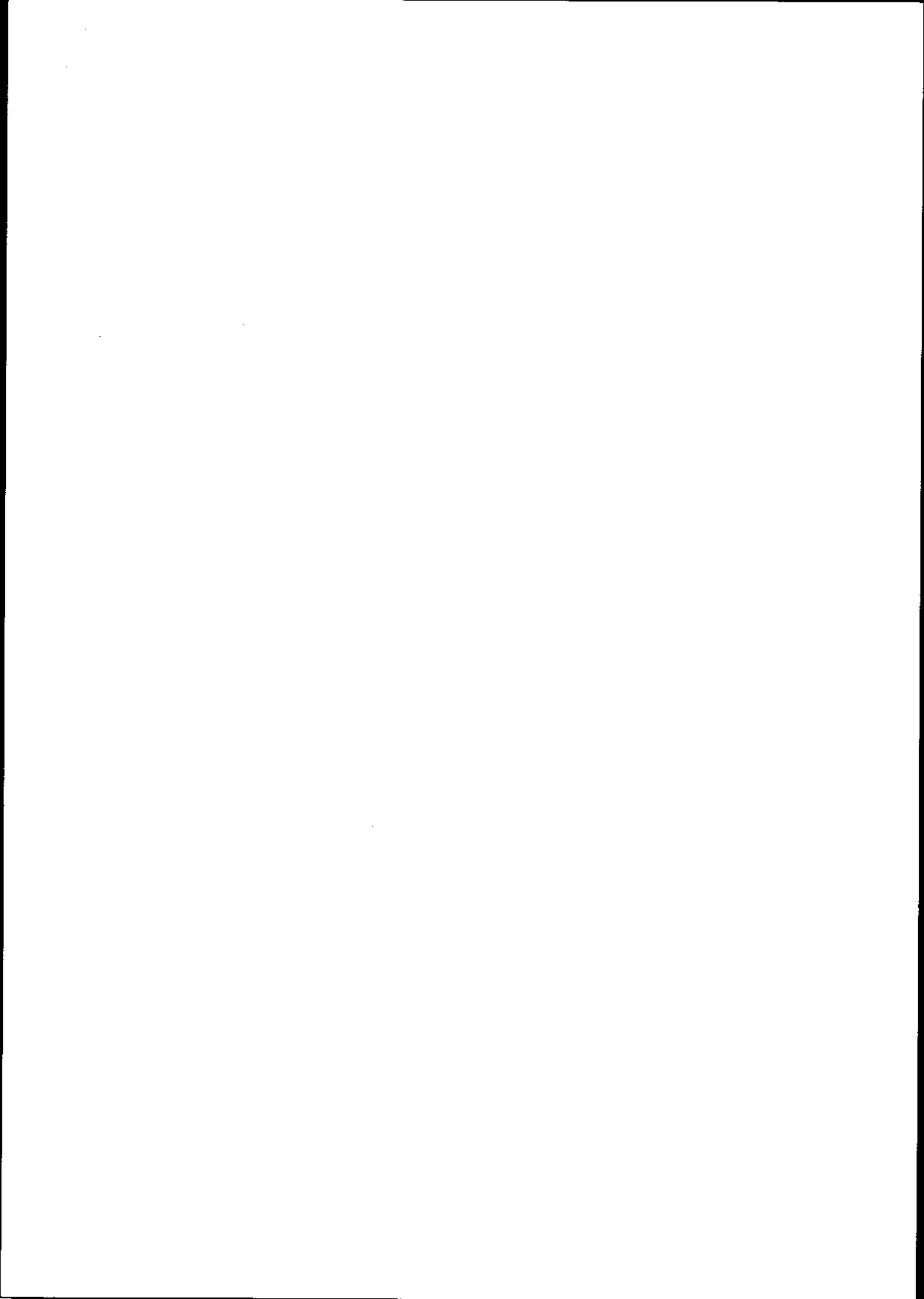




**SERVICE SUPPORT FOR CHILDREN WITH A  
CHRONIC ILLNESS OR PHYSICAL DISABILITY  
ATTENDING MAINSTREAM SCHOOLS**

**NHS 1576 10.98 JL/SW/PS**

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and  
Patricia Sloper*



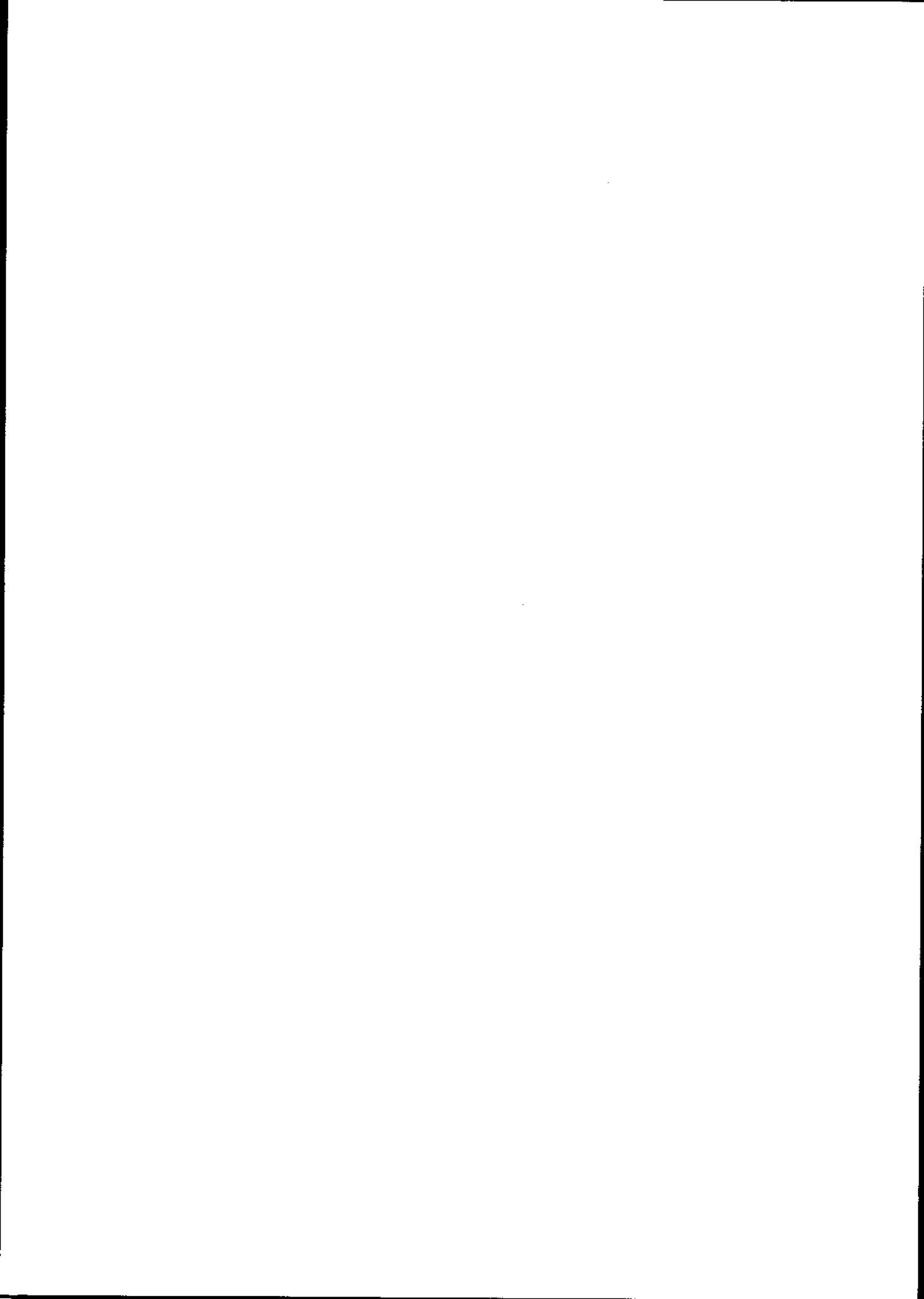
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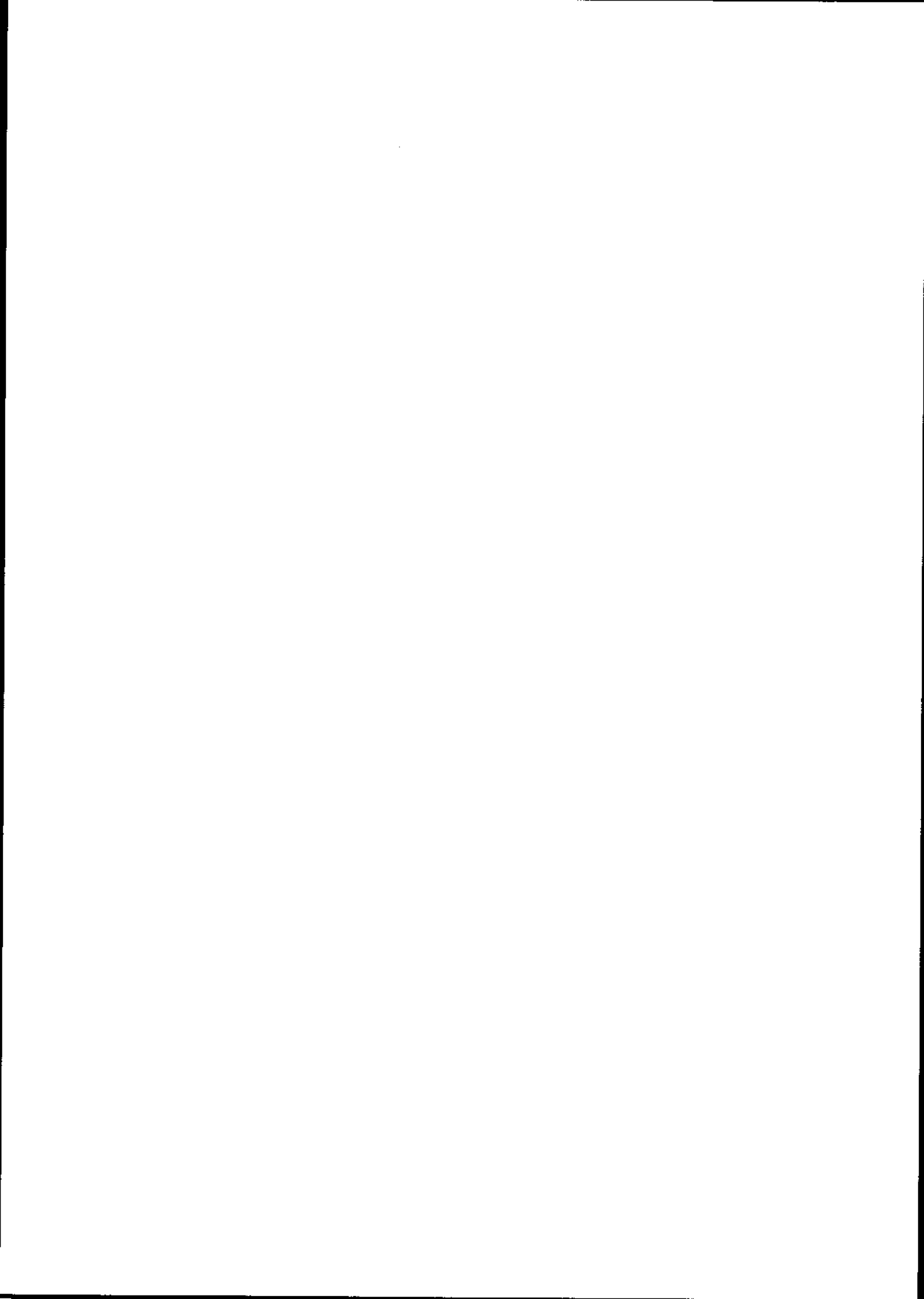
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## GLOSSARY

DfE	Department for Education
DfEE	Department for Education and Employment
DoH	Department of Health
GCSE	General Certificate in Secondary Education
GHS	General Household Survey
HA	Health Authority
IEP	Individual Education Plan
LEA	Local Education Authority
ME	Myalgic Encephalomyelitis
NACC	National Association for Colitis and Crohn's Disease
NAESC	National Association for the Education of Sick Children
OFSTED	Office for Standards in Education
PSA	Pupil Support Assistant
SCMO	Senior Clinical Medical Officer
SEN	Special Educational Needs
SENCO	Special Educational Needs Co-ordinator
SHS	School Health Service
SNA	Special Needs Assistant
UN	United Nations

## EXECUTIVE SUMMARY

**Project title** Service support for children with a chronic illness or physical disability attending mainstream schools. (MCH: 13-09)

**Lead researcher** Dr Tricia Sloper, Senior Research Fellow, Social Policy Research Unit.

### **Project findings**

#### ***Objectives***

1. To identify needs for NHS support for schools as expressed by children with special health needs, their parents, and teachers.
2. Reflecting on these findings, to investigate with staff from education and health services local arrangements for NHS support for schools, identifying possible components of good practice and developing recommendations for service development more generally.

