. In all, 2.6 per cent of students reported this type of accident.

### *Medical emergencies or planned procedures?*

The kinds of events requiring immediate medical attention at school included accidents and injuries, epileptic fits, asthma attacks, allergic reactions, fainting and issues relating to diabetes. All schools had procedures in place to deal with medical emergencies, but these varied widely.

Generally, the first task in an emergency was to locate a trained member of staff, usually a first aider or a school matron, and call an ambulance if there was any doubt about a student's welfare. Beyond these initial responses, schools differed in the support that staff were able to offer on site. They seemed to take one of two approaches: about half were willing to undertake specific responsive actions (such as administering rectal diazepam and using Epipens), while the rest said their responsibility could not go far beyond calling an ambulance. Some staff expressed a real concern about the correct course of action to take in the event of a student going into anaphylactic shock, even if they had received training in this area.

These are not emergencies, they are planned procedures and we would know who on the staff would have to do something like that.

(Member of school staff)

The basic thing is that we don't actually do anything, we phone for an ambulance, that is the basic type of information that goes around.

(Deputy headteacher)

Schools with full-time school matrons were not only more likely to undertake emergency procedures, but also had better developed protocols and a more detailed knowledge of students with medical needs. Several of the school matrons would, for instance, attend the scene with a student's healthcare plan in hand. A similar type of response could be advocated for schools reliant on non-medical school staff, particularly if trained in first aid and with easy access to the school database and information on both a student's condition and the course of action to follow in an emergency.

#### **Dealing with epilepsy in the classroom: a good practice example**

Schools that used information from medical needs registers to plan for possible situations were particularly effective in managing emergency situations. They might, for instance, have simple steps to follow such as making sure that all staff who teach the student are aware of his or her condition and how to manage it.

In one school, all teachers were aware of the procedures for supporting a student at risk of having an epileptic fit in the classroom. First, furniture is moved, students are cleared from the area, and two students are immediately sent to the school office to locate the school matron or another first aider. Reference is then made to the student's individual healthcare plan to decide on the appropriate course of action. If rectal diazepam is required, two members of staff must be present, and the area is closed to all other staff and students while the procedure takes place. Clean clothing is supplied if necessary, and soiled garments are held on the premises until they can be taken home. After the seizure, the student is taken to the medical room to recover. The whole event is logged, including details of any medication, and the information added to the student's school file.

### ***Does fear of repercussion prevent school staff from acting in an emergency?***

One of the biggest concerns school staff had about responding to medical emergencies was the threat of litigation. Many commented that, as a result, it was difficult to get staff to volunteer to undertake medical responsibilities, especially in emergency situations. The 2005 guidance states that the employer must take out employer's liability insurance, ensuring that full cover is provided for staff acting within the scope of their employment, but there seemed to be general confusion in relation to the issue of insurance in many of the schools. Even when insurance requirements were met, as it appeared they were in nearly one third of the schools, there was a surprising lack of awareness amongst staff with responsibilities for young people with medical conditions. In particular, it seems that greater clarification is needed about what 'acting within the scope of their employment' includes. All the same, staff reported a growing recognition that 'not acting' could be far more hazardous to a student – and therefore also to the school – than being prepared and willing to undertake emergency procedures, such as using an Epipen.

We wouldn't administer that [rectal diazepam] because that could be regarded as an assault. So we've never been asked to do that, and we would expect a parent to do that. Not our job.

(Deputy headteacher)

It is a worry that people in general now are very conscious of being found liable, and of prosecution and so forth, and it is a great shame but I think they are concerned that if something goes wrong it is them who carry the can.

(SENCO)

An interesting development in the 2005 DfES guidance is the suggestion that members of a school's support staff may be given responsibility for the administration of medication and dealing with emergency situations, and that this should be included in their core job description. There is no requirement for the post to be full time, and it might not resemble the traditional 'school matron' role, but it is important in going part of the way towards ensuring that children and young people are supported in educational environments. Although the development of this role is likely to make an important difference, it is also self-evident that having one highly trained or specialist member of staff does not eclipse the need for all staff to be aware of how to act in a medical emergency.

### ***Young people and emergencies***

On the whole, the students who took part in the case studies were happy with arrangements for any possible emergencies they might experience, and their only reservations seemed to concern the information staff might have about their condition. In practice, several young people felt that their friends were better than school staff in supporting them and knowing what to do in emergency situations. Several schools specifically mentioned how they had trained students' friends to administer emergency medication, such as using Epipens, or to know what to do in the case of an episodic condition. Often, students commented that they had more confidence in their friends than they did in the staff at the school.

Sometimes I really black out. I can't see very well 'cause my vision goes blurry. My friends help me. That's probably about it, no one else.

(Boy with diabetes)

Well, I've been on two school trips, and because of what happened then basically I won't be going on any more out of school things because I collapsed there ... They didn't ask the nurse about anything, they didn't bring Lucozade... They said that we would be getting a minibus somewhere but instead they decided to make us walk four and a half extra miles instead of getting a minibus, which was quite terrible.

(Boy with diabetes)

### **The involvement of friends and peers in managing emergency situations: a good practice example**

A young person with epilepsy, embarrassed by the condition, used to hide somewhere on the school premises when she felt a fit coming on. Sensing the danger in this situation, the school trained two of her friends to recognise symptoms and understand the necessary procedures in the event of a fit. As a result, the school knew where the student was if she had a seizure, and exactly what had happened, and could make suitable arrangements.

Particular issues arose during school trips, and some young people said that they felt that staff organising trips had not properly considered what could happen if there was a medically related emergency. This is another aspect of risk assessment and planning, and an area in which established procedures can ensure that appropriate staff are informed about the needs of students with medical conditions. Healthcare plans can play a useful role in planning school trips and if there is a need to deal with an emergency, when the usual procedures cannot be followed and specialist staff, such as the school matron, are not available.

### **The issue of personal care**

Research studies have highlighted the difficulties students with personal care needs may experience at school. Such needs might include help with toileting and washing, or support to use technological devices such as feeding pumps or tracheostomies at school. Cavet's study (2000), for example, focused on children and young people with impairments that are not visible but result in incontinence. She found that these students faced stigma at school and that their needs were not always met. Young people wanted to be treated like their peers, their privacy to be respected and staff to be well informed about their needs and able to respond accordingly.

In order to explore this aspect of students' needs, the student survey included a question on personal care needs: 'Do you need help with personal care at school?' Answers suggested that all respondents did not understand what was meant by

'personal care' because 69 students who had reported not having medical needs said they had personal care needs. However, a larger percentage of those who reported a medical condition, disability or injury compared to those who did not, said they had personal care needs – 4.8 per cent compared to 1.6 per cent.

### ***Personal care needs***

Findings from our interviews suggest that students' personal care needs are not widely recognised by schools and that the majority of staff are unaware that any young people had difficulties in this area. Those who did mention these needs focused on three main reasons for personal care. These were for help in using toilet facilities due to impaired mobility, for specialist toilet facilities because of a particular condition, and assistance following 'accidents' which might occur, for example, during a seizure.

Students who participated in the case studies and had personal care needs included those who had impaired mobility and were wheelchair users, and those who were sometimes incontinent. Support with personal care could mean helping students with toileting and washing – including lifting them – and providing them with clean clothing if needed. None of the case study students were technology-dependent, although one girl with cystic fibrosis occasionally had to use a nebuliser at school.

### ***Facilities and support***

Students with physical disabilities are likely to have a statement of SEN and the funding attached to the statement may be used to provide support staff for them at school. The students in the case studies who were wheelchair users were given support to gain access to toilet facilities and help with toileting. However, both were unhappy about using toilet facilities at school. One, a girl with congenital muscular dystrophy, who was being encouraged to drink more, preferred not to drink so much because she had to use the school toilet at set times. The other, a boy with Friedreich's ataxia refused to use the toilet at school at all, even though staff offered to support him. He felt embarrassed by being supported by female staff but, even when he was offered the support of a male member of staff, he preferred to use only the toilet at home. He was also too shy to shower in front of other students after PE lessons, but this difficulty was solved when the headteacher offered him use of the staff's shower facilities.

In one school, a specially adapted toilet had been built for the use of one student with spina bifida who uses a catheter. However, if she had any problems she was more likely to contact her mother than to ask for help from members of staff, no matter how sympathetic and supportive they were. In some schools, students who needed to make use of the toilet during lesson times were given a special stamp in their planner, or a card to show to the teacher, and were allowed to leave the classroom discreetly.

### ***Difficulties faced by students***

Although most students were offered support at school, this was not always the case and, in one school, a student who used a wheelchair had been excluded for a few days on the grounds that supporting her endangered the health and safety of staff. There seemed to be a question about the safety of moving and handling her,

and the number of times it was reasonable for her to use the toilet. Her parents were unhappy that neither the student nor her family had been involved in any assessment of the situation, or in discussion about how her needs could best be met.

Another student had problems with continence and was offered no support at school. If she had an 'accident' she contacted her mother, who came to collect her. There were no private washing facilities or lockers for spare clothes at school and no individual to whom she could talk confidentially. This student had experienced bullying and, according to her mother, had been taunted by other students. The school nurse did not know that she was facing any difficulties at school and there seemed to be no communication between the young person, her mother, school staff and the specialist nurse at the hospital clinic that she attended. The sensitivity of the issue, and the young person's embarrassment and subsequent unwillingness to discuss it, meant that no arrangements or facilities were put in place to support her. Like one of the other students, this young person did not want to be seen getting changed and therefore had not learned to swim; she preferred to miss the lesson rather than be put in an uncomfortable position.

### ***Supporting students with personal care needs***

Some members of staff seemed unsure about how a school could support students who needed help going to the toilet or had other personal needs. A positive, 'can do' attitude on the part of staff would help, as would staff training and resources. Cavet (2000) also suggests that school students, both disabled and non-disabled, would benefit from a wider understanding of disability. Some students had experienced bullying or been ostracised because of their condition and might be deeply embarrassed about seeking help. Staff should be sensitive to their feelings and ensure that they do not draw unnecessary attention to them.

## **Key findings**

- Students were likely to turn to the school health service if feeling unwell, particularly if the school employed a full-time school matron.
- Provision for students with medical conditions was most organised and extensive in schools with a full-time school matron. It was also particularly appreciated by parents.
- Not surprisingly, however, students would seek support from members of school staff they liked and got on with.
- Most schools had both formal and informal procedures for determining staff responsibility for students with medical conditions.
- Responsibility for meeting the needs of students without a statement of SEN and not on the SEN register was not, however, always clear.
- Schools varied in their approaches to administering medication, particularly in terms of logging and monitoring distribution.
- All schools required parental consent to hold medication on site.

- Arrangements for self-administration were less clear, and school staff were often unaware that students were bringing medication into the school grounds.
- In the absence of a full-time matron, administration of medication was usually the responsibility of support staff. The knowledge of support staff varied, and not all staff administering medication were aware of what it was for.
- School databases can be a useful way of monitoring distributed medication.
- Space restrictions meant that students requiring medical treatment were often unable to undertake this in privacy.
- Some young people did not want to draw attention to their condition, so would not take medication at school, regardless of the effect that this might have on their health.
- Emergency treatment is more likely to be required following an accident, rather than related to medical need.
- All schools had procedures in place to deal with medical emergencies but these procedures varied widely between schools.
- School approaches were split between those where staff were willing to undertake medically based procedures and those where staff would carry out basic first aid and call an ambulance.
- Many staff were concerned about the threat of litigation in responding to medical emergencies.
- There was a lack of confidence about staff responses to medical emergencies on schools trips or out-of-school activities.
- Students who had personal care needs often felt embarrassed about using the toilet or showers at school.

