CHAPTER THREE

RESULTS

3.1 FRAMEWORK FOR RESULTS

Throughout our interviews and focus groups, it was clear that young people were making efforts to attend school and be involved in its academic and social life. They were themselves actively managing the effects of their condition in school, but in order to do this optimally they needed support from others. The purpose of the research was to investigate young peoples', parents' and teachers' views on how service providers can best support pupils with a chronic physical condition and the framework for the analysis of data reflected this aim. The focus of the analysis was on aspects of school life which presented difficulties for young people, parents and teachers, and the support they needed and valued in relation to these difficulties.

Given the lack of previous research in which young people with a chronic physical condition have been asked for their views on service support, data from young people were given priority in the sense that issues of concern to young people were identified first. Next, the data from parents and teachers were analysed in relation to these themes, then any additional themes were added. Overall six major themes were identified: school absence; exclusion from school life; peer relationships; emotional support; a teacher who understands; and medical care. The first five themes were raised in all data sets, while 'medical care' was raised by parents and teachers but not by young people.

In presenting the results, we describe life in school for this group of pupils, outlining the concerns of young people, parents and teachers in relation to each theme, highlighting any differences in opinion. For each theme, there is also a section on participants' suggestions - or 'messages' - for education and health services, derived from asking participants about appropriate service support. Some of these 'messages' are about spreading existing good practice, while others stem from identifying gaps in meeting needs. Messages have been summarised so that they are general rather than specific to the needs of any individual pupil.

The anonymity of the research participants has been protected by attributing quotes simply to 'Pupil', 'Parent' or 'Teacher'. In the case of pupils, details of the young person's age are also given.

3.2 SCHOOL ABSENCE

Young people, parents and teachers all talked about the importance of attending school for academic and social reasons and had similar concerns about how pupils were supported during periods of school absence. The significance of absence from school was reflected in the efforts many young people made to prioritise school:

> I miss enough of it when I'm really poorly and I just enjoy it when I'm there, so if I've got a bit of a headache I don't tell anybody... I have off days but I don't really want to come home.
> (Pupil, age 12)

All young people had some time away from school for appointments with health professionals. In the most extreme cases, illness or treatment meant long periods of absence.

3.2.1 Academic implications of school absence

Being absent meant missing school work. In order to catch up, pupils used lunch times and free periods to work, made arrangements to prioritise particular subjects and asked classroom assistants to take notes in their absence. Friends helped by lending notes and explaining difficult work. While some pupils made a point of saying they were having no difficulty keeping up with work, a third felt that they were not getting the help they needed. School absence was of particular concern to older pupils due to sit public examinations:

> It didn't matter too much before...it was easy in the first three years...I could pick it up... But now there's no way I can handle all the GCSE course without doing all the work.
> (Pupil, age 15)

Generally, young people were dissatisfied with being left solely to rely on other pupils' notes to catch up with school work. Young people and their parents were also dissatisfied with difficulties in getting work sent home. Many schools did not have systems for sending work home automatically and teachers sometimes did not respond to their requests for work. Home tuition was appreciated by pupils who received it, although teachers and parents were concerned at how difficult it was to obtain, particularly for pupils who attended school on a part-time basis or whose need for such support was unpredictable.

3.2.2 Social implications of school absence

Pupils who had experienced long periods of absence mentioned losing contact with friends, not knowing their classmates or feeling uncomfortable around people their own age. Parents emphasised the importance of their children staying in touch with friends during periods of school absence, and their own role in making efforts to ensure social contact was maintained for their child.

School Absence: Participants' Messages for Education Services

In relation to school absence, support needs from school staff were identified both during absence and on return to school after a period of absence.

Help when absent

- Young people and parents felt that school staff should keep in touch with the pupil to counter feelings of isolation and to encourage him/her to return to school.
- Young people and parents called for a system and a teacher to take responsibility for making sure work is sent home or to hospital.
- Where the pattern of a pupil's illness results in frequent but relatively short periods of absence, parents and teachers argued for relaxation in rules about the waiting time before home tuition can begin.

Help re-integrating into school

- Teachers felt that pupils might find it easier to re-integrate into school life if there is a quiet place to withdraw to when feeling unwell rather than having to go home. Teachers from two schools spoke positively of having designated a room as a 'sanctuary' for pupils with special needs. It had proved particularly useful when re-integrating pupils into school after a period of absence as it allowed them to have time out of class without having to go home.
- Pupils needed help to catch up with school work; they wanted teachers to explain work they had missed; copying up notes is not the same.