#### ***Design***

This qualitative study was designed in two stages. The first stage involved data collection from pupils (semi-structured interview), parents (focus groups and some interviews) and teachers (focus groups) in two research sites, based on health authority boundaries. The second stage was more developmental in character and involved workshops with managers and professionals from health and education services in the research sites, to consider the findings from the first stage and make recommendations for policy and practice.

#### ***Setting***

The focus of the study was support for pupils in relation to school life. Data covered the interface between school, NHS care settings and family homes.

#### ***Participants***

Stage one: young people aged between 11 and 16 years (n=33) with a range of chronic physical conditions; parents of children of primary and secondary school age (number of families represented =58); teachers from 34 schools (n=35). Stage two: a total of 30 delegates attended one of two workshops.

#### ***Results***

The findings indicated that children were actively managing their health condition at school. However, there were areas of concern for all types of respondent in which service support was needed and valued, in particular: help to minimise absence and exclusion from academic and/or social life at school; emotional support (for pupils and for teachers); peer relationships; and the importance of an 'understanding' teacher, who is knowledgeable about the child's condition and its impact at school and who can make any appropriate special arrangements. In addition, parents and teachers were concerned about provision of medical care at school. Improving teachers' understanding was found to require attention to improving both the quality of health information and the process by which it is communicated to and within schools. Aspects of both good practice, and difficulties in support for pupils from education and health services, were identified. There were wide variations reported in the level of support from NHS professionals, in particular in school health, with the service poorly understood by some users. Respondents and workshop

delegates identified a number of specific 'messages' for education and health service purchasers, providers and national policy-makers designed to tackle the areas of concern identified.

### ***Conclusions***

Pupils in mainstream schools with a chronic illness or physical disability, their parents and teachers have a wide range of support needs, from both education services and the NHS. Overall, the needs of this group of pupils appear somewhat 'hidden', with special educational needs policy and the associated NHS contribution focusing on learning difficulties. Health-related support from the NHS is valued, but provision is patchy and communication with teachers appears poor. Action is needed at a number of levels: by individual schools; between NHS professionals and teachers; and by strengthening national guidance, to draw attention to the needs of this group of pupils, clarify professional roles and secure more equitable service support. All professionals need to take a holistic approach to caring for children, including consulting them about their own needs, since their views are not necessarily the same as adult proxies.

### **Relevance to the NHS**

The project identifies a number of specific ways in which NHS professionals can support pupils, parents and teachers in relation to life in school for pupils with a chronic illness or physical disability. Professionals with lead health care responsibility for a child might review the coverage of the consultation with the child and his or her parents, along with arrangements for passing information to schools and other ways of liaising with teachers. The role of the school health service in respect of this group of pupils warrants review.

### **Dissemination**

#### ***Target audience***

Policy-makers, practitioners and managers in health and education services, relevant voluntary bodies and researchers in similar fields.

#### ***Dissemination activities to date***

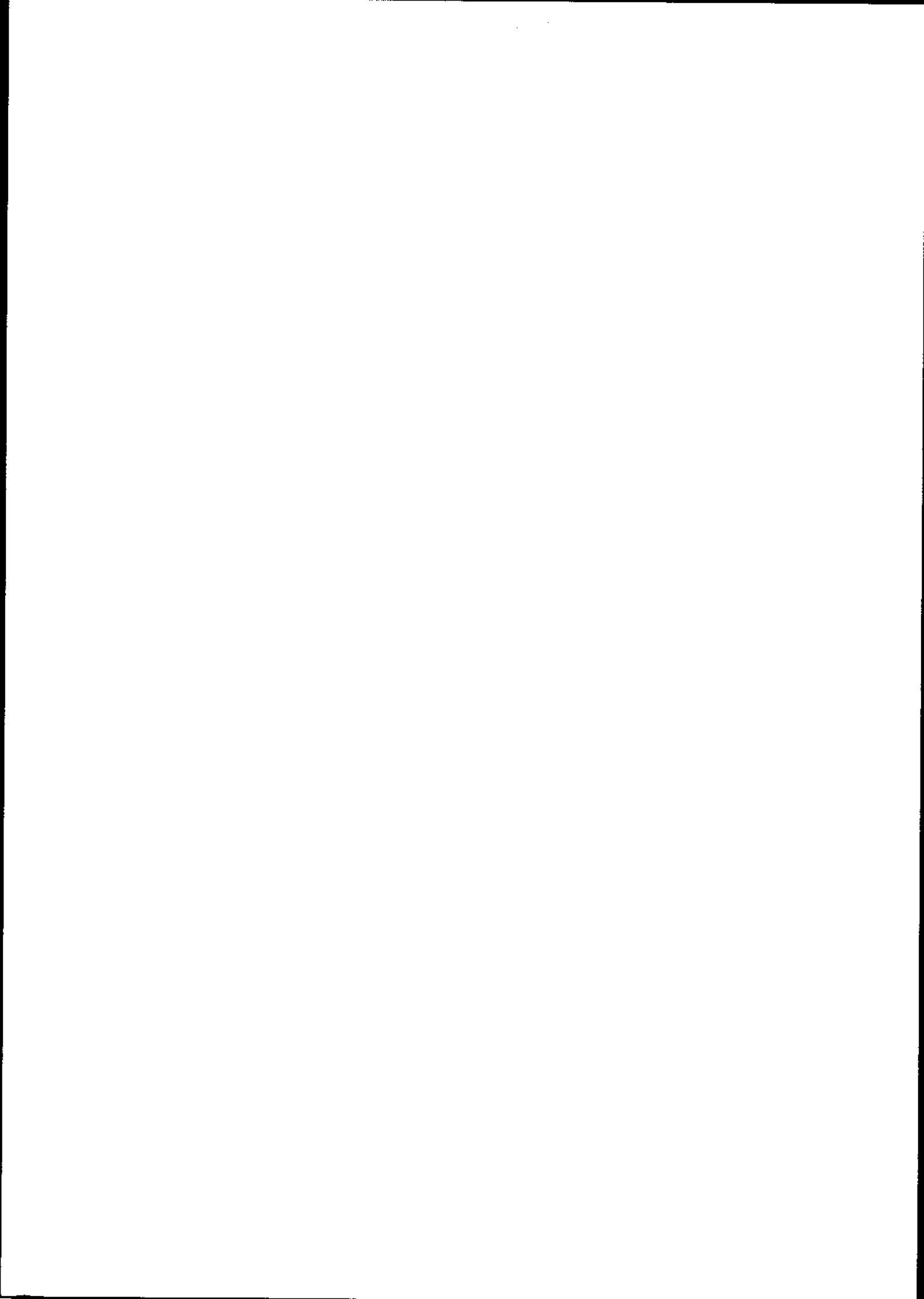
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4. What should health professionals be doing to support pupils in mainstream schools? Presentation to a national conference organised by the National Association for the Education of Sick Children (Nottingham, June 1998).
5. Supporting pupils with a disability in mainstream schools: messages for health professionals. Paper presented at the tenth annual meeting of the European Academy of Childhood Disability (Helsinki, June 1998).
6. Supporting pupils with special health needs in mainstream schools. Paper presented at the annual conference of the Social Policy Association (Lincoln, July 1998).
7. Do we need a health worker in schools? Paper presented at the seventh biennial conference of the European Society of Health and Medical Sociology (Rennes, August 1998).

8. Coping with chronic illness and physical disability in school: what support do young people want? Paper presented at the British Psychological Society Winter Conference (London, December 1998).

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## CHAPTER ONE

### LITERATURE REVIEW

#### 1.1 INTRODUCTION

This research study stems from knowledge that a sizeable and growing number of children and young people in mainstream schools have 'special health needs'. For our purposes, a child is defined as having special health needs if s/he has a chronic illness or a physical disability which has an impact on school life. In turn, this definition encompasses a variety of needs and includes children with one or more of the following characteristics: a serious recurrent illness; a life-threatening condition; requiring continuous health support during the school day; mobility difficulties; dependent on technology; regularly absent from school due to chronic illness; and/or regular hospital stays. A wide range of conditions fall into these categories, for example allergies and asthma (where severe), cancer, cerebral palsy, cystic fibrosis, diabetes, epilepsy, ME, muscular dystrophy, renal failure and rheumatoid disorders.

The growing population of children in mainstream schools with conditions such as these is influenced both by general trends in illness and disability and by education policy. Looking first at trends in illness and disability: analysis of General Household Survey data between 1972 and 1991 suggests that long-standing illness among children (aged between five and 15 years) more than doubled (Woodroffe *et al.*, 1993). In 1991, almost one in five children were reported by parents as suffering from a long-standing illness, although only 50 per cent of these had a resulting limitation in activities (Botting and Crawley, 1995). However, Woodroffe *et al.* did note that trends over time may in part reflect changes in parents' expectations of their children's health, and a greater assessment of morbidity resulting from increased access to health care. The GHS Disability Survey (carried out in 1985/6) found that three per cent of children aged between five and 15 years had a severe disability, again reported by parents (Bone and Meltzer, 1989).

There have also been changes in the overall pattern of childhood illness and disability. While immunisations have led to infectious diseases becoming much less common, for some chronic conditions - such as cancer and cerebral palsy - there is evidence that medical advances have resulted in improved survival rates and so, in turn, an increase in prevalence (Botting and Crawley

1995). Some of the most prevalent chronic conditions among children are: asthma (12 per cent); eczema (8 - 10 per cent); diabetes (1.8 per cent); epilepsy (0.26 - 0.46 per cent); congenital heart disease (0.2 - 0.7 per cent); cerebral palsy (0.2 per cent); and cancer (0.17 per cent) (Edwards and Davis, 1997; House of Commons Health Committee, 1997; Botting and Crawley, 1995). Although the numbers of these children are small in relation to the whole school population, they do suggest that most medium to large secondary schools would include affected pupils.

Education policy has also had an important part to play in the growing number of pupils with chronic illness or physical disability in mainstream schools. Inclusion of pupils with a variety of special needs has been an explicit policy goal since the 1981 Education Act and a recent report shows that the percentage of pupils nationally in special schools is - at 1.4 per cent - the lowest ever (Norwich, 1997). While pupils with some chronic conditions - such as asthma, diabetes and eczema - have traditionally been educated in mainstream schools, developments in medical technology now mean that a growing number of children surviving with long-term and sometimes complex health needs are able to join their peers in mainstream schools. It follows that, increasingly, these schools are a setting for the provision of health-related support.

Clearly, life in school for these children is affected by numerous factors. Bronfenbrenner's socio-ecological model of factors affecting the child provides a useful framework with which to consider the way in which different levels of influence may interact. Bronfenbrenner suggests that the environment can be thought of as a number of different systems, each impacting on the child's development. The child's immediate environment is the *microsystem*, which has its own individual features and within which the child will have a role and take part in particular activities. School is one such microsystem. The interaction between the various microsystems in a child's life, for example, school, home, and hospital, forms the *mesosystem*. At the highest level is the *macrosystem*, which consists of the over-arching institutional patterns of the culture, for example, economic, political and social systems (Bronfenbrenner, 1997; Sameroff, 1991). Clearly the policy framework is part of the macrosystem, and will have an impact on both the microsystem and the mesosystem. This model recognises that a child's life in school will be influenced by resources and support available within and outside of the school, and more broadly by health and education policies.



In this chapter, we set out findings from our review of the relevant policy and research literature. First, we set out the policy context: to what extent are children's special health needs at school identified in health and education policy, along with responsibilities for meeting these needs? Secondly, what does the existing research evidence reveal about the difficulties experienced by and the support needs of this group of pupils? Against this background, we conclude the chapter by setting out the rationale for and aims of the present study.

## **1.2 POLICY CONTEXT**

At the broadest policy level, children have arguably become a more visible group: both the United Nations Convention on the Rights of the Child (1989) and the 1989 Children Act focus on the rights of children, including their right to have decisions made about them on the basis of their best interests and including listening to their own views. The UN Convention - to which the UK Government agreed to be bound from 1991 - includes the rights of children both to education (article 28) and to health: to be as healthy as possible and receive good health care when needed (article 24). The Convention states specifically that disabled children must be helped to be as independent as possible and to be able to take a full and active part in everyday life (article 23). The Children Act was important for disabled children since, for the first time, they were included within a definition of children 'in need' and so their needs have been within the remit of strategic inter-agency Children's Services Plans.