## Chapter 6: Absence from school and education out of school

Absence from school, whether for short or longer periods, and whether on a single occasion or intermittently, can be a significant issue for students with medical conditions. This chapter examines the patterns of absence for young people in our study; how these varied according to the needs and conditions of students; the impact absence could have; whether and how contact was maintained between schools and students during absence; ways in which education was continued while away from school; the support offered when students returned to school.

### Rates of absence

The school survey provided an opportunity to look at levels of reported absence from school among young people with and without illnesses and medical conditions. All young people were asked how much time they had taken off school because of ill health in the past year. As Table 6.1 shows, around one fifth of the sample as a whole said they had not been absent at all, and a similar proportion were not sure how long they had had off. Just over one in 10, however, said they had taken more than two weeks off during the year.

**Table 6.1: Absence and self-reported illness, injury or disability (percentages)**

	Amount of time taken off due to illness in weeks						
	None	Under 1	1–2	2–4	4–8	8 +	Not sure how long
All responses (N=6,244)	28	31	10	6	2	2	21
Illness, injury or disability (N=1,708)	22	29	11	8	4	3	23
No illness, injury or disability (N=4,536)	31	32	9	5	2	1	20

Differences between those with and without a self-reported illness, injury or disability (15 per cent and 8 per cent) were less than might be expected, and the data were re-examined using only the reclassified, single-condition categories to gain more information. It emerged that students reporting conditions classified as viruses and infections had the highest levels of absence: 7 per cent reported absences of over eight weeks, and a further 7 per cent reported absences of between four and eight weeks. Students with long-term medical or musculoskeletal conditions reported the second highest levels of absence. In both of these groups, 6 per cent said they had been absent from school for at least four weeks due to illness in the last year.

### ***Reasons for absence***

Students were asked to describe, in their own words, the reasons for their absence in the past year. What they said fell within five main groups and related to: medical conditions; common illnesses; accidents and injuries; healthcare appointments; and non-medical reasons. The most common cause for absence among all groups was common illnesses, which was the reason given by 88 per cent of students who reported 'No illness, injury or disability', and 71 per cent of the others. One in five of those with a long-term or serious medical condition said that they had been away from school due to their condition; and those with some form of illness, injury or disability were also more likely to attend healthcare appointments or hospital visits during the school day. Overall, 17 per cent of students reporting a medical condition, 11 per cent reporting an injury, disability or illness, and 4 per cent of those with no medical condition had missed school because of healthcare appointments.

### ***Patterns of absence***

It was apparent, particularly from the case studies, that patterns of absence could take very different forms. These could be defined as prolonged periods of absence, recurrent absence and 'indirect' absence.

#### **Prolonged periods of absence**

Prolonged periods of absence refers to consecutive absence from school for over a fortnight. In the case study sample, two young people had been absent from secondary school for at least one three-week period because of their medical condition. In both cases, an initial absence was followed by further periods off school, leading to a significant amount of absence during their secondary school careers. The mother of a young person with cystic fibrosis estimated that her daughter had been absent for at least half of the last two academic years.

It varies an awful lot. Her disease is so unpredictable. Sometimes she will be off school for two or three days at a time, maybe at home – usually at home if it's a short spell like that. She might come home part way through the day just because her chest is feeling tight and she will come home because she can't really walk round the school and she doesn't feel comfortable in the lessons. Other times she can be in hospital, and at home for part of the time, for up to four weeks at a time.

#### **Recurrent absence**

Recurrent absence was most common for young people in the case studies. There were eight reports of young people who were frequently absent from school but usually for less than 15 consecutive days. In all cases, either the parent or the young person was concerned about the amount of time they had taken off school because of their medical condition. Patterns of attendance varied between students: some took several days off every week or so, whereas others were away for much longer periods. One student with diabetes estimated that he missed about half of each school year, even though he was never off for longer than two weeks at a time. His mother described the pattern:

It tends to be a week off, three days back, the next two days off, another few days off, a few days back. It's on and off. I'd say he's probably at school two-thirds of the time and off one-third of the time.

Another student reported that not a week went by when she did not become ill and need time off, and in three instances absences of around two weeks had been followed by further absences of shorter duration. Recurrent absence can be as disruptive to schooling as prolonged absence: a boy with sickle-cell anaemia pointed out that missing individual days or weeks meant he missed bits of most lessons and had a lot of catching up to do.

Recurrent absence can mean much time off school, but may not have the same impact on school staff as a student's single long spell away. Asked about absent students, most staff tended to mention only those receiving home education – in most cases students with mental health needs rather than medical needs. This suggests that the negative effects of recurrent absence may go unrecognised by many school staff and indicates the need for greater awareness in this area.

#### **'Indirect' absence**

Having a medical condition affected school attendance less directly for some students. Even though they might not need time off because of the condition itself, common illnesses and minor injuries might have a greater effect on them than they would on other students. For example, students with chronic medical conditions often needed longer to recover from common illnesses or injuries. The mother of a son with haemophilia pointed out that he had needed to take a week off school for treatment of a sports injury. Many medical conditions also meant that young people tired easily, especially towards the end of term. Sometimes they would be unable to complete a whole term, and keeping up with work was difficult if staff had forgotten about their absence by the start of the next term and did not offer extra support to catch up.

So when I get colds I get them really bad, so I've had like probably a week off because of a cold, and that's probably twice I've had a cold this year, so that's probably at least two weeks off this year.

(Girl with severe asthma)

Normally, if I get an infection it will keep coming back, and say I've got a really bad cold one week, I get rid of it and then the next week I will have it again.

(Boy with diabetes)

She misses a lot of lessons every year, every term, every month for a number of different reasons. She has physio, for example. But every so often there might be situations when she's taken out of her class ... taken out of a class to attend to her physical well-being. There are quite a number of those days every year. In addition to that she obviously attends hospital appointments, so that again we've got quite a number of days out of school.

(Parent of a girl with cystic fibrosis)

Young people, parents and teachers were very concerned about the amount of time students took off school to attend healthcare appointments, especially when they might otherwise have a good attendance record. Most referred to the negative impact on education, but one student also said the school seemed hostile each time she said she had to go for an appointment, even though the timing was beyond her control. It did seem, however, that the problem was recognised and that hospital staff were becoming more willing to arrange hospital appointments for out-of-school hours. Regular hospital appointments were always arranged outside school hours for five of the young people who participated in the case studies, and most others appeared to be offered some flexibility. Arranging separate hospital visits on the morning and afternoon of the same day, scheduling appointments at the end of the day so that only the last hour of the school day is missed and arranging for planned operations to take place during school holidays were some of the ways in which time away from school was reduced.

## The impact of absence

The school survey asked young people who reported an illness, medical condition, disability or injury if this had an effect on their attendance at school. Between 10 per cent and 30 per cent of those with a condition of some kind said it did. Students with infections and viruses were most likely to say that it had an effect.

Students were also asked to describe, in their own words, the effect absence had had on their schooling and life at school. Responses fell within six main categories:

- missed school work/had to catch up/school work suffered
- missed out on social activities, including missing school trips, extracurricular activities, spending time with friends and gossip
- other negative effects, including being bullied, feeling out of place, stress and depression, and teachers' negative reactions
- positive experiences, including enjoying the rest, and being looked after at home
- physical effects, including being unable to do PE on return to school, becoming tired easily, and feeling weak
- no effect/not much effect.

Six in 10 students with medical conditions reported absences, and most of them (62 per cent) said their health had no effect, or not much effect, on their schooling or life at school. More than one in three (36 per cent), however, said that their medical condition meant they missed school work. Response patterns did not differ markedly by type of medical condition, although a particularly high proportion (about half) mentioning infections or viruses said that they needed to catch up with school work and/or that their school work had suffered. The more important and unsurprising point, however, was that the more time students had spent off school, the more likely they were to say there had been a negative impact. Thus, while 33 per cent of students with under a week's absence said their school work had suffered, the same was true of 56 per cent of students with over eight weeks' absence.

The findings from the case studies reiterated those of the school survey.

She has missed a lot of school, she always feels as though she is catching up. I don't think she ever really feels on top of everything and up to date with it all because she missed school.

(Mother of a girl with cystic fibrosis)

Sometimes you'd be in class and people say, 'oh we done that in Year 8' and I'd be like, 'did you?' I probably wasn't here at that time, so sometimes like the work and all the revision and stuff you think, 'I don't remember doing this'.

(Girl with curvature of the spine)

He's always been really, really keen to be at school. And now, I mean he's just – wild horses can't keep him away from school, he's so desperate to do well.

(Form tutor of a boy with sickle-cell anaemia)

The only thing I really had was like, one, missing school, missing lessons and stuff and, two, not really having friends. Because when you miss school, you miss out on different things and different gossip and stuff like that.

(Girl with diabetes)

Young people and their parents mentioned particular concerns about the impact of absence on falling behind at school, exams, missing out on education and friendships.

### ***Falling behind***

Many parents said that they were worried about their child falling behind in their schooling, especially as some students had been moved into lower sets in subjects that they were previously doing well at. The young people could feel they lacked control over their education, and that they were always fighting to keep up. Often they did not realise that topics had been covered in lessons until revision lessons or exams. Some also worried that missing lessons at the start of Key Stage 3 could mean they had not built up a necessary grasp of the basics to allow them to progress in later years.

### ***Effect on exams***

Young people and their parents expressed their concerns about the effect that school absence – including short periods of absence – had on exam performance and results. This became particularly important as young people approached public examinations, such as Year 9 SATs and GCSEs. Some case study participants wondered what would happen if a student were absent on an exam day. Most current arrangements do not allow for papers to be taken again, and some schools require parents to pay for GCSE re-sits.

Often she will miss the tests because she has not been there for at least part of the work or she is not there for the tests themselves so she doesn't really get the opportunity to show how well she is doing.

(Mother of a girl with cystic fibrosis)

### ***The importance of education***

Young people placed a great deal of importance on their education and their performance, and became frustrated when they had to miss school. Teachers commented that it was this dedication to learning that kept absent students on track with their schooling. One parent, however, felt that schools could do more to understand and appreciate young people's determination to learn. She felt her son's school did not take his education seriously simply because of the amount of time he took off because of illness.

They make the assumption that because he is off sick a lot and because he has got diabetes it doesn't matter and that the parents really aren't that interested in his education.

### ***Absence and friendships***

Absence from school was found to have an impact not only on educational achievement but also on the social aspects of school and friendships. Things change rapidly within the social world of the secondary school, and even a short period off school can mean that a young person feels left out of current interests and friendship circles on his or her return. In extreme circumstances, this can lead to social phobia, as young people become anxious about returning to school, prolong their absence and exacerbate the problem.

## **Maintaining contact between schools and students during absence**

Patterns of contact between schools and absent students were variable. In some cases the school, usually via the form tutor, facilitated contact but, in others, young people or their parents commented on their lack of contact with the school. It seemed that the type of absence makes a difference, and that contact was more satisfactory for students with prolonged periods of time off school than for those with shorter, recurrent absences. Certainly it was two young people who had had prolonged periods off school who were happiest with their schools' contact and for whom links were maintained most effectively.

School staff conceded that facilitating contact with friends was not something they usually did, beyond sending a card if a child had a serious or acute illness or was admitted to hospital, although some schools said they occasionally arranged hospital visits. However, as one case study participant commented, this could be problematic and planned trips rarely happened.

One form tutor actively encouraged members of the tutor group to keep in contact, through notes and emails, so that the absent young person would not feel out of touch. These actions were, however, thanks to the individual teacher rather than part of school policy.