School Absence: Participants' Messages for Health Services

Participants suggested a number of ways in which the NHS can help to minimise absence and assist pupils with returning to school.

Minimising absence

- Young people and parents appreciated the efforts made by some consultants to schedule appointments and treatment after school or in school holidays.
- Young people and parents who had hospital appointments valued arrangements for collecting prescriptions locally rather than prolonging time spent away from school by having to wait at the hospital pharmacy.
- Teachers urged the provision of therapy in the school setting.
- All types of respondent wanted pupils to have access to medical equipment (for example, nebulisers, equipment for monitoring blood) on school premises rather than having to go home to use it. It was suggested that the NHS loan such equipment to schools.

Help with returning to school

- Young people said they valued health professionals who encouraged them to feel confident about planning their return to school after a long absence.

3.3 EXCLUSION FROM SCHOOL LIFE

When in school, most young people had difficulty keeping up with some part of school life. They spoke about difficulties in relation both to the curriculum and to their social life in school.

3.3.1 The curriculum

Only four of the 33 young people who participated in the study felt that their condition made no difference to participation in class. Others said school work was difficult owing to pain, tiredness, or problems with motor coordination. It was important to pupils that teachers were aware of these difficulties, were flexible about the pace of work and gave them the appropriate extra attention:

> Some of the teachers, if I asked them to explain it they would just say 'it's your own fault for not being there' and I would say 'well it ain't my fault'.... I would like more help with the work. I just couldn't understand it sometimes cos I was in so much pain or just upset because I still had pains in my legs and teachers couldn't

> understand that, they just thought I wasn't bothering or sometimes they didn't try and explain the work to me and they'd say 'Oh, you know what you're doing'.
> (Pupil, age 13)

Ability to participate in class was also affected by school resources. For example, a pupil who needed computing equipment in order to take notes in class was unable to use this equipment for four months because of delays in school staff organising the replacement of a battery. Teachers also spoke of difficulties which arose regarding inclusion of pupils in classroom activities due to the lack of appropriate equipment. They reported that delays in pupils receiving equipment arose from lack of clarity between the NHS and the LEA about who was responsible for its purchase, maintenance and insurance.

Pupils appreciated the efforts some teachers and school doctors made to ensure access facilities and resources were available. The importance of professionals consulting pupils about their needs was highlighted by a pupil who reported that staff had not spoken to her prior to fitting ramps in school and had put them in the wrong place. Pupils using wheelchairs occasionally spent lessons in a separate room from their classmates due to access difficulties. Pupils disliked being left to work alone and were grateful to teachers who arranged for them to be accompanied by a friend.

Pupils who had mobility problems, or needed to avoid being knocked over, had difficulty getting from class to class. Getting around the building was made easier when pupils were allowed to leave class early and if friends and support assistants SNAs (PSAs) carried bags. Taking part in PE was difficult for pupils with mobility problems and for those who needed to take care not to put their health at risk, for example by taking part in contact sports or by being outdoors in bad weather. One third of the pupils we spoke to did not take part in such lessons. Only three young people said their condition made no difference to involvement in PE. Pupils were unhappy when forced to take part in physical activities they felt unable to manage:

> He had me running around the field. He had me walking, jogging, running and I said 'Sir I can't do this, I'm going to be sick', I was in such a state, I was blue... and I felt really poorly after. I was upset because I thought, well, all the teachers know, but they don't seem to care... I said 'I can't do this and if you make me do it I'll be seriously poorly'. But they still made me do it.
> (Pupil, age 14)

Young people appreciated the efforts made by some teachers to adapt lessons so that they could take part. Pupils appreciated being allowed to decide for themselves whether they were able to participate. When they were not able to take part in PE, they appreciated teachers who made constructive alternative arrangements, for example allowing them to use the time for physiotherapy, to catch up with school work, to take an additional GCSE, or simply to spend time with others also unable to take part in the lesson.

Teachers also had concerns about PE, reporting that they sometimes found it difficult to know whether to expect a child to take part. This was particularly problematic when health professionals were not specific about the child's capabilities, using vague terms such as 'avoid strenuous exercise' when writing to schools.