In terms of more specific policies, the group of children with chronic illness or physical disability straddles the policy boundary between education and health: there is no single policy document which sets out to identify and address the range of their needs. However, they do feature in separate policy guidance, in both education and health, and in joint guidance. In this section we draw attention to the main policy provisions affecting pupils with special health needs. We then outline a number of ambiguities and gaps in policy concerning this group.

### **1.2.1 Education policy**

A policy commitment for inclusion of as many children as possible in mainstream education was established under the 1981 Education Act. Building on this legislation, the 1993 Education Act addresses the needs of children with health conditions in two ways: first, education for sick

children absent from school and, secondly, the inclusion of children with chronic illness or physical disability under 'special educational needs' policy.

*1993 Education Act: education otherwise than at school*

The 1993 Act established a duty on Local Education Authorities (LEAs) for the first time to provide education 'otherwise than at school' - that is, in hospital or at home - for sick children (section 298). Guidance in respect of this new duty was issued by the Department for Education in May 1994, supported by the Department of Health and the NHS Executive (DfE, 1994a).

The guidance places emphasis on the need for *continuity* in education for sick children, their health permitting. Although parents are assigned a key role as information-givers between professionals working in schools and hospital, good liaison between education, clinical and administrative staff within the hospital is also seen as essential, in three key areas. First, hospital teachers should have as much advance warning as possible of when a child is to be admitted to hospital and for how long. Secondly, these teachers can make a valuable contribution to the health care of children through passing on to clinical staff any concerns expressed by the child, for example about pain or the effect of medication. Thirdly, the guidance urges co-operation between hospital teaching and medical staff to minimise disruption to the child's education while in hospital by carrying out routine procedures outside teaching time. Among education workers, liaison between a child's home school and hospital teaching staff is seen as crucial for continuity. The guidance suggests a number of ways of improving liaison, such as a named teacher in the 'home' school taking responsibility for liaison with hospital teaching staff, and joint in-service training for teachers.

*1993 Education Act: special educational needs*

The chief mechanism through which pupils with special health needs access extra support at school within education policy is through the identification and assessment of their 'special educational needs' (SEN). Section 156 of the 1993 Act defines a child as having SEN if s/he 'has a learning difficulty which calls for special educational provision'; that is, provision additional to or different from that which is generally available in the local area. The Act aimed to assist the interpretation of special needs policy by issuing a Code of Practice on the Identification and

Assessment of Special Educational Needs (DfE, 1994b). Although schools, LEAs and others who have statutory duties under the 1993 Education Act - including health authorities - must 'have regard' to the Code, its advice is in the form of a general framework rather than being prescriptive.

The Code argues that, although about 20 per cent of pupils nationally may fall into the category of 'special educational needs' at some time, there is a continuum of severity of SEN. For the vast majority of these pupils, their needs can be met by their school, with outside help if necessary. Nationally, only around two per cent of pupils have needs complex or severe enough to warrant a statutory assessment by the LEA leading to provision of a formal 'Statement' of SEN, which allocates additional resources to support the child at school.

To help schools manage their response to these varying levels of need, the Code sets out a five-stage model of SEN in which early stages are managed by the school with increasing outside specialist expertise being brought to bear (from Stage 3 upwards). An SEN Register should be maintained in schools to record pupils' needs according to the various stages. In each school a designated teacher - the Special Educational Needs Co-ordinator (SENCO) - is responsible for day to day operation of the school's special needs policy, including the Register, and for liaison with colleagues, parents and other agencies.

Where do children with special health needs fit into current SEN policy guidance? Despite its focus on *learning* difficulties, the legal definition of SEN in the 1993 Act does include children with a disability 'which prevents or hinders them from making use of educational facilities'. In addition the Code draws attention to the *potential* impact which a medical condition may have on education:

Some medical conditions may, if appropriate action is not taken, have a significant impact on the child's academic attainment and/or may give rise to emotional and behavioural difficulties.  
(para 3.89)

Relevant criteria for proposing a statutory assessment for pupils with an illness or disability include clear evidence that: the child's difficulty significantly impairs his or her mobility; the child has significant self-help difficulties, for example dressing, toileting or feeding; the child has

difficulty accessing the curriculum or participating in aspects of school life; the child's condition gives rise to serious safety issues; the child's difficulty places him/her under stress; or there is evidence of significant and recurrent absences from school.

In anticipating the consequences for education of 'medical needs', the Code urges collaboration between those who have expert knowledge about the child:

Children with identified medical needs will not necessarily have an associated learning difficulty, but the consequences of their illness or disability... may lead to future difficulties if there is not close co-operation between the school, the relevant child health services, and parents.  
(para 2.49)

So far as health authority responsibilities are concerned, each is required to have a 'designated medical officer' to lead and co-ordinate the local NHS contribution to assessment of pupils with SEN. This contribution includes: alerting LEAs to children they think may have SEN; co-ordinating medical advice from colleagues for assessments within prescribed time limits; and identifying the NHS contribution to be specified in a Statement. The designated medical officer is also responsible for making sure that all schools have a named contact (usually the school doctor) for seeking medical advice on pupils who may have SEN. Russell (1996) draws attention to the assumption in the Code that *individual schools* will be seeking information and support directly from health professionals, when formerly liaison was more likely between health professionals and *LEAs*. She considers this change significant in representing new challenges for inter-agency collaboration.

### **1.2.2 Health policy**

Within the NHS, the School Health Service (SHS) has an advisory and preventive - but not a treatment - role in meeting the health needs of school children in relation to their education. The twin aims of the SHS are 'to promote the physical and mental health of school age children' and 'to enable children to achieve their educational potential' (DoH, 1996: para 8.1).

In meeting these aims, one specific objective of the school health service is 'minimising the consequences of illness and disability in children for their education' (DoH, 1996: para 8.2). Although the role of school health workers is not prescribed nationally, guidance from the

Department of Health suggests that they should be providing advice to school staff, parents and children on medication and on reintegration into school of pupils with long term medical conditions. School health staff should also be making a contribution to the assessment and support of children with SEN and medical problems in schools (para 8.6).

### **1.2.3 Education and health: joint guidance**

The growing number of pupils in mainstream schools with medical needs has exposed a lack of clarity as to the responsibilities of school staff in meeting these needs. In response, joint guidance was issued by the DfEE and DoH in 1996 setting out the legal framework of school's responsibilities, followed by a Guide to Good Practice to help schools draw up policies on managing medication in schools and to put in place systems to support pupils with medical needs (DfEE/DoH, 1996). Children with 'medical needs' are defined as those with 'medical conditions which, if not properly managed, could limit their access to education' (Good Practice Guide para 7).

In law, LEAs are responsible for health and safety policy in schools (Health and Safety at Work Act 1974), which the guidance says should include procedures for supporting pupils with medical needs. However, parents are responsible for their child's medication: there is no legal duty which requires individual members of school staff to administer medication, this is a voluntary role and the Head is normally responsible for deciding whether the school can assist (para 11).

Drawing up clear protocols in the form of an 'individual health care plan' is recommended to identify and clarify the level of medical support needed at school (para 75). The pro-forma plan in the Good Practice guide focuses on daily care requirements, what to do in an emergency and follow-up care. In addition to the child, parents and school staff, NHS professionals (school health staff, GP or other health professionals) may need to contribute to the plan, which should be reviewed at least annually.

### **1.2.4 Discussion: a 'hidden' group?**

It is clear that the education policy for inclusion, together with changing patterns in childhood chronic illness and physical disability, means that a growing number of pupils in mainstream

schools are likely to require attention to their special health needs. However, this group of pupils appear rather hidden in broad policy terms, and their needs potentially overlooked on account of weaknesses in specific areas of guidance.

#### *Children with special health needs: a policy gap*

Since guidance for this group of children is piecemeal rather than comprehensive, some needs arguably may fall into policy gaps. For example, Bolton (1997) notes that under the 1989 Children Act the needs of sick children are hidden, since only children with a disability are defined as 'in need' in the legislation, with a 'knock-on' effect limiting the scope of inter-agency children's services planning. She argues that, in general, children with medical needs are given less policy attention than children with other types of needs:

In general, children whose needs begin by being of a *medical*, rather than developmental or environmental nature have been largely outside the terms of recent social policy initiatives for children.  
(Bolton, 1997: page 73, emphasis added)

Straddling the remit of two government departments - education and health - may also serve to weaken the identity of children with chronic illness or physical disability as a group. There is some evidence to suggest that co-ordination between the two departments is insufficient for needs to emerge. For instance, the National Advisory Group which recently developed a new Green Paper on special educational needs (DfEE, 1997) did not include a representative from the NHS, nor does the Green Paper itself make any reference to this group of pupils. It may also be argued that education policy failed to take into account the impact of inclusion on the work of NHS professionals. For example, therapists need more time to work with the same number of pupils peripatetically across many mainstream schools than formerly when more pupils with therapy needs were educated together in fewer special schools.

#### *Guidance is limited in scope*

Analysis of the Code of Practice on SEN reveals that it is much clearer about procedures for assessing, recording and meeting needs relating to *learning* difficulties as opposed to needs produced by a health condition *per se*. Despite flagging up the importance of taking 'appropriate action' to minimise the impact of a medical condition on school life, the Code provides little guidance as to where these pupils fit into the staged system of identifying and assessing SEN.

The scope of the individual 'health care plan' suggested in joint good practice guidance is somewhat narrow, focusing on clinical needs in school (DfEE/DoH, 1996). Although the guidance only set out to consider medical needs, the proposal for a health care plan represents a missed opportunity to acknowledge that children's needs in relation to inclusion in school life are much broader, covering academic, emotional and social needs, as indicated in the Code of Practice on SEN. Indeed, many pupils with a chronic illness or physical disability may not have clinical needs at school.

#### *Guidance can be inflexible*

Even when guidance is focused specifically on the needs of children with an illness or physical disability, some children's needs may still remain hidden. For example, Bolton (1997) argues that the 1994 DfE guidance on the education of sick children is insufficiently flexible in respect of home tuition eligibility criteria. She argues that the time delay allowed (four consecutive weeks of absence) before provision of home tuition discriminates against children whose pattern of illness results in a cumulative period of missed education split into repeated short absences.

#### *Guidance defines responsibilities insufficiently*

Although legislation imposes duties on agencies to help each other in respect of pupils with SEN, the provisions are weak: health authorities must comply with a request from an LEA in connection with pupils with SEN, unless they consider that the help is 'unnecessary' or is 'unreasonable' in the light of available resources (Education Act 1993: section 166).

In addition, where responsibility lies for meeting the clinical needs of pupils when at school is not clearly identified, despite the 1996 joint DfEE/DoH guidance seeking to address this issue directly. The guidance assigns elements of responsibility to parents, school staff and health professionals. Following submission of evidence about health services for children and young people in the community, a recent Health Select Committee was highly critical of the current situation:

There is a considerable degree of confusion about whose responsibility it should be to provide care for children with clinical needs at school... The government had an opportunity [in issuing guidance] to dispel this confusion but unfortunately failed to take it. On this important issue the guidance takes refuge in vagueness and in

verbal formulations which impose no obligation: 'usually', 'normally', 'in some cases', 'is likely to' or the ubiquitous 'may'.

(House of Commons Health Committee, 1997: para 88)

Acknowledging that children's clinical needs vary widely, the Committee nevertheless recommended that to avoid children being 'potentially the losers' there should be a recognition that, 'as a matter of principle, a certain level of service, including where necessary hands-on care, should be provided for pupils who need it' (para 89). The Committee took a firm view that it was unreasonable to expect parents to be called into school to help with their child's clinical needs. At the same time, a teacher's role *in loco parentis* should extend only to what an 'averagely competent and caring' parent would do, and so it would not be reasonable to expect teachers to undertake specialised 'hands-on' care. However, the Committee recommended that a requirement should be imposed on *schools* to ensure that they have sufficient staff with appropriate specialist 'hands-on' training, so that an appropriate service can be available for pupils at all times. In the Committee's view, recruiting trained children's nurses as school nurses could be an integral part of the planning and provision of this service (paras 91-2). Such a proposal would have significant implications for the future remit and funding of the SHS, which currently has a preventive and advisory role, with a small workforce visiting schools on a peripatetic basis (British Paediatric Association, 1995).