The school is great for keeping in touch. The Headteacher is a fantastic chap, he visits them in hospital and makes regular calls ... If they've requested that they have some work sent home, just to keep them in the picture, then that's organised.

(School matron)

It's [maintaining contact] patchy, to be honest, because they're teenagers. And if she has a long period of absence, they tend to lose interest a bit, and the thing that upsets her the most, I think, is that they stop contacting her. Like, they texted her at first, and they just kind of, well, obviously, a lot of the time she doesn't reply because she's in hospital, and they just ... I mean, she has some very good friends, but some of them are supportive up to a point, but they're teenage girls and they're a bit fickle, aren't they?

(Form tutor of a girl with cystic fibrosis)

## **Education during short or recurrent periods of absence**

To be eligible for out-of-school education a child or young person needs to have been, or be likely to be, absent from school for three consecutive weeks (15 school days). In the meanwhile, and for shorter absences, many students and their parents wish to have school work sent home. School practice was, however, variable and not all students could expect to receive school work or, if they did, have it marked. Indeed, 7 students from four different schools across both study areas, 4 of whom had experienced recurrent absence, reported that no work was sent home for them although all would have liked to work at home. In one case, the problem was so severe that the student returned to school before he was well as he was becoming so anxious about falling behind. It seems that the school had failed to provide work for him, despite many attempts by the mother to arrange it.

I've phoned up a couple of times and said to the secretary, 'can he have some work because he is off?' And they don't give it that way, they just say, 'oh he'll catch up when he comes back'. But he doesn't and the thing is that he's not that ill that he can't do work at home. It's just he's here because he can't be there.

(Mother of a boy with diabetes)

There was, however, another side to the story. For teachers, there were questions about the usefulness of sending work home, as well as concerns about the effect that organising homework had on teachers' workloads. One headteacher pointed out that the school did follow a policy of sending work home – with class teachers asked to arrange work for absent students at the staff briefing in the morning – even though it recognised that this was not an ideal situation for students or teachers. There was also the issue about sending work home only for it not to be done. Several teachers mentioned this, but were unable to suggest a way to overcome the problem.

If you have a long-term absence and you are asked to set work, it is quite difficult. If you can just go on and on setting work it does beg the question,

what is the need for a teacher then? Well there is always a need for a teacher because there is teaching to be done. One of the problems is that just setting work will often be not new material but sort of consolidation of prior learning stuff. There is a difficulty around it and it would just depend on how long the absence was going to go on for.

(Headteacher)

However, there were some very positive reports of schools sending work home. One parent commented that the school was always accommodating when organising work to be picked up by parents. Other schools sent work home via post or email, or by asking a student's friends to deliver it. This latter option was regarded favourably as it also helped to maintain social contact. These schools were aware of the issues involved in sending work home, but saw them as outweighed by the advantages – especially where it was difficult to arrange home tuition. Also acknowledged was the importance of home liaison officers and teaching assistants in organising work, taking it to the student, and spending time covering new topics.

### **Home education**

The recommendations of *Access to Education for Children and Young People with Medical Needs* (DfES 2001) stipulate that where a student has a condition that may result in prolonged or repeated absence, alternative education should be arranged immediately. However, only one young person in our study had received home tuition following prolonged absence. Not only did she receive tuition at home when she was absent from school, but the school also arranged for the home tutor to visit the school to provide extra support in free lessons when she went returned to school on a limited timetable. Although each school reported that around three students were currently receiving home tuition, usually related to school refusal or mental health issues, none of the young people with recurrent absences had ever been offered this option. Several parents had tried to gain access to home tuition and one was investigating making use of private tuition. It appears that some of the students in our study were failing to receive the tuition they needed and were entitled to.

It's quite hard to get children into the home tuition service; the demand is greater than the availability.

(Headteacher)

If we can see that it's an ongoing thing that's going to not be the sort of situation where you'd want to keep sending work home for say six or eight weeks, 12 weeks, it's just inappropriate if a child's off that long. There we would try to get something from the home and hospital service. Even then it's very difficult to get it. It's very limited – extremely.

(Headteacher)

He's not being taught outside of school, he hasn't had home tuition. I've approached some local people who do private tuition to see if I can get him

caught up a bit, even if it is only for internal tests this year, at least for maths and science.

(Mother of a boy with diabetes)

Schools, however, did not necessarily recognise that repeated absence could necessitate home tuition. Although most school staff were aware that home or hospital tuition could be implemented after three consecutive weeks of absence, not all were aware of the statutory guidance. This was evident in the lack of personal education plans and school policies outlining the school's approach to home tuition (only two schools had instigated such policies and they were still at the development stage). In one of the schools that was in the process of developing a school policy, the headteacher said that arranging home tuition was in itself so problematic that the school preferred to make its own arrangements, usually in the form of sending work home.

It appeared that the issue was one for LEAs as well as schools. A deputy head pointed out that assigning a tutor to a young person was not the school's decision, suggesting that there are also problems at an LEA level in providing young people with the support they are entitled to. Others explained how tuition was not routinely provided for all students and that, for instance, a student absent from school with a broken leg would be unlikely to receive support. With such problems making access to out-of-school education difficult even for those absent for long periods, it is perhaps unsurprising that there are so many problems in gaining access for students with repeated yet shorter absences. One headteacher emphasised how hard it was to get the irregular support necessary for students with recurring illness.

Two schools in the sample, however, were positive about home tuition. The key factor in both instances seemed to be the development of a relationship with the home tutor who had previous links with the school. Also effective was making the home tutor a member of the school's inclusion team. This meant not only that the tutor could be contacted directly as needed, but also that strong links could be maintained between the taught curriculum and home tuition. In both cases, the home tutor would also provide tuition at the school in a student's free lessons. Other examples of good practice included using support staff to organise and supervise teaching at home. Three schools were employing a home liaison officer who could liaise with the LEA and home tutors to ensure that appropriate and timely lessons were offered.

Where possible the home tutors have gone into school and fitted the tuition around her free lessons, but they have been to the house occasionally if she is off school and at home and relatively well. They have come and done tuition at home; it depends partly on what her needs are. They look at it on a week-by-week or month-by-month basis or depending on whether she has caught up, then it stops for the time being and then it can kick in again once she needs it. It's not an ongoing process, it's as and when.

(Mother of a girl with cystic fibrosis)

**Continuing education through school absence: a good practice example**

This case study is an example of how joined up working, effective procedures, and excellent communication enabled a girl with cystic fibrosis to continue her education in the face of prolonged, repeated and unpredictable periods of absence. Peers contributed to providing support which might be seen as controversial in some schools.

*On the first day of absence*

Several students from the young person's class were assigned the role of subject representatives. On the first day of absence or, if she is missing from a lesson, the representatives collect work from teachers and make copies of notes. At the end of each day the collected work is given to the head of year who gives it to the girl on her return, or sends the notes home on a weekly basis, if absence continues. The home tutor is also informed, via the school or the parents. If she is well enough, teaching can continue at home with the notes collected at the school.

*During hospital stays*

The mainstream school has close links with the hospital school and provides the staff there with a copy of subject curricula to ensure that the same topics are covered. The hospital tutor telephones the mainstream school when the girl is admitted and arranges for work, collected by the subject representatives, to be delivered or emailed to the hospital. The head of year keeps in contact with the hospital school and, at the time of interview, was investigating the possibility of video-conferencing facilities.

*Tuition at home*

Parents liaise directly with the home tutor and, depending on the girl's condition, tuition is arranged using materials supplied by the school. Test papers provide a revision aid to identify any missed areas.

*Reintegration into school*

A multi-disciplinary meeting is set up, including the student and form tutor or head of year, to ascertain needs. The student is given the option of working to a flexible timetable or dropping certain subjects, and a quiet place is provided if she needs to rest. The home tutor visits her in free lessons to help her catch up with the work she has missed.

***Education in hospital***

Seven young people in the case study sample had been hospitalised at some point during their secondary school education, and all had received tuition in hospital, even if their stay had been short. On the whole, they and their parents seemed satisfied with hospital teaching facilities. They did, however, have some concerns about the appropriateness of the school work offered, and this seemed due to poor communication between mainstream and hospital schools about suitable subject matter. Young people reported that hospital teachers provided age-relevant worksheets with little regard to ability levels. Consequently, work provided was either too easy or too difficult, or a repeat of topics already covered at school. There were also concerns about continuing practical subjects such as science outside school, although students told us that, in the short-term at least, they were happy to rely on worksheets.

The quotes below show the difference in responses to the question of continuity in education.

Our teachers have supported her. Our teachers actually go into the schools as well, so in terms of giving support, our teachers here will go in and say 'this is educational needs, this is what it should be' and the teachers here will actually go into the school and talk to them as well. So it's a case of teamwork, really. There's a lot of people involved here. You know, we've got teachers, social workers, psychologists, physiotherapists, nurses, doctors, the lot.

(Specialist paediatric nurse)

If the child is in hospital, I think it is then taken out of our hands. It is for the hospital to provide an education for them.

(Teacher)

Describing their experiences, young people said they received tuition at their bedside or in the hospital classroom if they were well enough. Work was sometimes offered to young people even when they did not feel well enough to do it, but they explained that there was no pressure to complete it so they did not mind. On the whole, young people were satisfied with the resources on offer. They seemed particularly impressed that hospital schools had several rooms – often a teaching room and a computer room.

The two young people who had been in hospital for the longest periods reported favourably on the teaching they were offered in terms of its level and the topics covered. It seemed that, in these two cases, particular efforts had been made to provide continuous education and forge links between the mainstream and hospital schools.

## **Support for students following absence from school**

The reintegration of students into school after a period of absence is an integral aspect of the guidance *Access to Education for Children and Young People with Medical Needs* (DfES 2001). However, helping students to catch up on missed work and reintegrating them into the school were the two main issues that arose for young people returning to school following prolonged absences.

Falling behind with work was one of the students' biggest concerns and, because of the lack of home tuition services, most relied upon catching up on missed work when they returned to school. In five schools it seemed there was little extra support available, and students had to borrow friends' books and copy up notes. This was not, however, a complete solution as catching up with certain subjects, such as languages and science, meant more than just copying work from textbooks or friends' books. A supportive teacher could help, but it seemed that the main responsibility generally remained with the student. In addition, it seemed that extra work sometimes remained unmarked and students received little feedback on their progress. Communication with the family and a balanced approach are helpful. One parent commented that help in catching up is appreciated but that teachers must take care not to overload a student on his or her return. This was reinforced by a

teacher who said that the key to helping a student catch up with work is identifying and focusing on the skills and knowledge that will be important for further work.

They didn't make me catch up too much, they just said 'oh, copy the last lesson's work or just look at somebody else's book'.

(Girl with asthma)

They don't always say what to catch up on if I'm off school for something. It's up to me to go up to them and say 'what have I missed? Can you tell me?'

(Boy who has migraine)

I think they've been very reticent at offering support educationally. I think they've ignored it and their attitude has been you are not achieving so just go down a group instead of supporting him to achieve his potential.

(Mother of a boy with diabetes)

Not to have a burden of stuff, just mindless copying up of things you have missed ... If she wasn't here for the Tudors there you go, she's not here for the Tudors, it doesn't matter. I don't know when any of the Tudors were on the throne, only very vaguely. She'll live without it, it's not life or death, she doesn't need it for GCSE.

(Parent of a student who had been absent from school)

Most of the school staff we spoke to acknowledged that the school did not have formal reintegration policies or procedures but said that they tailored their approach to individual students. It seemed that sometimes this worked better than others. The two students absent for prolonged periods were generally positive about the school's approach to their reintegration, while six other young people in the case studies were less happy. They had each taken over two weeks off due to illness over the preceding year and, in all but one case, said they had been offered no support at all. In one of the most extreme cases of recurrent absence, the young person reported a detention on returning to school, something his mother felt was an unfair punishment.