3.3.2 School social life

All the young people we spoke to except one said that their social life at school was restricted to some extent by their condition. Sometimes the child's condition was the cause of the restriction: for example, they felt too tired, or were physically unable to take part. However, problems with access facilities, having treatment during break times, and needing to go home on pre-arranged transport also prevented young people from getting involved in activities. A few young people, parents and teachers mentioned difficulties with school trips including: schools not being able to provide an additional member of staff to assist the child with special health needs; schools having a policy that staff should not take responsibility for medication; difficulties obtaining insurance, and the places visited not having appropriate facilities.

Young people were appreciative of any concessions teachers made to allow them to spend time with friends; for instance, they liked being accompanied by friends when having lunch early or when staying indoors over break time. They also spoke enthusiastically about teachers adapting extra-curricular activities, such as drama events and making arrangements to enable them to go on school trips.

Exclusion from School Life: Participants' Messages for Education

General recommendation

- Teachers recommended that all schools should have a basic minimum of adaptions - a disabled toilet, ramps and handrails.

The curriculum

- Young people wanted teachers to be flexible about the pace of their work (for example, to allow extensions to homework deadlines), and to take account of the impact of pain, tiredness and difficulties with concentration on their pace of work.

- Young people wanted PE teachers to talk to them about what they can manage, and to help arrange constructive alternatives when they cannot do PE.

School social life

- Young people and parents urged inclusion in all aspects of school life by adapting extra-curricular activities and school trips.

- Parents wanted funding for someone to accompany pupils with special health needs on trips.

Exclusion from School Life: Participants' Messages for Health Services

- Where therapy was provided in school, there were individual differences in whether pupils had therapy in class or social time. Flexibility and consultation with teachers and pupils about the timing of therapy services would help to avoid the timing of therapy sessions contributing to pupils' exclusion.

- Young people in the study attached great importance to health professionals teaching them to manage their own medication, since this enabled them to be able to take part in activities such as school trips.

Exclusion from School Life: Participants' Messages for Education and Health services

- Teachers and parents wanted health and education services to clarify who is responsible for the funding, purchase, maintenance and insurance of equipment needed by pupils with special health needs to access their education.

3.4 PEER RELATIONSHIPS

Young people talked about the impact, both positive and negative, that their condition had on their relationship with peers. Just over a third mentioned being bullied on account of their condition. For most pupils bullying consisted of verbal abuse, such as being laughed at and name-calling. Two young people spoke of physical abuse. A few young people seemed somewhat isolated, mentioning being ignored by their peers or the difficulty of 'fitting in' when they returned to school after a long period of absence.

Pupils perceived that they were bullied when they were seen to be different from other young people, for instance; if they coughed frequently, took tablets, used a wheelchair, appeared different physically, needed help from a classroom assistant, or had special equipment. Teachers treating the pupil differently, such as allowing them to break school rules or treating them like the 'teacher's pet', could also lead to problems.

Young people reported a number of strategies for dealing with bullying. These included ignoring the bully, 'laughing it off', or avoiding situations likely to lead to bullying. Examples of avoidance included not wearing glasses in school, not wearing splints, not doing sports, and staying away from school. Some young people retaliated, for example by making the bully feel guilty for picking on an ill person.

Some young people thought that teachers could help them with their peer relationships by being discreet about their illness or disability in front of other pupils, and by intervening when they were bullied. Many pupils were unhappy about being asked questions by peers who were curious about their condition. Peer curiosity was problematic because it meant spending a lot of time answering questions, particularly at the start of the school year when there was an influx of new pupils. Some young people also tried to avoid this situation by not drawing attention to themselves, for instance, taking tablets privately.

Although a considerable number of pupils reported difficulties with peers, they also developed close friendships in school. Friends helped young people deal with curiosity, by explaining the condition to those who asked and with bullying by 'sticking up' for the young person. They also helped in a number of other ways: with crisis tasks, such as alerting others when the young person needed medical attention; providing ongoing physical care, such as carrying bags and pushing wheelchairs; being someone to talk to about health-related worries; helping to keep up with school work; and keeping in touch with the ill child when absent.