Existing guidance assumes that, among health professionals, staff working in the SHS will be a key source of information and advice to school staff. However, since the role of the SHS is not prescribed nationally, levels and types of support for schools cannot be guaranteed and there is known to be much variation in practice both between NHS Trusts and individual practitioners (Lightfoot and Bines, 1997; Bagnall and Dilloway, 1996). It follows that guidance intended to inform school staff about the support they might expect from health professionals inevitably resorts unhelpfully to the vague terms so criticised by the House of Commons Health Committee. In 1994, the Department of Health published findings from a pilot study on 'service level agreements' for school health services, negotiated between school health staff and staff from individual schools. Among a range of potential benefits from such an 'agreement' was a framework for supporting the growing number of pupils in mainstream schools with 'medical



problems', for example to ensure timely health assessments and specify health service provision (DoH, 1994).

#### *Guidance cannot guarantee funding for policy implementation*

Fundamentally, commentators note the need for services to secure funding. In her review of 'what works' in inclusive education, Sebba (1997) makes the point that legislation cannot ensure services which are, in turn, dependent upon resources. Similarly, Bolton argues that sick children continue to be marginalised in policy terms since, without ear-marked funds for LEAs, the level of service is discretionary and 'education for sick children has continued to compete with other educational priorities in the current climate' (Bolton, 1997, page 65).

Overall, then, a range of factors point to children with chronic illness or physical disability as a hidden and somewhat neglected group, and to the likelihood of variation in the responsibilities and activities of practitioners who have roles in respect of meeting their needs at school.

### **1.3 THE RESEARCH LITERATURE**

In this section we review existing research evidence on the support needs of children with a chronic illness or physical disability, with a particular focus on school life. The term 'children' will be used throughout this review to refer to children *and* young people of school age. The review is in three parts. We begin by drawing together evidence about the variety of ways in which these children constitute a group of pupils 'at risk' and so have potential needs for service support. Secondly, we look at existing research knowledge about the importance of school for this group, together with the unique difficulties they experience there and why these place children 'at risk'. Finally, we consider what is already known about the support needs of these pupils in relation to life in school.

There has been very little research in which children have been asked about life in school and the help they need to manage an illness or disability in this setting. Until recently, adults have been apprehensive about involving them in research, perceiving them as a vulnerable, incompetent group (Morrow and Richards, 1996). Since children with a chronic illness or disability might be seen as an even more vulnerable group, it is not surprising that even fewer of these children have

been involved in research (Beresford, 1997). Most of the research to date on the experiences and needs of this group of children has used parents as proxies for their child and most studies are specific to particular conditions. Yet there is evidence that parents are not a reliable source of information about the child's perspective: research in which parents and children have both been consulted about the same issue has consistently found differences in the responses of the two groups, (Beresford, 1997; Ennett, *et al.*, 1991; Tackett *et al.*, 1990; Menke, 1987; Le Febvre and Munro, 1978).

### **1.3.1 Children 'at risk'**

There is research evidence that children with chronic conditions are at greater risk than their peers of developing psychosocial or academic problems. Such findings are of significance to service providers in that they suggest that, even if children with chronic conditions are receiving the medical care they need to be well enough to attend school, they may not be receiving the support they need to manage their condition within the context of their every day life.

#### *Psychological adjustment*

Recent reviews of the psychology literature conclude that children with chronic physical conditions have an increased vulnerability to develop psychological adjustment problems. A meta analysis of 87 studies of parents' and mental health professionals' ratings of overall adjustment found that over twice as many children with chronic conditions had problems with psychological adjustment as those in comparison groups (Lavigne and Faier-Routman, 1992). However, researchers emphasise that there are considerable individual differences and that overall only a minority of children with chronic conditions experience such problems (Wallander and Varni, 1998; Eiser, 1990a). Few researchers have investigated the *type* of problems children develop, but those that have report that children with chronic conditions are more likely to display internalising disorders, such as anxiety, rather than externalising symptoms ( Wallander and Varni, 1998; Lavigne and Faier-Routman, 1992).

There is also evidence to suggest that children with chronic physical conditions are at greater risk of having psychological problems as adults. For instance, Pless *et al.* (1993) analysed data from a cohort of 16,000 British children from the National Child Development Study, and found that

men with chronic physical disorders in childhood were at greater risk in adulthood in three respects: having suffered from anxiety and depression; having received specialist psychological care; and having obtained poor educational qualifications. Although women had fewer adjustment problems, they were more likely than their peers to have seen a mental health specialist. Findings such as these suggest that problems in childhood are not transient, and that children with chronic conditions may benefit from psychological support.

### *Relationships with peers*

There has been a great deal of research interest in the peer relationships of children with chronic physical conditions. Although it would be incorrect to conclude that all chronically ill children experience poorer peer relationships, some children do have difficulties (Spirito *et al.*, 1991). Researchers have speculated that changes to the child's physical appearance following treatment may contribute to problems with peer relationships. Research indicates that children who have paediatric conditions which visibly affect appearance, such as growth hormone deficiency, cranio-facial anomalies, burns and cancer, experience social difficulties. It has also been suggested that pupils who have a condition which requires a change of lifestyle (for example, avoidance of particular foods, or irritants), and so draws attention to the individual and disrupts normal social activities, will be at greater risk of having problems with peer relationships (La Greca, 1992; Spirito *et al.*, 1991). Such suggestions are further supported by research in which children have been interviewed about their experiences with peers, with respondents reporting difficulties due to changes in their appearance and restrictions in their physical activities. These findings indicate that this group of children may have peer difficulties which are qualitatively different to those experienced by 'healthy' children (Spirito *et al.*, 1991).

In SCOPE's retrospective study involving 326 adults with cerebral palsy, 47 per cent of participants reported being bullied while attending mainstream school. Notably, when responses of adults aged 18-24 years were looked at in isolation, the rate of bullying increased, suggesting that the social inclusion of pupils with disabilities has not improved in recent years (Lamb and Layzell, 1994).

Findings in this area have long term implications, since children who have difficulties with peer relationships are believed to be at risk of developing psycho-social problems later in life (Spirito *et al.*, 1991).

#### *Academic performance*

Children with chronic illness have been shown to perform less well academically than their peers, even when a chronic illness does not result in cognitive impairment (Midence and Elander, 1994; Nettles, 1994; Howe *et al.*, 1993; Fowler *et al.*, 1985). In the long term, poor academic performance, compounded by low expectations among teaching staff, a lack of work experience, and poor careers advice may limit a young person's employment prospects (Eiser, 1998; Spencer *et al.*, 1995; Howe *et al.*, 1993; White and Shear, 1992).

In summary, the evidence that children with chronic physical conditions are at greater risk of developing psychosocial, peer relationship and academic problems than their peers suggests that they may be in need of additional support.

### **1.3.2 The importance of school in a child's life**

So why should we be concerned specifically with the support children receive within the school setting? In the psychological research, a number of factors are hypothesised to affect the way in which children respond to having a chronic condition, including socio-ecological factors extrinsic to the child (Wallander and Varni, 1998). While there has been a great deal of work on factors within the family environment and their impact on a child's adaption to his or her condition, less is known about the impact of the school environment. Given that children spend much of their time in school, experiences in school are likely to have a major impact on their life and are worthy of research (Wallander and Varni, 1998; La Greca, 1992). Here we outline existing research evidence regarding the unique benefits and difficulties children with a chronic condition may experience through attending school.

#### *The benefits of attending school for pupils with chronic physical conditions*

There are a number of ways in which school can be beneficial for this group of pupils. In a recent study by the National Association for the Education of Sick Children (NAESC) on provision of

education during school absence, 100 parents and 40 children absent from school because of an illness or accident were interviewed (Bolton, 1997). Participants commented on: the need to keep up with school work so that the child's future education is not compromised; education as a welcome distraction from pain and treatment; and the positive impact education can have on a child's recovery. While parents of children who are terminally ill have questioned the importance of education *per se*, they do value their child attending school, believing it provides a context in which children can succeed, experience friendship, and is a distraction from the illness (Closs and Burnett, 1995).

#### *The difficulties encountered by pupils with chronic physical conditions*

Although school may be beneficial for pupils with a chronic physical condition, it also presents them with additional stresses not encountered by their peers. In general, school absence rates are high for the group of pupils with chronic physical conditions (Fowler *et al.*, 1985). In Freudenberg *et al.*'s (1980) research into problems encountered at school by pupils with asthma, one of the problems cited most often by parents was long or frequent absence. Children undergoing hospital treatment appear to be particularly vulnerable to experiencing problems as a result of absence. Not only do they have time away from school due to being in hospital, but they may also require regular outpatient appointments and have additional absences due to feeling unwell. For example, Charlton *et al.* (1986) carried out a retrospective survey of 72 children receiving hospital treatment and reported that, in addition to time needed for inpatient treatment, pupils with cancer were on average absent for a further 35 per cent of the school year. Pupils with other chronic diseases were absent for 19 per cent of the school year, and pupils with orthopaedic conditions for 13 per cent.

There is evidence that children who have been absent from school for a long period worry about returning. For example, in a study in the USA involving children with a wide range of chronic conditions parents reported that, prior to returning to school, their children were concerned about being behind their classmates in school work, how their peers would react to them and changes in their physical appearance (Lynch *et al.*, 1992). In another USA study, young people with cancer referred to a school re-entry programme owing to school-related problems reported worries and concerns about: being teased; the embarrassment of changes in appearance;

difficulties in talking about the illness; and not being able to take part in school activities, particularly as this might lead to others thinking they were 'weird' (Henning and Fritz, 1983). In a UK study, parents and teachers of children with chronic physical conditions reported that children experienced a wide range of problems on return to school. These included: physical problems, for example, pain and tiredness; psychological problems; worries about appearance; behavioural problems, such as aggression, irritability and social withdrawal; and academic problems, such as catching up with work and difficulty with concentration (Larcombe *et al.*, 1990).

One reason why children may withdraw socially on return to school might be that time spent in the company of adults while absent leads to difficulties interacting with peers (Eiser, 1998). In relation to school work, lack of teaching input during periods of absence, rather than simply falling behind in work, may be the cause of poor academic achievement on return to school. Research has found that pupils with chronic conditions have particular difficulties with subjects which require teaching input and are difficult to catch up with by working alone, for example, mathematics (Howe *et al.*, 1993; Charlton *et al.*, 1986).

Aside from school absence, pupils with a chronic physical condition may miss school activities when they require treatment while at school, or if their condition prohibits them from taking part in particular activities, for example, physical education (PE), or school trips. In Freudenberg *et al.*'s (1980) study, children with asthma reported that some teachers prevented them from taking part in activities, while others would not let them rest when they did experience symptoms. Children who experience symptoms during the school day may have difficulty in keeping up with school work. For example, observational work with pupils with cancer found that these children had problems with concentration, lacked energy and were less willing to try new things (Lansky, 1980). Interviews with children with physical, mental and emotional impairments revealed that they felt learning was more difficult in schools which preferred pupils who could do well academically and where the pace of lessons was quick (Shaw, 1998).

Another difficulty faced by pupils with a chronic physical condition is managing medications at school. Freudenberg *et al.*'s (1980) study revealed problems with administering medication for

asthma and with the side-effects of drugs. Associated problems included knowing how to handle symptoms in school and how to decide when the child should stay at home.

As previously mentioned, pupils whose illness or physical disability is clearly visible to other pupils may be more likely to experience difficulties with peers. Researchers have also suggested that children who are tired, slow or clumsy are likely to be excluded from activities because their peers are unwilling to involve them (Mulderij, 1996). Interviews with young people (Shaw, 1998) suggest that school support assistants may also be the cause of some peer difficulties, with pupils worrying that the presence of an assistant may make it difficult for them to form friendships. However, pupils also acknowledged that not having an assistant can reduce their ability to take part in activities.

Difficulties in their peer relationships may be associated with emotional and behavioural problems. Research involving children with cancer and children with limb deficiencies found that perceptions of classmate and teacher support were the most important predictors of psychosocial problems (Wallander and Varni, 1988; Varni *et al.*, 1989). Poor academic progress may compound psychosocial problems. In a five year follow-up study on children with cancer (Sloper *et al.*, 1994), academic problems following the initial absence for treatment were found to be predictive of behavioural and emotional problems five years after the initial diagnosis. In addition, those pupils who were rated by parents and teachers as having behaviour problems perceived themselves as having problems with school work and with peer relationships. The authors suggest that support with school work and peer relationships may help to prevent the development of behaviour problems.