He gets detention and when I queried it one of the teachers phoned me and said, 'well it's for his own benefit so he can catch up and I can give him some work'. I said, 'that's fine, that's really fine, but don't call it detention because he thinks he's being punished all the time'. It's not his fault he's sick. I want him to catch up but it's the way it's said.

(Mother of a boy with diabetes)

What seems to be important in ensuring a student's smooth reintegration back into education is not necessarily a formal policy, but set strategies and procedures that aim to identify the needs of students returning from absence. Only one school in our study routinely followed such procedures. Absences were discussed at regular 'inter-services' meetings attended by both senior teachers and representatives from other agencies, such as the school health service and education welfare. The needs

of returning students were considered, a reintegration package arranged, and form tutors and subject teachers consulted and informed. The only thing missing from this approach seemed to be a method to ensure that the student's own views were taken into account.

However, other strategies also appeared effective. The use of support staff was found to be particularly helpful, either for focused support in the classroom or for helping students in free lessons. Negotiating free time to catch up, either through dropping some lessons or getting support during time normally spent on non-core subjects, was also regarded as constructive. Good communication between students and teachers was key. From the students' point of view, they wanted teachers to be approachable for help, and they wanted recognition of the difficulty they faced in catching up in some subjects (maths, languages and science, for example) and of the efforts they were making to do so.

### **Making reintegration work: a good practice example**

#### *Flexible timetables*

The most common reintegration strategy, and indeed the only strategy mentioned by the majority of schools, was the flexible timetable. This meant that students were offered the choice of structuring their return to school, and gradually increasing the amount of time spent in class. Thus, students might attend only every other day, or participate only in morning or afternoon lessons.

#### *Attending school but not lessons*

Two schools offered a variation of the flexible timetable whereby students were encouraged to attend school even if they did not come to lessons. This allowed young people to re-establish social contacts and get used to the environment. Similar strategies provided the student with space in a spare classroom or the school library to work, sometimes together with a friend.

#### *Extra educational support*

Both schools offering the above option encouraged young people to work in the SEN department with help from assigned members of staff. This enabled clarification of any issues that the student had not understood. In one school, one of the student's friends was given permission to work alongside him or her. Another school offered access to a Saturday club where students could catch up with work.

#### *Dropping subjects*

In some schools, young people were able to drop certain subjects to ease the workload. The decision about which subjects might be dropped was discussed with the student and his or her parents.

#### *Support of friends*

None of the schools used any form of formal peer mentoring, although a number commented that students were sensitive and naturally friendly to returning students. The use of circle time and PSHE (Personal, social and health education) lessons in reintegration were also seen as helpful in some cases.

They're very supportive on a natural basis. If we think there's some help they can give then we will. For [student] who's epileptic, we did circle time quite a bit so that she could talk her problems through with them and that was quite effective.  
(SENCO)

One headteacher said the school was considering introducing peer support that could be used to help to reintegrate students. Another commented how friendly students would be asked, informally, to support returning students if they did not have any close friends of their own.

#### *Putting support mechanisms in place*

Staff at several schools explained that the reintegration process was made easier if students' needs were identified and suitable support mechanisms put in place. These included arranging for the student to have somewhere to store their belongings, providing cards to allow him or her to leave the classroom mid-lesson and arranging a place for the student to rest. The more successful strategies appeared to have identified needs before the student returned to school.

## Key findings

- One in five students with medical conditions had been absent because of their condition. More generally, those with medical needs had more time off school than other students.
- The impact of a medical need on attendance varied both between and within conditions: 14 per cent of students reporting illness classed as infections or viruses and 6 per cent with medical conditions had taken over a month off due to illness in the previous year.
- Half the young people who took part in the case studies had experienced above average levels of absence (more than two weeks) in the previous 12 months.
- Absence experienced by young people can be described as prolonged, recurrent or indirect.
- Recurrent absence was found to be particularly disruptive to a student's education and was often overlooked by school staff.
- Both young people and their parents saw school absence as having a negative impact on education, particularly in falling behind with school work and affecting exam results. However, absence does not have to be prolonged in order to have a negative impact on education.
- Young people in particular were concerned about the negative impact that absence had on the social aspects of school.
- Contact with friends and teachers can have a positive effect on young people's recovery and anxiety about returning to school. Despite this, only four young people in the case studies reported that the school had made contact other than to identify the reason for absence.
- Demand for home tuition outweighed provision.

- There was a great deal of variation in school practice in sending work home, and the onus was often on young people to catch up, themselves, on missed work when they returned to school. However, teachers could be helpful in putting time aside to identify the key areas of new or difficult topics.
- Support staff and teaching assistants were used effectively in some schools to provide students with additional support on returning from absence.
- Only two schools had procedures relating to reintegration strategies for students returning to school after absence.

## Chapter 7: Sharing information and working together

The collection, dissemination and use of information about a young person's medical condition and needs at school are all important elements in providing effective support for students, and for maintaining positive relationships among young people, their families and the professionals working with them. The ways in which individuals and agencies work together, and their respective roles, are also significant. This chapter looks at school policies and procedures for collecting and updating information on students with medical conditions and needs, information sharing, and how issues of confidentiality are encountered and dealt with. It also examines the role of school health services as well as the wider community health and hospital services.

### Information on students with medical conditions

All schools held information about students, including their health status, on computer systems. The nature and availability of details about students' health and medical needs varied widely among schools in both format and procedures for updating. This contrasts with data on, for example, achievement and absence, which were recorded much more consistently.

#### *Admission to a new school*

All study schools asked parents, at the point of entry to secondary school, to complete a form outlining any medical conditions their child might have, ranging from common ailments to life-threatening illnesses. This information was supplemented by other details from feeder primary schools and the school nursing service, and collated for all students in the year group.

We ask them if the kids suffer from hay fever, do they wear glasses, do they have a hearing problem, because a lot of parents don't perceive those as things which will actually need some sort of care in school.

(Deputy headteacher)

At some schools, dialogue with parents was seen as a way of ensuring that they understood what the school could offer their child, and demonstrating that school staff could respond to his or her special needs. The matron at one school described how she used parents' and children's introductory visits to discuss the needs of potential students and the suitability of the school for them.

In many schools, a named member of staff – who may be the head of Year 7 – takes responsibility for liaising with feeder primary schools, working with colleagues to support the new intake of students. Information is collected during the transition itself and shared with other members of staff.

### ***Storing, updating and using information***

Information gathered from admission forms may be held by the SENCO, a senior teacher, office staff or the school matron. There was little consistency across schools about how it was stored and shared, or about its format and availability. Arrangements for updating this information were also variable and depended on the effectiveness of communication between parents and staff. Parents did not always know who they should give information to, and this sometimes meant it went unrecorded. As one respondent explained, the school finds out about a new diagnosis or other relevant matters in a number of ways – from a letter or phone call from a parent to the headteacher or another member of staff, through to less formal communication at school or on the telephone. Some methods were evidently more effective in getting the message across than others.

I wonder how many of the teachers actually know he's got migraine because obviously I sent a letter to his form tutor and it probably just goes in a little file somewhere.

(Parent)

While it is necessary for schools to know about students' medical conditions in order to respond to their needs, it seemed that some schools held information centrally but did not use it effectively. In only two schools did respondents – both school matrons – say that they used student health information for monitoring or planning purposes. One explained how the school's database helped her plan training on particular conditions for staff and parents.

### ***Information-sharing between members of staff***

Some schools held regular meetings between members of staff with pastoral responsibility for students with special needs, including those who had medical conditions. A senior member of staff convened these meetings and both school staff and other professionals were invited to attend.

At one school, for example, the deputy head with pastoral responsibility convenes a weekly meeting, which includes all heads of year, the SENCO, school nurse, educational welfare officer, learning mentors, the Connexions adviser and, if appropriate, the local authority educational psychologist. At another school in the same study area a 'student support group', comprising heads of year, the school nurse, the SENCO, staff from the learning support unit and the member of staff responsible for home-school liaison, meets fortnightly to discuss issues relating to students from a particular year group. Any member of staff with a concern about a student can make a referral to this group. Starting with Year 7, all five year groups to Year 11 are considered in this way over a 10-week period.

We then come back to Year 7 and we evaluate what has happened and any progress that has been made in the time.

(Deputy headteacher)

A school matron explained how she sits in on reviews of students with disabilities 'so that we are all aware of how it's all going'. She also informs faculty meetings about

relevant issues relating to students with medical needs. The head of student services at another school explained how issues can be raised at daily briefing sessions held every morning before school and attended by all staff.

Procedures varied across schools. One headteacher described how heads of year were responsible for coordinating support for a particular young person, and that this might entail sending a note to all subject teachers, or holding a meeting to ensure that all staff understood the young person's needs and their role in meeting them. Another deputy head explained how important a teacher's knowledge is to enabling a school to be properly 'inclusive'.

Making sure that absolutely everybody [all teachers] knows who's sitting in front of them in class. I think that's crucial. It's no good the office just knowing, it's got to be that absolutely everybody knows, particularly with our more extreme students with life-threatening conditions.

Inevitably needs are, in practice, addressed on an individual basis. One SENCO described her school's response to supporting students as:

a mixture of proactive and reactive, we've been told [about a student's condition] therefore we do something about it.

## **The question of confidentiality**

Our study found that schools had different policies for sharing information about students' medical conditions and that, unlike health professionals, staff did not always have clear protocols about how personal, medical information should be shared. The research team did not define the meaning of 'confidentiality' and schools varied in their understanding of the term. In five schools there was open access to health information for all staff while, in the others, a level of confidentiality was maintained. In the latter schools, access to health information was described as being on a 'need to know' basis and was available to staff who had a level of pastoral responsibility for a particular young person. In most schools, heads of year had access to health information and, in some, so did class teachers. The judgement about who could have access and under what circumstances was made by a member of the senior management team, the SENCO or the school matron.

Interviews with school staff revealed some tension between the two aims of informing staff about a particular student's condition for safety reasons and maintaining students' confidentiality about their personal and health circumstances. Clearly, class and subject teachers should know if a student they teach has a condition that may have an impact on their learning or their health at school, but schools also need to respect the privacy of students, particularly if conditions are of a sensitive nature. However, although there was no consistent policy across schools, senior staff with pastoral responsibility had considered this issue and attempted to tread a middle way between allowing staff full access to medical information and a more cautious, sensitive approach that protected but did not compromise the young person.

We have in the past had an HIV positive pupil so there were certain staff who were aware of that, but that wasn't common knowledge and it wasn't on any database.

(Deputy headteacher)

Schools also described how they had changed their practice because of concerns in this area. At one, all members of staff had in the past been given a printed list of students with medical needs but more recently this arrangement had been stopped as lists were 'just being left around and it was inappropriate'. Practice at another school was to provide printed information marked 'confidential', so all staff were informed and there were therefore no excuses for a member of staff pleading ignorance about a particular student's condition.

Because we think better safe than sorry, because you never know.

(Deputy headteacher)

Occasionally, disagreements arose between schools and parents about the disclosure of a young person's medical condition to members of staff. Although teachers understood the sensitivity of some conditions – HIV status, bowel and bladder problems, mental health issues and anorexia were all mentioned – they also felt that staff must be aware of medical needs if they are to take responsibility for students' care, particularly on school trips.

Once a child is in school we're their parents in a way, you know, we have that much responsibility. So we do try to get parents to realise how difficult it can be if you haven't got full information on something.