In turn, young people drew attention to the reciprocal nature of their friendships, talking about the types of support they were able to offer friends. For example, one young man who had spent time in a wheelchair talked about helping his friend with dyslexia:

> He helps me physically and I help him mentally, so we get on very well.
> (Pupil, age 13)

Young people's views on the impact their condition had on peer relationships were reflected in data from parents and teachers. Parents spoke about the difficulties experienced by their children and also about school friends as a valuable source of support. Teachers and parents felt that difficulties with peers tended to be more prevalent in secondary schools since older pupils were more aware of being 'different'. Both teachers and parents wanted peers to have information about the child's condition since this might encourage them to adopt a more supportive role. However, there were individual differences between young people as to whether they wanted peers to know about their health support needs. The reasons young people gave for wanting their peers to know about their health condition included: that it would mean peers would know what to do in an emergency; that they might take care, for instance, with physical contact; and that they would generally be more understanding. Reasons for not wanting peers to know were that peers did not need to know, and a desire to maintain privacy. Whether or not young people wanted their peers to know about their condition, they were anxious to minimise the amount of attention being drawn to ways in which they were different from other pupils. For those pupils who wanted their peers to know about their health condition, visits from a health professional to school to help with explanations and answer questions were valued. Among our sample, only those pupils who attended specialist facilities for their condition, for example renal failure and hemophilia, appeared to have access to outreach nurses providing this kind of service.

Peer Relationships: Participants' Messages for Education Services

- Young people wanted teachers to be discreet when referring to their health condition in front of other pupils and not make a fuss when making special arrangements in school.
- Young people wanted teachers to intervene if they were bullied.

Peer Relationships : Participants' Messages for Health Services

- Children who wanted other pupils to know about their condition found support from health professionals helpful in explaining their condition. Pupils differed in whether they wanted health professionals to talk to the class on their behalf or wanted help in preparing to do this themselves. It follows that the type of support needed should be negotiated with individual pupils.

3.5 EMOTIONAL SUPPORT

Almost all of the young people in the study spoke positively about support from individual teachers. Such support was usually provided by SENCOs or pastoral care staff, and included being asked how they were feeling and acknowledging when they were absent due to illness. Just over a third mentioned having a teacher they could talk to about worries. A few teachers took an active role in supporting pupils, for example encouraging pupils to return to school after a period of absence, and nominating a pupil for a school bravery award. Pupils were highly appreciative of this support:

> When I first went back, he kept taking me into his office, just asking how I was, just letting me know he was there... it would be better for everyone in my situation if they had someone like that.
> (Pupil, age 15)

and

> You can go to them if you've got any problems or anything and they'll listen to you and you can just go there at lunch time or whatever and talk, which is good.
> (Pupil, age 15)

However, a few young people had difficulty getting such support from teachers, pointing out that they did not always feel comfortable talking to the person they were told to go to if they had problems. Four young people commented that they felt SENCOs were more helpful to young people with learning difficulties than to those with health-related needs.

Parents and teachers felt it extremely important for children to have emotional support. Teachers were particularly concerned about helping pupils come to terms with their difference from other pupils, as difficulties with this were thought likely to lead to behavioural problems in school. However, both teachers and parents expressed concerns about whether school staff had the necessary counselling skills to provide this support. Teachers from large secondary schools were also worried that they did not always have the time to offer such support. Teachers from primary schools pointed out that, since it was usual for class teachers to take responsibility for emotional support, there was a gap in support during non-class time. Primary school teachers thought that this situation was different from secondary schools where formal systems of pastoral care might cover this gap.

Young people, parents and teachers had differing views on who should provide support. Some teachers mentioned that school nurses offered weekly ‘drop-in’ clinics for pupils. They felt that this service probably reduced the number of pupils who approached them with health-related worries and that pupils probably preferred to talk to a school nurse about health issues. However, only one of the young respondents said that she spoke to a school nurse and made a point of saying that this nurse happened to be an expert on her condition whom she had first known in the nurse’s previous job in hospital.

Overall, young people saw the school nurse as having a specific role of carrying out general health checks on all pupils, and not as someone to talk to about health-related worries. Since school nurses were rarely available at times when pupils could speak to them, for example over lunch breaks, young people felt that it would be difficult to build up a relationship of trust which would be needed to confide in someone. Similarly, very few young people reported contact with school doctors outside annual reviews of Statements. Two pupils who had seen their school doctor or nurse were surprised to discover that these professionals had very little knowledge about their individual case or treatment. As a result, they had decided not to approach these professionals for help in future. Young people talked about seeking out a sympathetic teacher for emotional support, based not on their formal role but on their personal qualities, in particular, as someone who takes a personal interest in them, for instance by asking how they are feeling and by keeping in touch when absent.