The research outlined in this section has suggested aspects of school life likely to be problematic for this group of pupils and explains why they may be 'at risk' compared with their peers. Such findings are useful in identifying areas where children might need support. In the following section, we build on this evidence by examining research in which children, parents and teachers have been asked directly about the support needed for this group of pupils.

### **1.3.3 Support for the pupil**

The research available on the support needs of children with a chronic illness or physical disability in relation to school can be divided into two types: studies which focus on pupils not attending school; and those concerned with pupils' support needs while at school.

#### *The support needs of pupils not attending school*

Research on pupils absent from school for health reasons tends to focus on education provision. In a recent study by the NAESC, parents reported on the difficulties of maintaining education when a child moves between the hospital, home and school at different stages during their illness, and wanted a single person to co-ordinate education during this process. Based on pupils' and parents' suggestions as to how to improve their current situation, the author recommended the development of a model for liaison between hospital, home tuition services and mainstream school (Bolton, 1997). The need for closer liaison is also highlighted in Charlton *et al's* (1986) study on children returning to school after treatment for cancer, where it is reported that when children received hospital teaching it often bore little or no resemblance to work being taught at school.

#### *The support needs of pupils attending school*

Similarly, there has been limited research to identify the types of support needed by children with a chronic physical condition who are attending school on a regular basis. The evidence we have already reviewed on the difficulties experienced by this group of pupils suggests that there are three areas in which support may be required at school: managing the condition itself; managing the curriculum; and managing school social life. Research to date has not identified types of support which would help pupils in managing their health condition at school, but there is some evidence of the types of support needed in respect of the other two areas.

*Managing the curriculum.* As mentioned earlier, absences from school or time out of class due to appointments, treatment or illness can lead to difficulties in keeping up with school work. Pupils may also have difficulty when deciding which subjects to prioritise, particularly if they do not receive adequate careers advice. In a study involving young people with bone cancer, complaints about a lack of realistic advice about career opportunities were common (Eiser, 1998), suggesting that improvements are needed.



Attempting to keep up with school work may not always be a priority for pupils. Parents of children with a life-threatening condition have pointed out that teachers need to be able to adapt the curriculum to meet the child's changing needs, suggesting that it is not always appropriate for these pupils to follow the national curriculum (Closs and Burnett, 1995). The authors suggest tailoring education to the individual child's needs requires sensitivity to the child's circumstances, including the family's approach to the condition.

*Managing school social life.* Evidence that young people with chronic physical conditions experience difficulties in their social relationships has led to the development and evaluation of social skills training and school reintegration programmes for this group of pupils (Varni *et al.*, 1993; Eiser, 1990b; La Greca, 1990). Children who received these interventions perceived their classmates and teachers as more supportive and had fewer behaviour problems. Other researchers have taken a different approach, aiming to improve the attitude and behaviour of pupils towards the child with the chronic condition (Eiser, 1990b; Armstrong *et al.*, 1987). However, we have no evidence about the approach children themselves would like professionals to take in supporting them with their social relationships in school.

#### **1.3.4 Indirect support needs: support for friends and school staff**

Within school, both friends and school staff can be sources of support for the pupil with a chronic health condition. However, in order to provide such support, they in turn may need assistance.

Although the importance of good peer relationships has been highlighted by the psychological literature, it is only recently that researchers have begun to investigate peers as a resource for the child with a chronic condition. La Greca (1992) interviewed 74 young people with insulin-dependent diabetes about the support they received from family and friends in relation to their diabetes. While both family and friends were reported to provide emotional support, friends were more orientated towards helping the young person to feel accepted within their peer group. Friends provided young people with more 'companionship support' than families, for example, adjusting arrangements for eating and exercise to fit in with the child's needs. In addition, they assisted the child with the day-to-day management of their diabetes, reminding them about taking

medication and helping them deal with adverse reactions. Researchers have yet to examine the support peers need in order to take on such roles and responsibilities.

There is research available on the help teachers need in order to support pupils with chronic conditions appropriately. The literature indicates that many teachers have concerns about teaching a child with a chronic physical condition. For instance, in Johnson *et al.*'s (1988) survey of 341 teachers in the USA, 24 per cent thought they would have major problems in teaching a child with a chronic health condition in their current classroom setting. In Eiser and Town's (1987) UK study of teachers enrolled on a postgraduate course, just over half were concerned about teaching a pupil who is chronically ill. Research with parents and teachers has identified three main areas where teachers require support: having information about a pupil's special health needs; integrating the pupil into the classroom; and providing emotional support.

#### *Teachers' information needs*

The importance teachers place on having information about a pupil's health needs is highlighted by Johnson *et al.*'s (1988) USA study in which teachers were asked to rank critical issues in the educational management of children with chronic health conditions. Teachers rated having knowledge and skills to deal with the condition as the issues which most concerned them.

A number of studies which focus on teachers' knowledge about specific chronic illnesses (diabetes, cancer, leukaemia, epilepsy, and asthma) have found that teachers are ill-informed about these conditions. In particular, teachers report having difficulty knowing how to deal with emergencies, and how much to 'push' a child to keep up with school activities, both academic and physical (Court, 1994; Lynch *et al.*, 1992; Chekryn *et al.*, 1987; Eiser and Town, 1987; Charlton *et al.*, 1986; Bradbury and Smith 1983; Eiser, 1980).

The implications of not providing guidance to schools is highlighted by Eiser and Town's (1987) finding that teachers had low expectations of chronically ill children, believing they were not able to participate fully in the curriculum. In a retrospective study with 326 adults with cerebral palsy who attended mainstream school, Lamb and Layzell (1994) found that 41 per cent felt that teachers had underestimated their abilities. Research has shown that teachers who feel they are

well informed about childhood conditions have more confidence in their ability to accommodate a child who has a chronic condition in their classroom (Eiser and Town, 1987), suggesting that it is important for teachers to have relevant training. It is also important that professionals providing such training do not wait for teachers to request it. In a study concerned with teachers' knowledge about diabetes, no association was found between teachers' assessed level of knowledge and their anxiety about having a child with diabetes in the classroom (Bradbury and Smith, 1983), suggesting that teachers in need of training may not be concerned enough to seek it. In order to ensure that teachers receive the information they need, it has been suggested that they be included in any inter-disciplinary team involved in planning the child's return to school (Chekryn *et al.*, 1987).

Teachers' lack of knowledge is not surprising given that many teachers report not having had any health input in their initial teacher training. A survey of colleges in the North of England in 1994 found that health and medical input on courses was extremely variable. Although some courses included material on specific medical conditions, typically students received a health education programme covering only issues related to health promotion (Court, 1994).

In the past ten years, voluntary organisations and support groups have become more involved in providing advice to schools, visiting schools to speak directly with staff, and producing written materials. It is therefore particularly disappointing to find that in Court's (1994) study involving 286 teachers in the North East of England, knowledge about diabetes was similar to that reported by Bradbury and Smith in Liverpool in 1983.

A number of studies in the UK and the USA have found that parents are the primary source of information for school staff (Johnson *et al.*, 1988; Charlton *et al.*, 1986; Bradbury and Smith, 1983). However, there is evidence that teachers are unhappy about relying on parents for information. Part of teachers' reluctance to rely on parents for information seems to be concern about the quality of information passed on. In Court's (1994) research, only 39 per cent of teachers reported having confidence in the accuracy of information they received from parents.

Teachers' belief that parents may have difficulty in passing on accurate information to school staff is supported by a number of studies showing problems in parents' understanding and accurate recall of information from doctor-patient consultations. For example, a study on communication between parents, children and physicians during consultations at an outpatient clinic showed that, following the meeting, mothers and fathers reported a more positive prognosis for their child than that given by the physician during the consultation (Mulhern *et al.*, 1981). Teachers of children with a life-threatening conditions have also reported not wanting to ask parents for information for fear of intruding on their privacy (Chekryn *et al.*, 1987).

While teachers have concerns about relying on parents for advice and information, research suggests that parents may be keen to offer this support. For example, in a study involving parents of children with a chronic illness, parents expressed concern about teachers' lack of knowledge about their child's condition and suggested that one solution might be to improve communication between parents and school staff (Lynch *et al.*, 1992).

Studies which have asked teachers how they would like to receive information about pupils' special health needs indicate a desire for written material and contact with health professionals. For instance, in Bradbury and Smith's (1983) study on involving teachers responsible for children with diabetes, teachers said they would like to receive information through leaflets. Interestingly, pupils of teachers in this study were attending clinics which disseminated leaflets for school staff via parents. These leaflets did not appear to be reaching class teachers. In a UK study on children returning to school after treatment for cancer, teachers wanted contact with a medical expert for advice. They reported that the current arrangement was for parents to take responsibility for explaining the child's condition, informing staff when the child would be returning to school and discussing potential difficulties (Charlton *et al.*, 1986). Teachers' preference for contact with health professionals or information through pamphlets, rather than receiving information through parents is also replicated in Eiser and Town (1987) survey of 187 UK teachers.

### *Communication and collaboration between health and education professionals*

The research available - albeit limited - on communication and collaboration between professionals from health and education with respect to pupils with special health needs suggests difficulties with the current system in the UK. The evidence indicates that contact between teachers and health professionals is low. In Bradbury and Smith's (1983) UK study involving teachers responsible for children with diabetes, only 25 per cent reported receiving advice from school nurses and even fewer reported contact with other medical professionals. In another study, teachers in the North East of England were reported to perceive specialist nurses as their most effective source of information, but were more commonly receiving information on an informal basis from parents, other teachers and the media (Court, 1994).

Larcombe (1995) looked specifically at the case of children returning to school after treatment for cancer and found difficulties in communication both within health services - between hospital and community services - and between health and education services. In 1996/7, an OFSTED survey of 74 schools drawn from 19 LEAs, noted an increasing number of pupils with Statements on account of health-related needs (OFSTED, 1997). The report expressed concern about the fragmentation of support for these pupils:

Many schools are unclear as to who they have to contact, the nature of that person's responsibilities and the degree to which they have any control over the allocation of resources... In spite of joint circulars and other forms of guidance there is still very little evidence, in schools, of LEAs and health authorities collaborating closely to meet the needs of pupils requiring health authority support (OFSTED, 1997: paras 102-103)

In a recent study of communication between schools, LEAs and health and social services, teachers reported a number of communication difficulties with NHS professionals (Dyson *et al.*, 1998). Advice and information from consultants varied widely: although some gave prompt information which helped teachers to plan appropriate education programmes, others responded after considerable delay or even not at all, on the grounds of confidentiality. Teachers felt that NHS professionals failed to see them as partners, for example not asking teachers for information when children had medical assessments. Teachers argued that, although they did not have medical expertise, their experience of the child in his or her everyday life at school could yield valuable information.

### *Support with integrating the pupil into the classroom*

A number of studies have pointed to teachers' concerns about integrating pupils with chronic health conditions into the mainstream classroom (Eiser, 1990a; Eiser and Town, 1987; Charlton *et al.*, 1986; Henning and Fritz, 1983). First, teachers report concerns about dealing with the reactions of other pupils to the child. Teachers worry that classmates may be fearful of the chronically ill child or jealous of extra privileges, yet they avoid discussing the child's condition with other pupils and are particularly reluctant to explain life-threatening illnesses (Eiser and Town, 1987). Teachers also report wanting advice on answering pupils' questions (Charlton *et al.*, 1986). Secondly, teachers have concerns about the time involved in supporting this group of pupils. In particular, they refer to the difficulty of helping the pupil catch up with school work at the same time as being responsible for a whole class (Eiser, 1990b; Eiser and Town, 1987; Henning and Fritz, 1983). Thirdly, teachers may have difficulty knowing how to discipline a child with a chronic illness, with teachers of children with cancer reporting that tend to relax their usual discipline standards (Chekryn *et al.*, 1987). Such findings suggest that teachers need guidance on how to integrate pupils who have a chronic condition with the rest of the class, both in terms of managing their time and responsibilities and in dealing with the reactions of pupils to the child with a chronic condition.

### *Teachers' needs in providing emotional support*

As mentioned previously, pupils with a chronic physical condition are themselves at risk of experiencing emotional problems. Teachers of children with cancer reported difficulty in knowing whether to offer emotional support to a child in case he or she does not wish to discuss such issues with them (Chekryn *et al.*, 1987). As a result, they tended to wait for the pupil to approach them for help. These teachers wanted guidance on how to deal with the child's emotional reaction to the illness and its treatment. They also reported that being responsible for a child with a life-threatening condition caused them to feel shocked and worried. Teaching colleagues were their main source of support in dealing with such feelings.