(Headteacher)

The headteacher has a duty to all staff and to students. Three headteachers said they would not be prepared to compromise a teacher's position by withholding information that might be in the interests of a student's welfare. This 'need to know' was tempered by an understanding that aspects of a student's condition that did not impinge on life at school would 'go no further than the people who need to be aware of it'.

Schools provided examples of how a student's confidentiality could be handled in a sensitive manner. Systems can, for instance, be set up to allow a student to leave a classroom when necessary by showing the subject teacher a discreet card, or a stamp in their planner or diary. This can be more effective than, as at one school, asking teachers to remember exactly which students are allowed out of class to use the toilet. Staff may also be asked to 'keep an eye on' a particular student without necessarily knowing full details about their health status.

Staff members said it was possible to collect and disseminate information to colleagues, but more difficult to ensure that information was read and acted upon. Secondary school rolls are large and there may be 80 or more members of staff. Turnover among both students and staff can be rapid and making that sure teachers and support staff keep up to date with the needs of particular students can be challenging.

School staff and school health services staff may not always agree on the boundaries of confidentiality. For instance, a difference of opinion on access to the information provided by parents on health questionnaires was described at one school. School office staff wanted to log the relevant information about medical conditions into the school's database, but health services staff said this was confidential and should not be made available. The deputy headteacher in question described her frustration with this situation.

[It] is absolutely ridiculous because we're all working for the same end. But we just live with that. You know that's just a silly little quirk from them. I mean why they think it's information that's confidential to them when we need to know just as much as they do.

In this case, the school distributed its own health questionnaire in order to collect the same information. However, it would have perhaps been more constructive for staff from the school and from the health service to work together to define their interpretations of 'confidentiality' and develop sensitive and workable protocols for all staff to follow.

A difficult issue faced by staff, from both schools and the health service, was the extent of knowledge a student with a deteriorating and potentially life-threatening condition might have about his or her own health. In some cases, parents do not want their children to know the seriousness of the condition and staff have to accept this while maintaining, as much as possible, a trusting relationship with the student.

### ***Providing a confidential 'listening ear'***

Students may want to discuss a confidential issue with a member of staff and schools have policies to protect both students and staff. These underline how confidentiality cannot always be guaranteed. If a child or young person discloses information that suggests that they or another person is in danger of being harmed, it is the professional's responsibility to intervene and, if judged appropriate, share the information with others.

If they come in and say, 'can I talk to you privately?' ... I have to say, 'it depends what you tell me whether I can keep it confidential'.

(Matron)

You can never promise a child complete confidentiality from other professionals who can help that child.

(Matron)

Children who have got medical problems will sometimes only tell one or two people in their class and best friends, and they sometimes say to their best friends, 'don't let anybody else know', and I think we have to bear those wishes in mind. Unless it is something that is affecting their learning or their interaction or their access to the curriculum, we are not going to make a point because of the embarrassment it will cause to that child.

(Deputy headteacher)

However, one teacher said she had mentioned a child's condition to other students in an attempt to protect him from being bullied. This had seemed more important than preserving his confidentiality.

I used to just be honest and say 'look, you know the reason why he's small, you know he's got sickle-cell anaemia and it affects growth'. So I was quite open.

(Class teacher)

## The school health service

In both study authorities, school health services were relatively well-resourced and all schools had close links with a named nurse. The caseloads of school nurses (or school health advisers as they were called in some schools) were too large to allow them to be based at any one school on a full-time basis. However, they were able to visit most schools at least weekly and, even if less often, were in regular contact with school staff. The deputy head at one school described how the school had a service level agreement with the school health service that guaranteed a certain number of visits from the school nurse per term.

School staff valued the skills and expertise of school nurses and appreciated their ability to provide both universal and individualised services for students as well as their willingness to give confidential advice to staff concerned about particular students.

Our relationship is very good and we communicate a lot. If I feel there is a concern or I need advice, I will speak to the school nurse.

(Deputy headteacher)

Any medical problem that we are unsure of, we call her in and she will come in. She is very, very good like that. She is pretty good and on the ball.

(Deputy headteacher)

School doctors could be helpful too:

Occasionally I've phoned our school doctor and said, 'this is what I'm worried about, what do you think?' and got some advice, and then gone back to the parents and said, 'look, I think you need to be going to your GP.'

(Deputy headteacher)

In many schools the school nurse was invited to attend pastoral team meetings, if these existed, to 'feed in' information about particular students causing concern. Nurses were seen as good at handling issues of confidentiality: they shared what was necessary but did not breach a student's privacy. One deputy head acknowledged the nurse's role:

She will often tell us without going into the details of it so that we are aware of it.

## ***Public health***

School nurses provided a number of services for study schools. They played a public health role in organising immunisations for all students and, in some schools, undertook routine health checks for new students starting in Year 7. School nurses also coordinated arrangements for eye tests and dental examinations attended by parents. In one school, the nurse met Year 10 students individually to give advice on sexual health matters:

She would see Year 10 students for an interview, in which they go through, sort of, well, men and women issues and that kind of thing.

(Deputy headteacher)

School nurses also had a broader public health role:

For instance, an area where we do use the school nurse in particular is over meningitis scares. We have those periodically and so we ring and she is in touch with the local diagnostic centres ... and will tell us what sort of meningitis [it is]. Is it OK? What we are supposed to do?

(Headteacher)

At one school, the nurse had organised a Health Promotion Day after different health agencies had provided information leaflets and advice on issues such as drug use and healthy eating. The school matron said that this was much appreciated by students and staff and hoped that it would become an annual event.

## ***Advising and supporting students***

Nurses also offered advice and support to individual students who elected to see them or were referred by staff or outside agencies. Nurses at three schools in study area one offered regular drop-in sessions where they gave confidential advice to students on a range of health issues, including sexual health. The majority of school nurses had a small caseload of students with particular needs. They might see these students regularly or occasionally, or might just be aware of them without making personal contact.

She contributes a lot to the school and to the welfare of the individual student rather than just coming in and doing vaccinations and dental inspections and those sort of things.

(Deputy headteacher)

School staff appreciated the responsiveness of the school nurse who could sometimes deal with issues that were outside the expertise of teachers. For example, one said that the school nurse had been able to advise students on personal hygiene. Another explained that the nurse was one of a number of people who might be contacted by a head of year concerned about a student's absence from school. One nurse had arranged, with the parent, for a student with epilepsy to have a change of clothes available at school. The fact that school nurses are able to access students' medical records, which school staff are not, and have working

relationships with primary care trust colleagues, meant they were also able to share information with school-based matrons about the needs of particular students. Their contact with health service colleagues also meant they could help teachers – who tend not to have these links – to refer students to other services.

### ***Information and training***

Another important aspect of the school nurse's role – and one that was universal across the participating schools – was providing training on medical conditions and procedures to school staff on INSET (teacher training) days. Nurses had given talks to staff, and sometimes to students, on a wide range of different conditions including anaphylaxis, diabetes, asthma, lupus, sickle-cell anaemia, epilepsy, tracheotomy, hearing impairment and eating disorders. They had also trained staff in using Epipens for treating anaphylaxis, dealing with hypoglycaemia in students with diabetes and managing an epileptic fit. School nurses liaised, where necessary, with community and specialist nurses, and parents, in providing this training. At one school, a parent who herself had epilepsy had offered to talk to students about the condition and was planning a session with the school nurse.

### ***The school curriculum***

The role of the school nurse can also include a contribution to the school curriculum. Nurses in at least two schools provided information for students on drug use and its effects, and school nurses contributed to the teaching of PSHE and Health and Social Care in another four. At one other school there were plans to involve the nurse in teaching sex and drug education.

### ***The profile of the school health service***

Despite the activity of school nurses, they were not always well known. Many of the parents and students interviewed for the case studies did not know who the nurse was in their school and, in some cases, did not even know that the school had a visiting nurse. The headteacher at one school commented on his puzzlement at the difficulty school nurses had had in becoming fully part of the life of the school over a long period. Despite having encouraged students to make use of her services, the nurse did not seem to be accepted as a member of the school's support staff.

They've offered drop-in sessions, they've offered to be here at lunchtime. It never quite seems to take off, so they are not as present to the girls as part of the pupil support mechanism and structure as I would like them to be. And I'm not quite sure why that happens – or why it doesn't happen, more precisely.

(Headteacher)

## **Community health and hospital services**

School staff described a range of departments and agencies with which they had contact inside and outside the local authority. These included community and specialist health services, educational welfare and home-school liaison services, educational psychology, social services in cases of child protection and looked after children, local mentoring and counselling schemes and the Connexions service. In

some cases, specialist nurses, physiotherapists and occupational therapists visited schools to consult with or treat students. One school, for example, which included a large number of disabled students, had an assigned doctor who visited the school regularly and carried out annual health reviews for students with statements of SEN. This school also had links with local physiotherapy, occupational and speech therapy services and used other specialist services when necessary. Interviewees also mentioned contact with voluntary organisations such as Young Minds and a young carers group.

The majority of parents taking part in case studies, however, were not aware of links between their child's school and health services. Poor contact with health service staff and a lack of understanding of their roles meant that building relationships was sometimes hampered. School staff also sometimes had difficulties.

There [with health services] you can sometimes have quite a battle. Sometimes it's straightforward. It really depends who you are dealing with ... it's as good as the individual you're working with, some are very helpful, some are not, it's very difficult.

(Headteacher)

Specialist nurses based in either community or hospital services were invited to schools – with the support of parents – to provide advice and training to staff and, in some cases, to see students with particular health conditions. A diabetes specialist nurse, for example, had visited at least four of the participating schools; nurses with specialisms in epilepsy, cystic fibrosis and haemophilia had also visited schools to provide advice and information to staff. Diabetes nurses, in particular, regarded visits to schools where they had patients as part of their routine duties. A diabetes specialist nurse in study area one, who held individual consultations at school, reported how these were both convenient for students and allowed her to assess how they were managing in the school environment. One of the case study subjects, recently diagnosed with diabetes, saw a specialist nurse on a weekly basis at school. Her mother, who herself was trying to come to terms with the diagnosis, was very appreciative of her support:

She's a very good lady. We love her.

Another parent was reassured by a meeting at school between herself, the SENCO, the diabetes nurse and her son soon after his diagnosis. During this meeting, the nurse asked him about symptoms of hypoglycaemia and how he would deal with them.

I knew that I had to keep my mouth shut and not prompt him one little bit because he was going to have to do this on his own at school.

(Parent of a boy with diabetes)

Another student with diabetes, who used an insulin pump, also appreciated the support of the diabetes specialist nurse. She had provided his school matron with training and information about the pump and, according to the student, 'persuaded matron to loosen up on me not having to go there to do blood tests'.

These were, however, isolated instances and the majority of parents in the 19 case studies did not know of any contact between specialist health services and school staff in relation to their child's needs. In fact, more typically, parents, school nurses and hospital staff described their frustration at the lack of communication among services. It seemed that developing links and coordinating contact often fell to a parent or school matron, and was less likely to be instigated by school or specialist health staff. Parental efforts were sometimes frustrated.

It's down to me to say to the hospital, which I've asked before, could you contact [the school] and give them the information, but it seems like they don't bother because they have lost her files.

(Mother of a girl with incontinence)

A community nurse who worked with one of the case study students was daunted by the lack of communication and rapport between schools and health services, admitting, 'I don't understand how education works'. Discussing how contact could be improved, she said:

Sometimes you need the formal things [meetings], maybe once a year, just to hear how everything's going and if there's any issues... So just having somebody you could ring and talk to at the school with the parents' permission. It would be helpful.