In two of the teachers' groups, participants mentioned the need for emotional support for school staff, to help them with bereavement and with teaching pupils who have life-limiting illnesses. For instance, one teacher spoke about a pupil with muscular dystrophy:

> I look at him every day and I can't bear to think of a future for him, whether he'll see his school days through. There are times when it's not just the family, the teacher has to deal with it. Sometimes teachers need support, it's a terrible position to be in.
> (Teacher)

Part of this terrible position was knowing how far to push the child, for instance, how important was it to bother about homework? At one focus group, teachers talked about the value of the support they had received informally from a local educational psychologist in helping staff and pupils to come to terms with the death of a pupil.

Emotional Support: Participants' Messages for Education Services

Support for the pupil

- Parents recommended that someone in school should provide emotional support, performing two key roles:
    - listening to children's worries, giving advice and reassurance where appropriate;
    - acting as a mediator when the child has problems with peers, parents or school staff.

To carry out this role, parents suggested that this person would need to be knowledgeable about the child's condition and be able to maintain confidentiality.

- Both parents and teachers recommended that, as part of school policy, there should be a named person to whom pupils could turn for emotional support.

Support for the school community

- Teachers recommended that schools should be offered support in coming to terms with the death of a pupil.

Emotional Support : Participants' Messages for Health Services

- Teachers suggested that schools be added to the list of contacts for outreach workers visiting home in cases of terminal illness or bereavement.

3.6 A TEACHER WHO UNDERSTANDS

3.6.1 The importance of a teacher who understands

One of the strongest themes to emerge from the data was the importance of having a teacher 'who understands'. These were teachers who understood the impact of the child's condition on their life in school and took action, making the appropriate special arrangements without 'making a fuss'. Pupils gave examples of teachers who 'understood': they allowed pupils to leave class to sort out medical problems; they adapted lessons so that pupils they could participate; and they were flexible about homework deadlines. Although young people had differing views on whether they wanted their peers to know about their condition, they all felt it important for teachers to be aware of their special health needs:

> I don't want the whole school to know, just teachers really.
> (Pupil, age 15)

> I'd prefer to keep it private but I think it's better if the teachers know.... just in case I get poorly.
> (Pupil, age 13)

When teachers did not understand the child's condition, young people and parents reported a wide range of problems. A few pupils were forced to take part in physical activities they felt unable to manage. Pupils with continence difficulties talked about being refused access to the toilet:

> In class she embarrassed me totally - 'Why do you need to go to the toilet? Are you on something?' What do I say? I'm always needing the toilet... it's not my fault.
> (Pupil, age 14)

Pupils with ME and juvenile arthritis talked about teachers not believing that they were ill, reporting that teachers made comments such as:

> I don't care if it was national ME week the other week, you're still making it up, it doesn't exist, it can't exist, it's impossible for it to exist.
> (Pupil, age 13)

A pupil who had major surgery to her legs, and another with a cranial tumour (prior to diagnosis), talked about teachers not believing they had symptoms such as pain, tiredness and nausea.

Teachers sometimes misinterpreted the child's failure to complete work. Parents reported instances where their child had been punished for handing work in late without consideration of the circumstances under which the work was done.

Teachers' lack of awareness could also have an impact on a pupil's health, with parents and pupils reporting occasions when they had been refused access to medication or that their usual treatment regime was disrupted by teachers who were unaware of their needs. For example, a mother of a child with diabetes told us:

> She has a pass to go into first lunch at school. The domestic science teacher insisted that she clear up all this other girl's stuff so she was running late. She said 'please miss, I've got to go because....' 'I'm not hearing any excuses', she [teacher] said. So immediately she was in a panic, her blood sugar goes really high and now she's feeling sick and then she's got to come home.
> (Parent)

The importance young people placed on having a teacher who understands is well illustrated by the following comments:

> The more people know, the less mistakes are made... ignorance is the root of all the problems I've had, it's people with a lack of knowledge that have made it difficult for me.
> (Pupil, age 16)

Parents and teachers of primary school pupils were much less concerned about teachers' understanding. Difficulties in communication, central to promoting understanding, seemed to be a feature of secondary school, and related to the number of people involved.