A series of studies in the UK suggest that teachers are ill-prepared to support children under stress, with teachers reporting needs for more training in pastoral care issues and communication (Carey, 1997, 1993). While the majority of teacher training institutions include pastoral care on

their syllabus, this usually involves lectures on issues which staff might be expected to teach. Few teachers receive any practical training in basic counselling or communication skills (Cleave *et al.*, 1997). It seems likely that even fewer teachers will have received training on responding to the very specific worries raised by pupils with a chronic condition.

#### **1.4 RATIONALE FOR THE PRESENT STUDY**

The overall aim of the present study is to contribute to improved NHS support for children in mainstream schools who have special health needs arising from a chronic illness or disability. Such a study is timely in view of the increasing number of children attending mainstream school with special health needs. Although previous research has provided some information on how best to support this group of pupils, this study addresses three gaps in knowledge: first, the views of pupils themselves; secondly, knowledge of support needs beyond a single condition to include a range of illnesses and disabilities which impact on school life; and, thirdly, knowledge about needs relating to routine life at school, not just at 'crisis' points such as re-integration.

The research objectives were, first, to investigate needs for service support in relation to school as expressed by children with special health needs, their parents and teachers. Secondly, in the light of these findings, to reflect on local arrangements between health and education agencies for service support, identifying possible components of good practice and making recommendations for service development which might be applicable more generally. To meet these objectives, the study was designed in two main stages: a research and a development phase.

#### **1.5 STRUCTURE OF THE REPORT**

The remainder of this report is divided into four chapters. Chapter Two provides details of our research design and methods. In Chapter Three we present our findings from the research phase of the project, going on to present the results of the workshops in Chapter Four. In Chapter Five we discuss the study's results in the light of existing policy and research literature and also reflect on the methods we used and the overall strengths and limitations of the study. We conclude by outlining the implications of the study findings for practice, policy and further research.





## CHAPTER TWO

### RESEARCH DESIGN AND METHODS

#### 2.1 RESEARCH DESIGN

We designed the research in two main stages to allow for a developmental component, since the overall aim of the research is to contribute to improved NHS support. *Stage one* involved primary data collection from key user groups: young people, parents and teachers. Given the research gaps in this field - particularly with children - we started from a basis of little systematic knowledge about the key issues in service support from a user perspective. The study was therefore exploratory in character and we adopted a qualitative approach. Although the overall aim of the study is to contribute to improved NHS support, project participants were asked about their support needs generally. There were two reasons for this approach. First, it allowed participants to raise concerns about any aspect of school life and did not presuppose that there would be difficulties in any particular area. Secondly, it provided information on the support needed from health *and* education services, acknowledging that both have a role to play in ensuring that this group of pupils get the most out of school life.

*Stage two* was more developmental in character, and comprised invited workshops of health and education professionals from the research sites at which we first presented the findings of stage one. We then asked delegates to use their knowledge and expertise, both to reflect on existing local services and to consider how services might be developed in practice for this group of pupils more generally.

Prior to the empirical research, we undertook various types of preliminary work: we carried out a policy and research literature review; we held a joint meeting with officers at the DfEE and DoH to find out their views of key issues; through voluntary organisations, we contacted a small number of young people to advise us on the development of the young people's topic guide and to help with piloting; and we established a small Project Advisory Group to advise on literature, methods and dissemination. We also recruited the research sites, details of which are given in the following section. In the rest of this chapter we go on to provide information about the research methods used and recruitment of participants for both stages of the project.

## **2.2 RESEARCH SITES**

We carried out the research in two 'sites', based on Health Authority (HA) boundaries. The aim was not to undertake a comparative study of two purchasing authorities, but rather to ensure that the study covered a range of local service and geographical factors potentially relevant to service support for chronically ill or physically disabled children in relation to school life. In particular, we sought variation in whether an area was predominantly urban or rural, and in the organisation and management of health services for children. While it has been argued that 'combined' hospital and community health services might yield benefits for co-ordination, at least among health professionals (Larcombe, 1995; British Paediatric Association, 1991), systematic evidence is not available for the superiority of particular organisational models for co-ordination between health and other agencies. It follows that selecting research sites on this criterion does not identify a 'good' or 'bad' site, but simply seeks to capture variation in models of service organisation and management. Two contrasting HAs were identified and agreed to take part. Approval was secured from the local research ethics committee in each case (four committees in total). Local Education Authorities (LEAs) within the two HA boundaries were also approached and agreed to support the study.

### **2.2.1 Characteristics of the research sites**

#### *Site A*

The health authority purchases services for a largely city-based population of 725,000, of whom 170,000 are under 18 years. There are two hospital NHS Trusts, both of which offer secondary and tertiary services for children from the city and from the surrounding region, which has a population of between three and four million. Services for children outside hospital - including community paediatrics, the school health service and a Child Development Centre - are managed in a separate NHS Trust covering community and mental health services. A consultant community paediatrician is the 'designated medical officer' with responsibility for working with the LEA on behalf of children with SEN and to lead the health authority's contribution to the statutory Statementing process.

The health authority boundary matches that of the LEA. Here, responsibility for pupils with special needs lies with the Assistant Director (Special Services) who considers the policy shift to

inclusive education well advanced locally. Although there are staff responsible for SEN advice and physical access issues, no officer has a brief focusing on the wider group of pupils with chronic illness and physical disability.

There are a number of local multi-agency groups which have both LEA and NHS representation, both for planning children's services generally and in respect of interpreting SEN policy. At the time of the study, a local initiative was being piloted in which families with disabled children who are in contact with more than one agency had a parent-held record. Professionals in contact with these families from the NHS, LEA and Local Authority Social Services Department, along with staff from voluntary agencies, were being asked to make entries on these records. The aims of the initiative are to: improve the quality of information available to parents; improve the co-ordination of services; share information better between agencies; and help to establish the local register of children with disabilities (which is a requirement on Local Authorities under the 1989 Children Act).

#### *Site B*

The health authority purchases services for a population of 552,000, of whom 175,000 are aged under 19 years. The population is spread over a large geographical area, mainly rural in character, but including several market towns and one city. Services are provided geographically by five NHS Trusts, each with its own range of hospital and community-based services. One of the Trusts covers the city area, with the other four covering the rural and market town population. The HA has recently undertaken a review of nursing and therapy provision in schools across its whole area, which was largely quantitative but also revealed a need for closer co-ordination between health and education in both assessing and meeting children's special health needs at school. There are two LEAs within the HA area: one covers the city-based NHS Trust area, and the other LEA covers the four more rural Trusts. Given the large geographical area and number of Trusts involved, we chose to focus on two contrasting Trust areas: *B1 and B2*.

Area *B1* is the city. The local hospital offers secondary services for children and the local Child Development Centre is on the hospital site. The nearest hospital tertiary services are provided by hospital Trusts in another HA area, around 30 miles away. A consultant community

paediatrician is the 'designated medical officer' for SEN purposes. The LEA is part of a new (1996) unitary Local Authority which sees itself as building on a local consultative tradition, and is currently developing a Youth Council to encourage participation of children and young people in service planning. Responsibility for pupils with special needs lies with the Assistant Director (Pupils, Students and Parents). There is a Learning Support Teacher who has extended her original role of physical and curriculum access support for Statemented pupils with physical disabilities to include pupils with a medical condition, whether or not they have a Statement. In carrying out this role, she liaises informally between families, schools and health professionals in the local NHS Trust. Referrals come via a family or school contacting the LEA. There is a multi-agency joint forum for children's services, which includes representatives from education, health and social services. The forum has a remit for collaborative service planning, delivery and funding.

Area B2 includes a coastal town with a large rural hinterland. The local hospital offers secondary services for children. The nearest hospital tertiary services are provided by NHS Trusts around 40 miles away. The lead consultant community paediatrician is the 'designated medical officer' for SEN purposes: at the time of the study, he was attempting to establish a 'special needs register' for the Trust which would provide a central record of all children (from birth to 16 years) with a diagnosed medical condition, whether or not they have a Statement of SEN. The aims of the system are to access and track health information on these children as a group and, where a child is under the care of more than one medical professional, to allow doctors quick access to information on each other's diagnoses and treatment regimes. Also at the time of the study, funding and premises for a Child Development Centre were being sought by the lead consultant community paediatrician, with a view to simplifying access to services by families and improving co-ordination between service providers.

The LEA covers the wider county of which area B2 is a part. Responsibility in the LEA for pupils with special needs is held by the Head of the Pupil and Parent Services Unit. There is a support teacher at the LEA who provides advice on physical and curriculum access in schools for pupils with a physical disability, but no-one has a brief for children with chronic illness. Senior LEA

managers meet with paediatricians from the local NHS Trusts and a HA representative about three times each year, to discuss matters of common interest in service delivery.

## **2.3 PRELIMINARY MEETINGS**

The purpose of preliminary meetings was to put the research into context by gathering information on policy and services relevant to this group of children at national level and in the two research sites.

### **2.3.1 Meeting with DfEE and DoH**

A joint meeting was held between the research team and officers from DfEE and DoH in December 1996. Although neither Department is funding the study, establishing contact with key officers was important for raising our awareness of current policy concerns. During a wide-ranging discussion, sources of known variation in local service support emerged. Examples of variation included: interpretation of the Code of Practice on SEN where a child's special needs are primarily health-related; handling of confidentiality issues in school; the role of the school health service, in particular the school nurse; how teachers access information and support from health professionals; and the extent of inter-agency collaboration. The recent (1996) publication of the joint DfEE/DoH guidance, *Supporting pupils with medical needs*, was deemed important in clarifying roles and responsibilities for meeting needs at school. Officers expressed an interest in any feedback on the perceived usefulness of the guidance in practice.

### **2.3.2 Meetings with key health and education staff in the research sites**

Meetings were held with key health and education staff in the research sites to find out about: local policies and service plans relevant to children with a chronic illness or physical disability; the provision and funding of school-based services; and sources of health-related information and advice for school staff. The Health Authorities, NHS Trusts and the LEAs involved in the study all provided a copy of relevant local policy documents. At these meetings we also took an early opportunity to inform managers about the workshops and to ask them to identify staff who might be invited to these events.

In *Site A* we spoke with a Consultant Community Paediatrician and a Community Paediatrician from the NHS Trust. From the LEA we spoke to the Assistant Director of Special Services, a Disability Access Officer, SEN advisor and the Parent Partnership Co-ordinator. In *Site B1*, we spoke with the Director of Paediatrics, a Consultant Community Paediatrician and a School Doctor from the NHS Trust. From the LEA, we met with the SEN Development Officer, Learning Support Officer and the Parent Partnership Officer. In *Site B2* we spoke to the Consultant Community Paediatrician, a School Doctor (SCMO), the School Nurse Co-ordinator (jointly with a School Nurse) and the Speech Therapy Manager from the NHS Trust. From the LEA we met with the Head of Pupil and Parent Services, Planning and Commissioning Manager, Educational Psychologist, and Physical Disability Support Teacher.

Preliminary contact with health and education managers revealed some difficulties in identifying the number of pupils in mainstream school with a chronic illness or physical disability. In one LEA, an officer was able to compile such a list, but did so manually from her own records. Although LEA systems could identify pupils who had a Statement on account of a physical disability, information was not readily available on other health-related reasons for Statementing. LEAs also reported that they did not have systems for collating numbers of non-Statemented pupils who had special health needs. Indeed, it was thought that pupils with a chronic physical condition but without learning difficulties would not necessarily be placed by schools on their SEN Register.

### **2.3.3 Meetings with young advisors**

Given the lack of previous research in this field involving young people directly, an important part of the preparatory work was to ask young people themselves to identify issues they thought important, both in respect of the content and handling of interviews. In total, we worked with seven young advisors. At the early stage three young advisors (all female) were contacted through national support groups for young people with chronic conditions. The conditions represented were diabetes, cystic fibrosis and cancer, and the young women were aged between 15 and 23 years of age. During the course of these meetings, a draft topic guide for interviews with young people was devised. We also received advice on the process of working with young people, for example ideas for 'breaking the ice'.

A further four young advisors were recruited from our research sites to participate in pilot interviews. So as not to reduce the numbers of pupils recruited for main stage data collection, at the pilot stage we recruited pupils just outside our target age range. Two of the young advisors were 11 years old and on the point of progressing to Secondary school. One of these pupils was male with asthma and the other female with diabetes. The other two advisors were 17 years old, one of whom was male and had both cystic fibrosis and diabetes. The other advisor was female and had asthma. After each pilot interview the young advisor gave us feedback on the content and process of the interview and we refined our topic guide accordingly.