This lack of communication could also occur between professionals working in health services. A school nurse, for example, who was doing her best to support a student described the situation.

I don't think I get any feedback from [the hospital] at all. Again, there is no communication ... we often tell parents 'we don't know the medical condition of your child. We've got no feedback.'... A lot of hospitals are not aware that we are there. It's not like we are prying.

An occupational therapist working with a wheelchair user described how she and her colleagues gauged the necessary level of contact:

We worry when schools don't contact us at all but then we worry if they're constantly on the phone to us. And then we worry if they don't contact us, and we go and they've a whole host of problems ... But I think the schools in [study area two] really are, generally, pretty good.

It appeared that where there were more formal procedures in place to discuss particular students' needs, and a member of school staff or a school nurse with enough time to make this feasible, developing 'joined up' services in the school setting was more likely to succeed. It is not necessary to 'medicalise' a student's needs at school any more than at home, but having someone with protected time to ensure that information, advice and training are available can improve students' educational opportunities and school experience. As one school matron said:

I'm not professing to know this, that and the other but I know somebody who'll be able to help me do that.

A SENCO agreed:

For a school this size I mean you really do need somebody around most of the time. I think it would be excellent to have a school nurse on site. Having been at a school where there was a school nurse on site it was an extra good adult who a lot of students, particularly girls, would go and chat to but the boys would as well. They would talk about a variety of worries.

## Key findings

- All schools kept information on students, including their health status, on computer systems, even though the nature and currency of this information was variable.
- Arrangements for storing, sharing and updating student information also varied between schools.
- Parents were not always clear who they should contact to update the information held by schools.
- Only rarely did schools use health-related information for monitoring and planning purposes.
- Schools had differing policies on how information about students' personal and medical conditions was shared, and not all had clear protocols.
- Tension could arise within school practice between providing teachers with information on students for safety reasons and preserving their confidentiality.
- Schools were clear, however, that student confidentiality could not be ensured if the student's well-being was at risk.
- School nurses had a broad role, which encompassed public health, individual advice and support, information and training, and input to the school curriculum.
- School nurses were generally valued by schools, although they were not always widely known by students or parents.
- Schools were in contact with a wide range of external services but most parents were not aware of these links.

## Chapter 8: Knowledge of medical conditions and needs, and implications for training

Previous chapters have looked at how mainstream secondary schools support young people in the administration of medication and medical interventions, in response to emergencies and in relation to personal care. Providing effective support in these areas depends on adequate knowledge of medical conditions as well as an understanding of their implications. Government guidance on managing medicines (DfES 2005) outlines how employers – including LEAs and school governing bodies – are responsible for ensuring that staff have adequate training to support students with medical needs, but that it is the duty of headteachers to ensure that their staff receive the training. The guidance, however, provides little detailed information on the content and implementation of training.

This chapter begins by examining evidence on teachers' knowledge of medical conditions and needs. It then looks at the content and delivery of training offered by the study schools, as well as teachers' views on its value and who should attend.

### How much do school staff know about medical conditions?

More than half the young people reporting a medical condition, disability or injury in the school survey said that school staff knew enough about their condition, just over one third were unsure whether they did or not, and one in 10 did not feel that staff were sufficiently well informed. A higher proportion (58 per cent) of the 19 case study students rated teacher knowledge of their condition as 'good' or 'very good', and a similar number (61 per cent) of parents also rated the teachers' knowledge as 'good' or 'very good'. At the other extreme, 16 per cent of young people who took part in the case studies, and 22 per cent of their parents, felt that the degree of information held by their school was 'bad' or 'very bad'.

Views were inevitably influenced by the young person's condition, the relationships parents and students had with school staff, and the school's approach to training. Indeed, not everyone had the same opinion about any individual school. Thus, while a student with anaphylaxis was confident about a particular school's ability to deal with anaphylactic shock, a student with epilepsy at the same school was concerned about how little staff knew about her condition.

School staff tended to agree that they would benefit from greater knowledge of students' conditions and, indeed, several expressed concern about their own level of information. Sometimes it seemed they had been told little more than to 'look out' for a particular student, with no explanation on what to look out for.

I suppose I would have liked to have known a bit more, yes. I used to ask him a lot, but I would have liked to have known ... because I didn't know about what he should be eating, I didn't know what he should be drinking, I didn't really know and I think I could have helped him a lot more. Yes, I'm sure I could have advised him, you know. Yes, I think I would have liked to have known a lot more about his illness, yes.

(Class teacher of a boy with sickle-cell anaemia)

Keeping everyone fully informed did, however, present logistical problems.

It is difficult to keep up to date because you get new staff in and you cannot devote every training day you have got to such issues, but we just try to keep people up to date.

(Headteacher)

The matron at one school said that she was surprised how little knowledge some school staff had, particularly about potentially life-threatening conditions and situations.

I think they could do with a bit more knowledge. I always imagine that teachers have a bit more knowledge about things than they actually do have. And it surprises me that they don't, actually ... in terms of diabetes, I think they should know the symptoms of hypoglycaemia, and how to treat it, because, if they're going into a severe hypo, then they do need something immediately.

(School matron)

## **What training do schools offer on medical conditions and needs?**

The training on medical conditions and needs offered by schools was very variable. Although all but two had, over the past year, undertaken more than just statutory first aid training, little was provided in the way of regular training and support. Most schools had offered some training on medical conditions over recent years, but this was inconsistent in both quality and quantity. What there was, had taken place alongside other topics on INSET days, and all schools but one had included a session on the use of Epipens for treating anaphylaxis. Training in supporting students with particular conditions was more likely to be arranged if the school employed a matron who had the authority to lead on health issues; and only half the schools involved had provided sessions on specific types of medical conditions such as epilepsy or diabetes.

Everyone that's allergic to nuts and things came and there was a meeting just about how to use the Epipen, and like a lot of teachers went and they learned how to use the Epipen. And a lot of students and parents went as well and basically just talking about it and the effects it has and stuff like that.

(Student with anaphylaxis)

The school nurse, who's in this area, comes in to give a talk about Epipens, and as many teachers as possible who can come do come to that. We do get quite a good response for that. But no, for other things they don't get much information.

(Deputy headteacher)

Many members of school staff commented that being involved in our research had led them to rethink their approach to staff training. First, they recognised that any training would have to be provided on INSET days as teachers and school staff were generally not willing to stay late after school to attend extra training. But, second, they did see the value in learning about support for medical conditions they might come across, other than the use of Epipens. Interestingly, there were no reports of incidents requiring the administration of adrenaline via an Epipen in any of the schools participating in this study.

### **Ensuring adequate training in medical needs: good practice examples**

Training in the management of students' medical needs may not be seen as a priority within the context of teachers' heavy workloads. However, a number of schools were finding ways of providing good information on common medical conditions and needs. These approaches included the following.

- **Adding a session on dealing with common conditions to the induction package offered to new staff, including support staff.** This ensured that all staff were equipped with basic knowledge from the start. Training covered basic first aid and how to support students with specific conditions. At one school, this information covered epilepsy, diabetes and allergic reactions.
- **Providing induction training, then following it up with regular INSET training with a different focus each year.** Specialist sessions were also provided for teachers with responsibility for particular students. This approach meant that all staff would know how to deal with an incident or emergency, but that a student's teachers would be equipped with detailed knowledge on how to support his or her everyday needs.
- **Assessing staff training needs using the information held on the medical needs register and obtained during the student intake.** The success of this approach is dependent on the school having up-to-date and accessible records on student health. Healthcare plans were useful in this context.

### ***Who provides the training?***

The school matron or the school nurse led much of the INSET training on medical conditions, although some schools employed staff from other organisations to run sessions. School matrons used a range of agencies to gain relevant information. These included voluntary sector campaigning organisations as well as local health services.

However, most of the health service staff we spoke to had tenuous links with schools and had not been approached to offer in-school training. It may be that school staff do not consider asking for support from health professionals because they simply do not know who to approach or what response they might receive.

In several schools, parents had provided training: this was seen to have the advantage of the 'personal touch' and was felt to foster stronger relations between school staff and parents.

At the moment I am liaising with a parent who is severely epileptic herself who wants to come along and talk in an assembly about what it's like to be epileptic. We will probably do that with Year 7.

(Headteacher)

Sometimes parents were invited along to sessions – although not always with the desired effect.

So they had a training day about diabetes for the parents and some of the staff. They showed a video which was outdated from Diabetes UK which says when a child is having a hypo give them something like a piece of chocolate. And I said no, you don't do that, it takes an hour-and-a-half for chocolate to get into the system, you have to give something fast-acting like Lucozade.

(Parent of a student with diabetes)

Healthcare professionals from charities or organisations, such as Epilepsy Action, had also been invited to provide training at three schools. In other cases, materials produced by charities and self-help organisations about specific conditions, and their management within the classroom, had been made available. Although information from leaflets and toolkits could be useful, school staff pointed out the necessity of ensuring that all information used is up-to-date, and that the member of staff running the training has adequate and independent knowledge.

### **The provision of training: good practice examples**

- Some schools took a very proactive and creative approach to their training. As well as using school nurses, they contacted relevant organisations to identify expert trainers, preferring to use individuals with the conditions themselves. LEA special advisors have also been used to conduct training.
- Several school matrons developed information packs on specific conditions. These packs were either distributed to teachers individually or put into folders for each department. Although, as one matron commented, you cannot force staff to read the information, producing posters and information and displaying them in the staff room provides a ready reference source. Government guidance on medicines in schools (DfES 2005) provides information on specific conditions, such as asthma, diabetes, epilepsy and anaphylaxis, and could be used in this way.

### ***Who should attend training sessions?***

Schools reported that, on the whole, attendance at training was voluntary, particularly in the area of medical needs. Only school matrons usually attended the more extensive external training, and it seemed that often the information gained was not well disseminated to other school staff.

There was a general consensus, amongst both school staff and young people with medical conditions, that training should not be limited to teachers with responsibility for students with specific conditions. Some students attending schools that employed matrons felt that there was an over-reliance on her and too little dependence on other members of staff. They also felt that they themselves had a role to play. Several schools provided training to friends of students with epilepsy, diabetes and severe allergies, and this approach proved popular with parents as well as young people.

I think some more teachers should be trained into knowing how to deal with someone with asthma. Because, if I was to have an asthma attack in the middle of the class, they'd think automatically to go and get the nurse, when really they shouldn't have to go and get the nurse, they should be able to do it themselves.

(Student with asthma)

#### **Open training sessions for staff, students and teachers: a good practice example**

One school held open meetings for staff, students and teachers. These sessions were well attended and students liked them. They seemed particularly useful in reducing the stigma associated with certain conditions. The school in question also offered sessions specifically for students to raise their awareness of medical conditions.

### **Key findings**

- Views were mixed about whether or not school staff were as well informed as they could be about students' medical conditions and needs.
- Although most schools provided some training, this was often limited and patchy.
- Where training was provided, this was usually conducted by school nurses and school matrons and, occasionally, by external organisations.
- Community or specialist healthcare staff were rarely asked to contribute to training.
- Attendance at training was usually voluntary.

- Providing training on medical needs as part of staff induction, and following this up with regular sessions during INSET days, is a good example of a structured approach to training.
- Young people and parents feel that all staff should be given training in meeting medical needs.
- Peer training on medical conditions is valued.

## Chapter 9: Key messages

Earlier chapters have described our study of students, parents, school staff and other professionals and their views and expectations about meeting medical needs at school. This chapter draws together the key findings to highlight nine main messages to emerge from the research as a whole.

### **A positive school ethos is an important factor**

First, there can be little doubt that the school environment plays a very important role in determining how far young people with medical needs are supported, and feel supported, at school. An inclusive approach that welcomes all students, whatever their conditions and needs, is appreciated by students and parents alike. This became very clear from the present research and is reinforced by other studies that show how teachers' awareness and consideration of students' health needs are strongly linked to effective support (Eiser 1993; Mukherjee and others 2000). Students value teachers who 'understand' (Lightfoot and others 1999), as well as those who treat these young people as 'normal' (Cavet 2000).

Success in integrating young people with physical disabilities into mainstream schools is, however, often due to the efforts of individual teachers (Llewellyn 2000). In the present study we encountered instances where particular members of staff had made a significant difference to certain students, often at some personal cost to themselves. This was particularly true if there was no whole-school approach to meeting medical needs. These members of staff seemed best supported where there was mutual respect and good communication between staff and family members, and the ability to be flexible (Bannon and others 1992; Johnson and Thomas 1999; Strong and Sandoval 1999). Johnson and Thomas (1999) suggest that a positive school ethos encourages a 'conversational dialogue' between parents, staff and students in order to develop successful partnerships and best meet the needs of all students.

### **School policies, formal and informal**

All study schools had admission policies that included reference to students with medical needs, but few had comprehensive policies to cover the support and inclusion of these students once admitted. It seemed that schools are, in many respects, more reactive than proactive when it comes to supporting young people with any kind of special need.

There are arguments both for and against an overarching policy in this area, although the argument in favour is most convincing. While a policy can act as a statement of intent, useful for families and staff alike, it is also apparent that there is little point in having a formal policy unless it is acted upon. As already suggested, school practice is highly dependent on school ethos and, on the whole, schools with a positive attitude to inclusion are likely to be good at supporting students with medical needs whether or not they have a formal policy on how this should be done. Conversely, schools with less positive attitudes may make a lesser provision regardless of their stated commitments.

Policies in specific areas may be more effective than a global policy encompassing all aspects of a school's responsibilities. Procedures surrounding medication and its administration provide a good example. Government guidance in this area (DfES 2005) covers areas such as: parental consent for medication taken at school, where and how medication is stored, self-administered treatment and the disposal of unused medication. It is interesting to note, in this context, that while most school staff felt they had procedures in place to deal with medication, some were unaware that students were in fact bringing medication to school and taking it without supervision.

In general, schools devised their own policies and displayed few universal practices. One, for instance, had a 'no nuts' policy in its catering department that seemed to work well. Guidance, with illustrations of good practice such as provided by Carlin (2005), could usefully assist schools in the development of procedures. In order to ensure that all students are able to go on school trips, for example, correct precautions should be taken in relation to food, medicines and so forth. Guidance should be inclusive and not restricted to students with a formal designation, such as a statement of educational needs. It should outline comprehensively the potential range of medical needs and provide pointers on identifying possible needs that may arise.

## **Defining and managing medical needs**

Policies should be flexible and respond to individual need if the goal is to support all students with medical needs. It is clear from the present study, as well as the wider literature, that there are many different types of medical condition where additional provision at school can be beneficial. As discussed in Chapter 3, young people themselves refer to many different conditions as 'illness', 'disability' or 'injury' (examples include dyslexia and 'bone problem'), and while many students report conditions that fall within conventional categories (such as cystic fibrosis or coeliac disease), many others do not, and categorised their condition as, for example, 'flat feet' or 'weak joints'.

Overall, however, certain categories of medical condition are more prevalent than others. Accidents and injuries, and asthma, for instance, stand out. Even so, these conditions do not have the same meaning and impact for all students, and neither do they have similar implications in terms of, for example, school attendance and hospital admission. Some conditions are more serious than others in terms of their effects on students, and some are relatively transitory while others are much longer term.

The challenge for schools is to be able to manage predictable and specific medical conditions as well as deal with unanticipated occurrences. Our study suggested that schools tend to be better equipped in some areas than others. It was striking, for example, that knowing how to respond to allergy and anaphylactic shock came high on the list for most schools, with the main focus of training on medical needs being the use of Epipens. Allergies are inevitably important issues for schools, particularly because a delay in treatment can lead to fatal consequences, but there remains a definite need for greater diversity in training.

Definitions and perceptions of medical needs depend on more than the physical condition in question. A child's parents, for instance, can make a considerable difference to his or her 'needs' at school. Some parents are well informed about their child's condition and skilled in providing the appropriate support, while others rely heavily on professionals and have limited views of their own. There can also be differences in the perception of 'illness' and its implications for both attendance at school and participation in the full spectrum of activities, and this may also be related to family attitudes to education and attainment. From the families we studied, it seems that language skills and familiarity with the school 'system' are among the factors affecting attitudes and behaviour. The length of time that a young person had a condition was also a factor in how families dealt with the issue.

## **Awareness of the impact of medical needs on young people**

Just as the characteristics of medical needs are highly variable, so, too, is the impact they can have on a young person's experiences at school. For some, the main effects may be on mobility or school attendance whereas, for others, it may be learning or friendship patterns that are most affected. Sometimes, the effects may be practical, sometimes, they may be intellectual and sometimes, they may lead to emotional difficulties and embarrassment. The recognition that every student is different, but that young people like to be treated like everybody else and not receive unwanted attention, is key. The mark of a school with a good 'ethos' is that personal needs are recognised and met.

However, it seemed from what both students and school staff said that there were few schools where there was no scope for improvement. School trips, for example, were not always managed as well as they might be. Sometimes, this was because routines were interrupted but, often, it was largely an issue of communication and somebody taking responsibility for ensuring that a young person had everything they needed for the day. As a more general issue, however, it appeared that some students felt that their school did not know enough about their condition and, sometimes, did not care enough. Although it is hard to comment further without more detailed documentary evidence, the main point is simply that it is crucial for schools to know whatever is necessary about all students in their care, and that they act appropriately on this knowledge.

## **Students need someone they know and can turn to**

Schools with full-time matrons (as they were usually called) stood out in terms of the provision they were able to make for students with medical needs. Staff in these posts came from a variety of backgrounds (not all are qualified nurses), and are not universally popular. However, they are known to students and their services are available to all.

The value of school matrons was confirmed when schools employing matrons were compared with those who did not. Students at schools without a matron were more likely than the others (11 per cent compared to 3 per cent) to say they thought that their school could do better in supporting students with medical needs. In particular, they wanted their school to be more caring and inclusive, staff to listen to and trust

students, and better facilities and services, including more health education, health checks and information on medical needs.

The role of a matron tends to be broad and covers the umbrella function of overseeing policies and practice for students with medical needs as well as being there to deal with daily matters as they arise. School nurses might also have a role to play, often in relation to the school curriculum or in providing confidential information and advice. These roles, however, are complementary and not alternative to that of the matron and, typically, they liaised regularly.

In summary, school matrons are generally much appreciated even if not always loved. Our research highlights the benefits of a person in this full-time role who is always available for students and who is responsible for responding to students with medical and other special needs. It does not seem to matter whether this person is a conventional 'matron' or a permanent first aider, but it is important that this role is not simply covered by an administrator in the school office. A key message is that, if at all possible, every secondary school should employ a member of staff in this post.

## **Effective communication channels are essential**

Whatever the school ethos, and whether or not schools have policies for students with medical needs, good practice depends on optimal communication. This relates to links between schools and students, between schools and families, among schools and external services and sources of support, as well as among members of school staff. The challenge to all concerned is to both ask for and give any necessary and appropriate information.

It has already been noted that all individual students have distinct needs that depend to some extent on family background. Finding out from students what these needs might be is, therefore, an important precursor to drawing up a student healthcare plan. Because young people and parents may not necessarily ask for what they want or require, it is important to have procedures in place to elicit this information from them. From our research, it seems there is less involvement of parents and students in drawing up healthcare plans than is recommended by government guidance.

Facilitating links between parents and schools, and sharing information, is the starting point. Schools varied in the amount of pre-entry information they collected on new students, and only one regularly updated records in consultation with parents. Determining what schools expect of parents and vice versa is also important. It is apparent, for example, that if parents do not know who to contact at school, and the reasons why they might make contact, they may not even try. All procedures should take account of the range of parents they are designed for, such as ensuring that arrangements are appropriate for parents for whom English is not a first language.

Another major area of communication is among staff within schools. Who should know what, and when they should know it, when it comes to students with medical needs. Policies and practice in this respect vary widely. All schools keep registers and/or databases with information on students with medical conditions, but not all use these in similar ways. For many, information is accessed on a 'need to know'

basis while, for others, it is made much more widely available. Although issues of confidentiality often prevail, sometimes the guiding principle is that full openness is best 'just in case'. This in turn raises questions about the boundaries of communication. Is there, for instance, a policy about communicating necessary details of a young person's medical conditions to supply teachers? Are staff briefed on the information that is available, and when and how they may access it? As school staff reported, school procedures and systems are only as good as the information they had personally received.

## **School policies are for all students**

School policies for students with medical needs potentially apply to all. First, around one quarter of the students completing our questionnaire identified some medical need they thought they had and, second, all students are at risk of becoming ill, developing a long-term condition (such as diabetes, which commonly commences in adolescence), or sustaining an injury. Third, a whole-school approach implies that policies also need to take account of friends and classmates without evident medical conditions, to help them understand the needs of their peers and contribute to their support.

Students who completed the school survey were asked what they thought their school could do to help students with medical needs to get the most out of school. About three in five answered this open-ended question (the final one on the questionnaire), and between them made a wide range of suggestions that fell within 16 categories. The most popular suggestions were for more staff and/or better teaching (14 per cent of students mentioned this); a more caring and inclusive school (12 per cent); improved facilities and services (such as a better medical room, 11 per cent); improved physical access (9 per cent); and the provision of special facilities (including accessible extracurricular activities) for students with disabilities, special educational needs and medical needs (8 per cent). Some (7 per cent) felt that change was not necessary, as the school was already good at supporting students, while others felt that listening to and trusting students (5 per cent), not treating students differently from their peers (5 per cent), providing information and training about medical needs for staff and students (3 per cent), offering health education and health checks at school (2 per cent), and better quality and more affordable food at school (2 per cent), were important.

Interestingly, there were few differences in the responses of students with and without long-term medical conditions, although a higher proportion of those with medical needs thought their school was already good at providing support and did not need to be improved. These students were also more likely to recommend more information and training on medical conditions, and to say that schools should provide health education and health checks.

## **Managing school absence**

Most young people are absent from school on occasion, but a few have prolonged or recurrent periods of absence directly due to their medical condition. Some students may also be regularly absent from school if their condition means they take longer to recover from common illnesses or injuries. There is a sense in which

school responses to absence suggested that 'out of sight, out of mind' was true for some of these students.

Several issues arise for absent students, but school work is key for most. Missing lessons, falling behind in class and needing to catch up, and feeling worried about being prepared for exams and being well enough to take them, were the primary concerns. Missing school and the effect on maintaining friendships were an extra worry for others. Not surprisingly, the longer students were off school, the more concerned they became. This was especially noticeable for those with intermittent patterns of absence who do not seem to come to the notice of teachers in the same way as those with prolonged periods away from school.

Students are not eligible for out-of-school education until they have been absent for three consecutive weeks, and only one student who took part in the case studies had received home tuition. Schools seemed variable in whether, and in what ways, they maintained contact with students absent for shorter periods. Some explicitly explained that the issue was less straightforward than it might appear. Teachers could find it difficult to know what work to set, particularly if the young person had been absent for some time, and were discouraged from setting work if it was not completed and returned. However, there were examples of good practice, and it was evident that efforts to keep in touch and send school work home were appreciated. This was particularly successful when home liaison officers and teaching assistants became involved and were able to provide a direct link between the school and the student, either at home or in hospital. Cooperative initiatives that enlisted fellow students could also be successful.