#### **2.4 THE RECRUITMENT PROCESS**

We began the process of recruitment by asking schools in the two research sites - A and B - to take part in the project. We took advice from the three LEAs involved as to how to proceed locally.

In *Site A*, the LEA nominated a member of staff to take responsibility for liaising with schools regarding the study. This person passed on letters about the research on our behalf. As a result, the research team did not have any contact with schools until they had agreed to take part in the study. In *Site B1*, the LEA agreed that the research team should liaise directly with all secondary schools and those primary schools thought likely to have pupils with special health needs. The research team wrote to these schools, inviting participation in the study. The letter mentioned that the LEA was supporting the project and that, in addition to the researchers, an LEA officer was available to answer questions about the research. This letter was followed up with a telephone call. In *Site B2*, the research team were invited to attend meetings for head teachers to discuss the research and invite schools to take part. This invitation was followed up a telephone call to confirm participation in the study.

The response to recruitment was as follows:

**Table 2.1: Number of schools recruited to the project by site**

Site	Secondary Schools	Primary Schools	Total
<b>A</b>	<b>(30) 10</b>	<b>(30) 9</b>	<b>(60) 19</b>
BI	(12) 7	(17) 5	(29) 12
B2	(13) 3	(19) 5	(32) 8
<b>B</b>	<b>(25) 10</b>	<b>(36) 10</b>	<b>(61) 20</b>
<b>Total</b>	<b>(55) 20</b>	<b>(66) 19</b>	<b>(121) 39</b>

( ) = number of schools approached

The overall response rate for schools was 32 per cent. When looked at separately, the recruitment rates for secondary and primary schools were 36 per cent and 29 per cent respectively.

Schools were asked to participate in two ways: to help with recruitment of families; and to send a representative to a teachers' focus group. We asked that the teacher nominated to attend the focus group had experience in supporting pupils with a chronic illness or physical disability. In practice, the teacher who had took responsibility for assisting the research team with recruitment was usually the person who attended the focus group.

Recruitment involved teachers completing a questionnaire (*see Appendix 1*) to provide anonymised information about pupils who met the study criteria: that is, that they had a chronic illness or physical disability with an impact on school life. Children meeting this criteria were defined as:

- children with serious, recurrent illnesses;
- children who require continuous health support during the school day;
- children who are technology-dependent;
- children with mobility difficulties;
- children with life-threatening conditions;
- children regularly absent from school, due to a chronic illness or physical disability;
- children who regularly have treatment requiring a stay in hospital.



We asked schools to include both children with and without a Statement of SEN. We did not include children with severe learning difficulties whom teachers felt would not be able to comprehend research questions concerned with service support.

At the outset of the project, it was our intention to recruit children at key transition points in their school career: children aged five, 11 and 16 years; equivalent to school years one, seven and 11. Such key points are times when there may be increased need for co-ordination between health and education services: starting school; transfer to secondary school; and possible school leaving age. Existing evidence suggests that these transitions are a source of potential anxiety for families in terms of securing adequate support (for example, Hirst and Baldwin, 1994; Wikler, 1981). However, a lack of detailed epidemiological evidence made it difficult to estimate the number of pupils with special health needs in these three age bands. As mentioned previously, meetings with health and education managers revealed that local agencies also had limited local information on the number of pupils with special health needs. Following contact with schools, it became apparent that there were insufficient numbers in these three years among the participating schools for us to meet our target levels of recruitment. Therefore, we widened our recruitment to include pupils in any school year who met the study criteria for chronic illness or physical disability.

Once the questionnaire identifying potential participants had been completed, researchers offered to visit each school to collect it, meet with the contact teacher and answer any questions about the study. Most schools accepted this offer. Those who did not returned the questionnaire by post.

To protect confidentiality, information packs about the research were then sent to families by school staff, without any names being divulged to researchers. Teachers adopted differing strategies in passing on information. While some simply posted on the information with a covering letter confirming the school's support, others opted to speak to families directly to encourage them to participate. Families wishing to take part in the project were asked to send a reply slip directly to the researchers including their name and address. Schools were asked to send one reminder letter approximately two weeks after the original invitation to take part.

For families with a son or daughter in secondary school, both parents and the young person were invited to participate. Separate information was sent to parents and young people. Young people were asked separately for their consent in addition to consent from a parent (see *Appendix 2* and *Appendix 3* for covering letters, information leaflets, response and consent forms for parents and young people respectively).

For families with a child in primary school, only parents were sent information and asked to take part, since very young children would have difficulty answering questions about service support. In the event, widening the criteria for participation did lead to recruitment of a few parents with older primary school children who might have been interviewed about service support. However, it would have been difficult to draw any meaningful conclusions from so few children in primary schools and so we decided not to alter our original research design.

## 2.5 PARTICIPANTS

### 2.5.1 Young people

A total of 33 young people of secondary school age took part in the study: 13 from Site A and 20 from Site B, representing a response rate of 36 per cent. Although this total falls short of our initial target of 40 young people it is sufficient for a qualitative research study. A breakdown of recruitment is as follows:

**Table 2.2: Recruitment of young people**

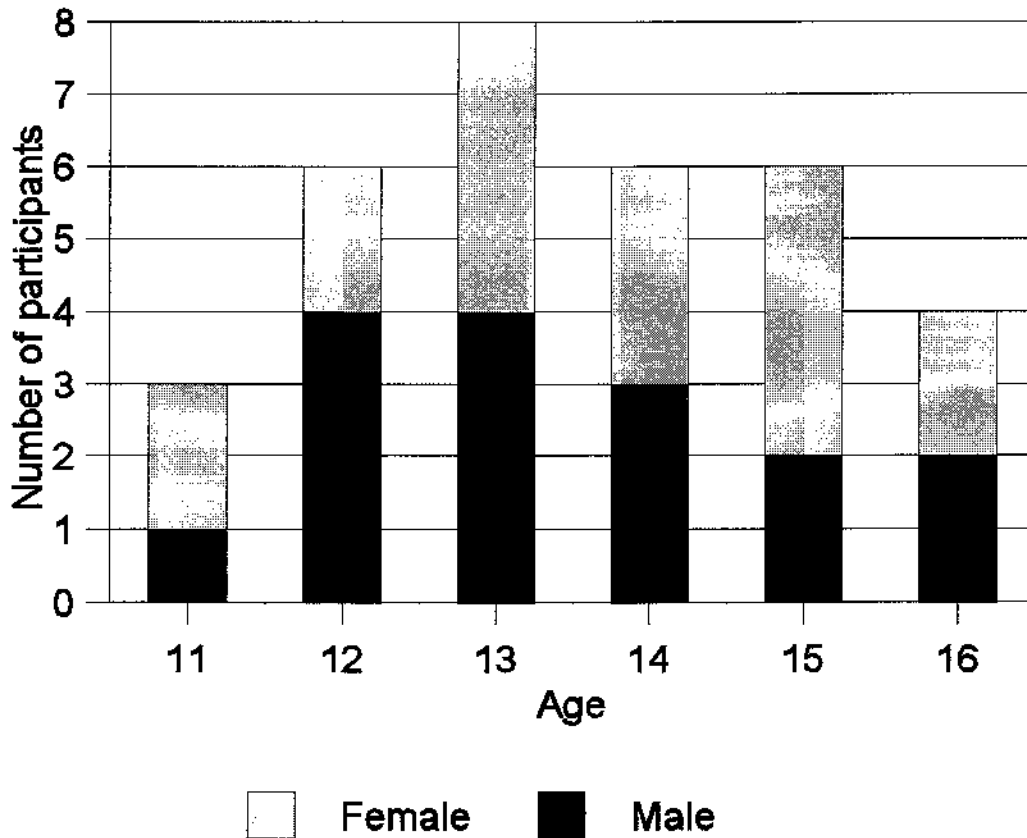
Site	Response
<b>A</b>	<b>(37) 12</b>
B1	(33) 13
B2	(21) 8
<b>B</b>	<b>(54) 21</b>
<b>Total</b>	<b>(91) 33</b>

( ) = the total number of young people approached

*Characteristics of the young people who participated in the study*

Of the 33 young people interviewed, 16 were male and 17 female. The distribution of participants by age and sex is shown in Figure 1.

**Figure 1: Age and sex distribution of young people interviewed**



A wide range of health conditions was represented among the participants (*see Appendix 4*). Fifteen of the 33 young people had had their condition since infancy. While the others had developed their condition at various stages of childhood, all the participants had a health condition which had been diagnosed for at least one year. Fourteen young people had a Statement of SEN. Eleven of the sample of young people had some form of extra support or assistance during the school day, to help with a range of health-related or learning needs.

### 2.5.2 Parents

A total of 58 families took part in the research: 26 from Site A and 32 from Site B. Target recruitment was 60 families: 40 'secondary' and 20 'primary'. A breakdown of recruitment is as follows:

**Table 2.3: Recruitment of families where a parent took part in the study**

	'Secondary' school families	'Primary' school families	TOTAL
<b>A</b>	<b>(37) 13</b>	<b>(21) 13</b>	<b>(58) 26</b>
B1	(34) 12	(8) 5	(42) 17
B2	(21) 8	(11) 7	(32) 15
<b>B</b>	<b>(55) 20</b>	<b>(19) 12</b>	<b>(74) 32</b>
<b>TOTAL</b>	<b>(92) 33</b>	<b>(40) 25</b>	<b>(132) 58</b>

( ) = number of families contacted

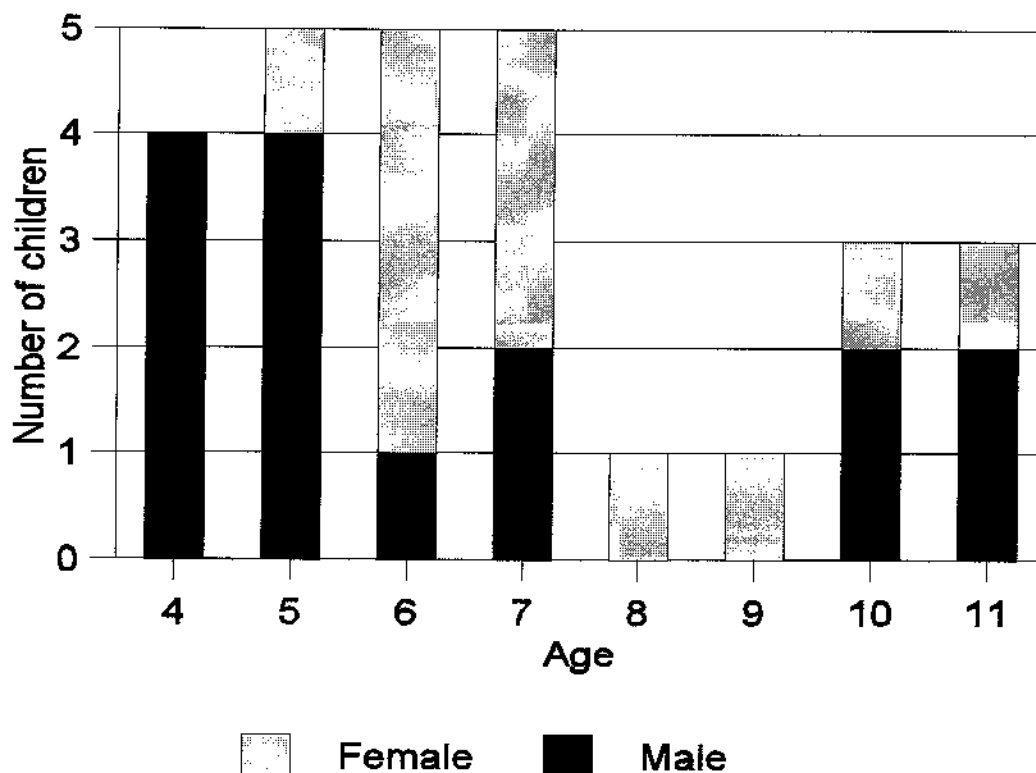
The overall response rate for parents was 44 per cent. The response rate was 36 per cent for secondary school families and 62 per cent for primary school families.

#### *Characteristics of parents who participated in the study*

For the most part, 'secondary' school families were parents of the young people recruited to the study. In Site A, the mother of a female secondary school pupil with diabetes was interviewed, whose daughter was a young adviser when in the final year at primary school (and so not part of the 33 young people in the main study). In Site B1, one mother took part whose child - with diabetes - declined. Conversely, a young person with charcot marie tooth disease took part, whose parents did not. In another case, a young person with diabetes took part whose mother had been interviewed during the previous school term when the child was still in primary school. This parent is included in 'primary' school families.