Supporting absent students involves considering their needs when they return to school. It seemed that students felt happier going back to school if they had maintained some contact while away but, beyond this, an important message from the research is that these measures work best if they are responsive to individuals. For instance, allowing returning students to work to a flexible timetable, and letting them take up subjects as and when they were ready, were seen as positive reintegration measures. Support staff were also reported to be very helpful in reintegrating students and providing this individual focus.

## **Supporting schools to support students**

The variety of medical conditions young people may have, their varying impact, and the nature and demands of normal school life, place a great responsibility on teachers and other school staff. A final message from this research is that schools also need support to meet their responsibilities to contribute to the Every Child Matters 'being healthy' outcome.

First, there is a call for more focused training. The teachers we spoke to did not show either a great awareness of DfES guidance or great confidence in dealing with medical needs. This is of particular concern, because these respondents were selected on the basis of being knowledgeable about their school's policies and practice; it suggests that other members of staff might be even less aware. Although many had received some training on how to use Epipens, the availability, quality and take-up of training was generally patchy. Many staff would welcome a much broader education and, encouragingly, said this would be valuable for all, and not only for

those who had specific responsibilities for students with medical needs. Teachers were concerned about whether or not they would know what to do in an emergency, and instruction on planned procedures (and the development of these procedures where they do not already exist), would seem essential. Concern seemed greatest in the schools that did not employ full-time matrons, which were the majority.

Training to deal with medical needs can be both formal and informal. Open sessions for staff, students and teachers, for example, proved popular in one school and could be adopted much more widely. Peer training by students on medical conditions was, where it had occurred, regarded as effective and valued, and there is a strong case for involving children and young people in this area. Good internet training packages could also be valuable in this context. All training could usefully be supplemented – by readily available information on common medical conditions, common responses and how to assess risk – to provide reference materials and engender greater skills and confidence. Examples of suitable materials are readily available and could be easily adapted and adopted in local areas.

Government guidance (DfES 2005) suggests that a non-teaching member of staff could be responsible for administering medication and dealing with emergency situations, and it is likely that training could encourage more staff to take on this part-time role alongside other duties. However, issues of accountability and responsibility would need to be clarified as many may be discouraged from taking this on if they feel the threat of litigation is a real one.

According to non-statutory government guidance (DfES/DH 2006a), services provided by school nurses should include 'supporting children and young people with ongoing or specific health needs'. However, our study shows that school nurses' ability to work with individual students is hampered by the need to manage large caseloads. Despite the value placed on the school health service by schools, it seemed that, in some cases, it was difficult for school nurses to fully integrate into school life. Again, this was likely to be caused by the limited time nurses were able to spend in particular schools. The school nursing service might consider highlighting the service to students and their families by attendance at parents' evenings and displays on school noticeboards.

Schools could also be supported by developing stronger links with other local services. This study does not provide a strong case for basing more services in schools, partly because many students with medical needs need to consult specialist rather than primary healthcare staff, but more exchange and communication among services would be valuable. Often, these already existed through statutory school nurses and other community-based staff and were particularly valued for providing training and contributing to the curriculum. There are doubtless other groups that could also play an important role, and it seems that a dialogue in this area needs to be established. School nurses, who have working relationships with other health and social care services, might act as an effective conduit to these other services.

Finally, schools would feel better supported if they were able to benefit from greater resources. Schools, almost without exception, found that physical space was at a premium and few were able to offer a comfortable, private place for students to take their medication or go if they felt unwell. Indeed, more than one in 10 students who

made suggestions for school improvements mentioned the provision of a better medical room. This is undoubtedly a difficult issue, but responding to individual needs includes respecting young people's privacy and their wishes. It should be possible to find a creative solution to this problem of space at school.

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## Appendix A: The school survey questionnaire

# Your Health at School



The National Children's Bureau is carrying out a research study to find out how many young people have a long-term illness or medical condition, a disability or an injury and how these might affect their education. We will use the information we collect to help schools improve the ways they support young people with medical needs.

Please fill in the questionnaire whether you have a medical condition or not. We do not ask for your name and nobody will know how you answered the questions.

### About you

---

Which year group are you in at school? *(please tick one of the boxes)*

Year 8

Year 9

Year 10

Are you?

Male

Female

How would you describe your ethnicity?

White

Black Caribbean

Black African

Indian

Pakistani

Bangladeshi

Chinese

Mixed

Something else? *(please describe)* .....

### About your health

---

In general, how would you describe your health?

Very good

Good

OK

Bad

Do you have

a long-term illness or medical condition?

a disability?

- an injury?  
 none of these?

**If you do have an illness, a medical condition, a disability or an injury, what is it?**

*(please describe)*.....

**If you do have an illness, a medical condition, a disability or an injury, does it have an effect on your**

**Learning?**

- Yes, a lot  Yes, quite a lot  Not very much  Not at all

**Ability to move around the school?**

- Yes, a lot  Yes, quite a lot  Not very much  Not at all

**Attendance at school?**

- Yes, a lot  Yes, quite a lot  Not very much  Not at all

**Friendships?**

- Yes, a lot  Yes, quite a lot  Not very much  Not at all

**If you have an illness, a medical condition, a disability or an injury, who knows about it at school?**

*(please state)* .....

**If you have an illness, a medical condition, a disability or an injury, do you feel happy that the school knows enough about it?**

- Yes  No  I'm not sure

**Time off school**

---

**Have you had time off school because of ill health within the last 12 months?**

- Yes, 8 weeks or more in total  
 Yes, 4 weeks or more but less than 8 weeks in total  
 Yes, 2 weeks or more but less than 4 weeks in total  
 Yes, more than 1 week but less than 2 weeks in total  
 Yes, 1 week or less in total  
 Yes, but I'm not sure how long  
 No, I haven't

If yes, why did you have time off?

(please describe) .....

If you have had time off, what effect has it had on your schooling and life at school?

(please describe) .....

### Medication

---

Do you take any medication (such as tablets, medicines, inhalers, insulin)?

Yes, every day

Yes, sometimes

No, I don't

If yes, do you need to take this medication at school?

Yes, every day

Yes, sometimes

No, I don't

### Hospital visits and stays

---

Have you had a hospital appointment during school time within the last 12 months?

Yes, more than once

Yes, once

No, I haven't

Have you stayed in hospital at any time within the last 12 months?

Yes, more than once

Yes, once

No, I haven't

If yes, why did you stay in hospital?

(please describe) .....

### Lessons and school activities

---

Within the last 12 months, were you (even though you were at school) unable to do any of the following because of an illness, a medical condition, a disability or an injury?

I was unable to go on a school trip or school journey.

More than once

Once

No

I was unable to take part in after-school clubs or activities.

More than once

Once

No

I was unable to attend certain lessons such as PE or science.

More than once       Once       No

If yes, which lessons did you miss? .....

### Diet

---

Do you have a special or restricted diet because of an illness, a medical condition, a disability or an injury?

Yes       No

If you have, how do you deal with this at school?

(please describe) .....

### Treatment and care

---

Have you had any emergency treatment at school within the last 12 months?

Yes, more than once       Yes, once       No, I haven't

If yes, why did you have treatment?

(please describe) .....

Do you need help with personal care at school?

Yes       No

### Support at school

---

Who would you go to if you felt unwell or needed help for a health matter at school?

(please state) .....

Do you feel that, on the whole, your school is caring towards pupils who have an illness, a medical condition, a disability or an injury?

Yes       No       I'm not sure

What else do you think your school could do to make sure that pupils who have health needs get the most out of their education and enjoy school?

(please describe) .....

**Thank you for your help!**

## **Appendix B: Medical conditions, disabilities and injuries reported by students who responded to the questionnaire**

These are presented in the six categories described in Chapter 3.

### **Sensory**

#### ***Eyes***

Colour blindness  
Coronal unilateral coloboma  
Cyst on eye  
Dominant optic atrophy  
Focusing problems  
Lazy eye/stigmatism/eye problem/squint/long sighted  
Visual impairment

#### ***Ears***

Ear condition  
Hearing impairment

NB: Earache is included below under **Infections, viruses and short-term illnesses**

### **Accidents and injuries**

Broken/fractured bones  
Bruised rib  
Car accident/run over  
Carbon monoxide poisoning  
Cuts  
Dislocated shoulder  
Head injury  
Leg pain/injury  
Minor injury  
Pulled muscle  
Skiing accident  
Sprained wrist  
Unspecified injury  
Whiplash injury

### **Infections, viruses and short-term illness**

Appendicitis  
Benign tumours  
Colds/flu/viruses  
Dizziness

Earache  
Fainting  
Fever  
Food poisoning  
Gastric/acid problem  
Gastroenteritis  
Granuloma annulare  
'Knot' in stomach  
Meningitis  
Nose bleeds  
Shortness of breath/bad lungs/bad chest  
Sinusitis  
Stomach pains  
Stomach ulcers  
Suspected brain tumour  
Tiredness  
Tonsillitis  
Travel sickness  
Tuberculosis

### **Musculoskeletal conditions**

Back problem  
Bilateral femoral epiphysis  
Bone problem  
Chondromalacia  
Costochondritis  
Flatfeet/dropped arches/'wrong' feet  
Hammer toe  
Hip growth problem  
Ingrowing toenail  
Ligament problems  
Missing/bent finger  
Neck problem  
Osgood-Schlatter's disease  
Osteochondritis  
Osteomyelitis  
Restless leg  
Scheuermann's disease  
Scoliosis/curvature of the spine  
Slipped hips  
Tenosynovitis  
Under-developed muscles  
Valgus knee  
Weak joints

### **Long-term medical or serious conditions**

Acne  
Achondroplasia

Allergies  
Alopecia  
Anaemia  
Anaphylaxis  
Aortic stenosis  
Arthritis  
Asthma  
Bicuspid aortic valve  
Bladder problems  
Blood disorder  
Bowel problems  
Cancer  
Cerebral palsy  
Coeliac disease  
Collagen disorder  
Congenital adrenal hyperplasia  
Congenital spherocytosis  
Crohn's disease/colitis  
Cystic fibrosis  
Cysts on ovaries/polycystic ovaries  
Diabetes  
Eczema/skin condition/acne/psoriasis  
Epilepsy/fits  
Friedreich's ataxia  
Gastro-oesophageal reflux  
Harelip  
Hay fever  
Heart condition/murmur  
Heart transplant  
Hemiplegia  
Hernia/hiatus hernia  
High cholesterol  
Histiocytosis  
HIV/AIDS  
Hole in the heart  
Irritable bowel syndrome  
Kidney condition  
Lactose intolerance  
Leukaemia  
Low blood sugar  
Low immunity  
ME/chronic fatigue syndrome  
Migraine/headache  
Muscular dystrophy  
Narcolepsy  
Paraparesis  
Periodic syndrome  
Sarcoidosis  
Sickle-cell anaemia/Thalassemia  
Spina bifida  
Stroke

Tracheoesophageal fistula  
Tuberous sclerosis  
Under-active thyroid  
Vitiligo

## **Non-medical conditions**

Attention deficit hyperactivity disorder (ADHD)  
Autism/Asperger's syndrome  
Claustrophobia  
Communication problems  
Depression  
Down's syndrome  
Dyspraxia  
Eating disorders  
Hand-eye coordination problems  
Learning difficulty  
Long-term memory loss  
Mental health problems  
Obsessive compulsive disorder (OCD)  
Panic attacks/hyperventilation  
Stammer/speech problems  
Turner syndrome