Twenty-five families with children of primary school age were also represented in the study. Between them these families had 27 children with a chronic illness or physical disability: 15 boys and 12 girls. The age and sex distribution of these children is shown in Figure 2.

**Figure 2: Age and sex distribution of primary school children whose parents participated in the study**



A wide range of health conditions was represented among these children (see *Appendix 5*). Thirteen children had a Statement of SEN.

### 2.5.3 Teachers

A total of 35 teachers, representing 34 of the 39 schools participating in the study, attended one of six focus groups. Most of those who attended were SENCOs (28). Others who attended included head teachers (two), a deputy head teacher, a head of year, a head of pastoral care, a class teacher, and a special needs assistant. Two of the SENCOs were also head teachers and two were deputy head teachers.

## 2.6 METHODS OF DATA COLLECTION

### 2.6.1 Data collection with young people

Our aim in collecting data with young people was to find out their needs for and experiences of service support in relation to school. Since the young participants had a variety of health needs,

were of a different ages, did not necessarily know each other and so might feel uncomfortable discussing their needs in groups, we decided that individual interviews would be the most appropriate method for gathering these data. All 33 young people were interviewed at home.

### *The interview*

Development of the content and structure of the interview was influenced both by our work with young advisors and by the literature on involving children in research (Beresford, 1997). The final result was a semi-structured interview which allowed young people to raise issues important to them. Interview topics included: feelings about school; the young person's condition and its impact on school life; sources (in or out of school) of support in relation to school; how they felt about this help and support and whether anything else was needed. (See *Appendix 6* for topic guide).

In developing and carrying out the interview, we bore the following principles in mind:

*The interview should empower the young person.* We wanted the interview to acknowledge the young person as expert on his or her own health condition. During the course of the interview the researcher reassured the young person that there were no 'right' or 'wrong' answers and that the researcher was seeking their advice on support in school. We also wanted young people to have control over the interview. As in interviews with adults, we made it clear that the young person did not have to respond to questions and could stop the interview at any time. We practised words with the young person that they would feel comfortable using to 'skip' questions and to stop the interview. In addition, we sought their permission to tape-record the interview and gave the young person the option of taking control of this equipment.

*The interview should avoid being problem-focused.* There is a danger in focusing on the difficulties young people encounter in school, that young people are not given an opportunity to discuss the positive aspects of school life. We sought to get a balanced view of life in school for this group of pupils by means of: beginning the interview by asking in general about life in school; asking about the impact of the condition in an open manner, for example 'what difference does

having [health condition] make to your school work?'; and probing as to whether anything positive had occurred in school as a result of their condition.

*The interview should be a enjoyable experience for the young person.* We decided to include a variety of techniques, to make the interview a more interesting experience for the participants. During the course of the interview, interviewees were encouraged to draw a diagram or 'map' indicating themselves at school along with any sources of help and support. Drawing the 'map' was designed to give young people increased control over the pace of the interview and enable them to express themselves non-verbally. A 'sentence completion' task was used towards the end of the interview, which provided the opportunity to: validate some of the earlier material; expand on comments about aspects of school life; and identify unmet needs. Using this range of techniques also meant that young people could be encouraged to use the medium with which they felt most comfortable, for example, drawing, writing, or talking.

### **2.6.2 Data collection with parents**

Our broad aim in collecting data with parents was similar to our aim in collecting data with young people, that is to identify and investigate what was working well and what was difficult about support for pupils with special health needs in school. While young people were asked about the support they needed for themselves, with parents we wanted to take a task-orientated approach in developing more general recommendations about service support for this group of pupils, including examples of good practice, as well as ideas on how any problems might be overcome. For this reason, a focus group format was considered appropriate. Group discussions give participants an opportunity to share their experiences and exchange different perceptions, which may lead to the formation of new ideas (Vaughan *et al.*, 1996), in our case about how to support this group of pupils.

We asked families who agreed to take part in the study to send one parent to a focus group meeting. Thirty-five families were represented at a total of eight focus groups. In most cases, it was the mother who attended, although both parents attended in three cases and in two cases only the father attended. Separate meetings were held for parents of children of primary and

secondary school age. The number of parents attending a meeting ranged between three and seven.

Practical arrangements to encourage parents to attend a meeting included holding group meetings in the local area, providing families with a taxi to and from the meeting and offering parents the option of attending a meeting either in the morning or in the evening. However, many parents found it difficult to attend a group meeting due to their family commitments. In order to ensure the views of all parents were included, we interviewed the remaining 23 parents in their homes. Almost all of the interviewees were mothers. In one case, a father was interviewed and, in two cases, a mother and father were interviewed jointly.

### *Parents' focus groups*

With recruitment generally low, we did not have the opportunity to pilot the topic guide with parents. However, we did pilot group work tasks with colleagues. In addition, researchers spent time at the end of each group meeting reflecting on the process and refining the task instructions in preparation for the next meeting. During our early meetings, we were assisted with this process by a student observer who gave us feedback on our facilitation.

Two researchers were present at each focus group, with one taking the lead in facilitating the group discussion, while the other took responsibility for practical arrangements, such as time-keeping and tape-recording.

Topics covered during the focus groups meetings were:

- Who helps this group of children in relation to school and what do they do? (including the role of families, health and education staff).
- Parents' evaluation of what is working well and what is working less well.
- Ideas for improving support.

The focus group meetings lasted for two and a half hours, and had two parts. The first part was concerned with parents' experiences, using the task of drawing a 'map' of sources of support. The second part was more evaluative, involving: a task in which parents talked about the different



emotions they had felt in relation to service support; a discussion about why parents were 'happy' or 'unhappy' with support; and ideas for improving services.

### *Parents' interviews*

The topic guide for interviews was developed after completion of the series of focus groups with parents. The overall aim was to keep the data gathered from interviews with parents as close as possible to that from parents' focus groups. However, there were two key differences between the individual and group topic guide. First, the opportunity to carry out some individual interviews meant that aspects of the group discussion could be explored further. In particular we wanted to: explore particular issues which emerged strongly in the group meetings (for example, the importance of emotional support); and to probe the level of importance attached to the school health service.

The second area of difference between the interview and focus group topic guides concerned the need to change the nature of the 'tasks' where these had been designed with group discussion in mind. Parts of the parent interview topic guide (see *Appendix 7*) were similar to the young people's interview guide, providing a more personal account of the child's health and its impact on school.

### **2.6.3 Data collection with teachers**

As with data collection with parents, the intention in collecting data with teachers was to take a task-orientated approach in generating recommendations about service support for pupils with a chronic illness or physical disability. Therefore, a focus group format was also employed with teachers.

Separate groups were held for primary and secondary school teachers in each of the three research areas (Sites A, B1 and B2). The cost of supply teacher cover to allow teachers to attend meetings was met by the project. The number of teachers attending each focus group varied between three and nine.

### *Teachers' focus groups*

The topic guide was developed after data had been collected from young people and parents. This sequence made it possible for us to gather teachers' perspectives on issues of concern to young people and parents, in particular teachers' access to information about a pupil's special health needs, and communication systems within school. Where possible, tasks found to be useful during the parents' meeting were adapted and incorporated into the teachers' focus group.

Topics covered during the focus group included:

- The extra help and support this group of pupils need in relation to school.
- The role of school staff in supporting this group of pupils, including what works well and what is difficult about this role.
- Information and support teachers receive from outside school, and what works well and what is difficult about this support (including parents, LEA and NHS).
- Ideas for improving support.

As with the parents' focus groups, it was not possible to carry out pilot work on the topic guide for teachers due to the small number of teachers available for participation in the study. However, the researchers did spend time reflecting on the success of each group meeting and refined task instructions accordingly.

Each focus group lasted two and a half hours. Participants were asked to draw on all their experience of supporting pupils with special health needs, not just the individual pupils involved in the study. As in the focus groups with parents, the task of drawing a 'map' was used to establish the various forms of support offered. The map was used as an *aide-memoire* throughout the session.

## **2.7 ANALYSIS**

All interviews and focus groups were tape-recorded and transcribed. A staged process known as 'framework' was used to analyse these qualitative data (Ritchie and Spencer, 1994). Stages included: familiarisation with the data through reading transcripts and, in the case of the data from young people, studying the maps and responses to the sentence completion task; identifying an

initial thematic framework; indexing the framework against transcripts and systematically charting the data; followed by interpreting the data through tracing patterns and associations, in order to identify over-arching themes. All transcripts were read by at least two of the three researchers in the team; themes were initially identified independently by each researcher and then a final framework was reached through discussion among all three members.

The data from young people were analysed first. In this case, the initial thematic framework was drawn both from *a priori* issues in the topic guide and emergent issues from the interview, including discussion about the 'map' of support in relation to school and responses to the sentence completion task. Data from parents, which included transcripts from focus groups and individual interviews, were analysed next. Since the focus groups were our main source of data, we charted these transcripts first. Once this was complete, we added the data from parents' interviews to these charts, checking whether any new themes emerged from the interviews. The one-to-one situation of the interview allowed parents scope to talk about all stages of their child's illness, including during pre-school years. For instance, several parents talked about their experience of diagnosis of their child's illness. However, no new relevant themes - that is, in respect of support associated with school life - emerged from the interviews.

In analysing the data from parents and teachers, we wished to investigate to what extent issues raised by the young people were reflected in parents' and teachers' views. Therefore, the framework for these data sets included themes which emerged from the young people's data, as well as *a priori* issues in the topic guide for parents and teachers and emergent issues particular to each data set.

## **2.8 WORKSHOPS**

### **2.8.1 Purpose**

The aim of the second stage of the study was that the project should go beyond data collection itself to consider the implications of the findings for developing good practice. To meet this aim, we wished to explore the research findings with experts working in health and education. We convened two separate one-day workshops, one for each research site *A* and *B*. At each workshop

we first disseminated the research findings and then delegates worked together to develop ideas and recommendations for improving services.

### **2.8.2 Recruitment**

We set a maximum of 20 delegates for each workshop, to promote active joint working. Our original research proposal envisaged that we might have two rounds of workshops, the first for professionals which would feed into a second round for managers. During the course of the study it became apparent that a single set of workshops including staff with professional and managerial roles would be more appropriate, for two reasons. First, attempting to separate 'professional' and 'managerial' issues may inhibit a broader discussion focused on children's needs. Secondly, such a separation proved difficult to sustain in practice for delegates with both professional and managerial roles.

The original research proposal also suggested that we might recruit a small number of parents and young people who had taken part in the study to attend the workshops. After careful consideration, we decided against this idea, since we wished to avoid the risk of family involvement being 'tokenistic'. Our primary aim from the limited workshop time available was to present the suggestions of family members to practitioners and managers who would also draw on their own expertise in developing ideas for moving services forward.

To recruit delegates, we returned to our preliminary senior contacts in the relevant agencies to ask for their advice on who would be appropriate and to secure their approval to release staff to attend a workshop. Potential delegates were contacted by telephone by one of the researchers. A follow-up letter with more information about the event was then sent, with a reply slip for delegates to confirm expected attendance. *Appendix 8* lists the job titles of delegates invited to both workshops.

The first workshop was held in *Site A*. Nineteen delegates were invited (nine education and ten NHS), 16 of whom were able to attend (seven education and nine health). The second workshop was held in *Site B* two days later. Seventeen delegates were invited (eight education, eight NHS

and one medical social worker), of whom fourteen were able to attend (seven education, six NHS and the medical social worker).

### **2.8.3 Format of the workshops**

Both workshops followed the same format:

#### *Morning*

- Introductions and background information on the study.
- Presentation and discussion of the research findings.
- Reflection in two smaller (single agency) groups on: the 'fit' between the findings and personal experiences; any important issues not raised by the study; identification of any aspects of local good practice.
- Feedback on small group work.

#### *Afternoon*

- Work in two smaller (mixed agency) groups to discuss 'what needs to change and how' in supporting pupils in mainstream schools with a chronic illness or physical disability.
- A final session with the whole group for feedback and to identify recommendations for national policy-makers in the DfEE and DoH.

The researchers did not participate in or observe the small group work. The whole group feedback and discussion sections were tape-recorded. Tapes, along with flip chart materials produced in the small group work, were used by the researchers to identify the results of each workshop. Before leaving the venue, the delegates completed an evaluation form (*see Appendix 9*).