Young people and parents felt that teachers' awareness of pupils' needs depended on the visibility of the condition. They reported instances where teachers had commented that staff had difficulty believing a pupil was ill because they could not see anything wrong. One mother felt staff were unaware of her son's needs because of the efforts he made to cover them up:

> Even if his fingers are bleeding he'll carry on writing because he's determined not to be any different from anybody else. I mean I can come home any night and he just grinds to a halt and he's a wreck, you know he's crying and saying 'I can't cope another day', but he does get up in the morning and he'll carry on. I mean to look at him most days, you wouldn't think there was anything wrong, but to me he's not getting the help he needs in school.
> (Parent)

3.6.2 Sources of information for school staff

In order to raise awareness about a pupil's special health needs within a school, someone in the school needs to be informed about the pupil's condition. Overall, teachers felt strongly that their need for health information was largely unmet. Project participants spoke in detail about the various sources of information for school staff: the child's previous school, parents, health professionals and the LEA. Details of what worked well and of problems raised are outlined below.

The child's previous school as a source of information

Secondary school teachers were concerned about arrangements for transferring information from primary to secondary school. Unless a child had a statement of SEN, there was no system in place for drawing attention to a child's special health needs. Staff were dependent on primary school teachers being proactive in drawing attention to children's health needs among other information being passed on. In addition, information provided by primary schools was often insufficient, for example it might not include current arrangements in school for dealing with a pupil's needs.

Parents as a source of information

All types of project participant saw parents as taking lead responsibility for ensuring school staff had relevant information about their child. Parents explained the educational implications of the condition, gave advice in dealing with emergencies, and provided training on medical procedures to be carried out in school. Parents also acted as mediators, resolving problems caused by teachers' lack of understanding about their child's needs. The capacity of individual parents to take on this role could have far-reaching consequences in terms of their child receiving support. One young person reflected upon the differences between the support she received in school and that received by another pupil with the same condition in the same school:

> But his Mum's quite forthright so I would imagine she gets things done, but my Mum is sort of quiet and mousey so she sort of doesn't... There's a big gap for people if you don't shout loud enough... then you don't get the help you need. I think you shouldn't have to do that, it should be there for you... you shouldn't have to throw a tantrum to get work home and stuff like that.
> (Pupil, age 15)

Teachers felt that most parents could provide them with the information they needed. Many talked about it being beneficial to meet with families to get specific information. Also, meeting parents gave teachers an insight into the family's attitude to the child's condition, which was important if teachers and families were to support the child in a consistent way. However, our research also revealed important difficulties in parents taking on the role of information-giver. First, both parents and teachers thought that not all parents were necessarily willing to pass on information. As one parent put it:

> Thankfully we're all caring parents, what about the poor kids who have an illness and the parents aren't bothered to phone up and ensure this, that and the other?
> (Parent)

and

> We co-ordinate things, we do that role.... but there are a lot of parents who wouldn't have a clue who needs to know what, where and when.
> (Parent)

Secondly, in the often stressful circumstances of a consultation with a doctor, parents could have difficulty recalling or even understanding everything that had been said to them and so might feel unable to pass on all information. In this situation, parents reported wide variation in support from doctors, including instances of good practice, where health professionals helped them by tape-recording consultations and sending them letters summarising the discussion.

Thirdly, some young people and parents argued that school staff did not always take seriously their advice on health issues and that information and advice was needed from health professionals:

> Then they have the doctor's notes, not just my Mum's word for it.
> (Pupil, age 13)

Fourthly, teachers said they needed professional advice on the specific implications of the child's condition for school and did not want to have to go through parents to access this. There were three reasons for not wanting to go to parents for this information: teachers felt the technical information they needed could only be provided by a health professional; they did not want to over- burden parents; and they did not want parents to think school staff could not cope with their child.

Given parents' responsibility for providing school staff with information, it was important that parents and teachers developed good relationships. Parents of primary school children were all positive about their contact with school staff, talking appreciatively of teachers asking how they were coping and of having regular meetings with SNAs and teachers. However, parents of children in secondary school had experienced difficulties in liaison with school staff, where they were not able to 'just pop in' in the way that had been possible when their child was in primary school. Parents were unhappy when they wrote to teachers requesting help and received no response. Some parents had experienced difficulty getting appointments to see the school SENCO, and of teachers speaking to them as if they were 'a child'. However, there were also instances in which secondary school teachers and parents had developed a very supportive relationship, with parents talking appreciatively about teachers who telephoned the home to enquire about their child, or made visits to the child in hospital.

Parents talked about systems of communication they found helpful. One of these was where SNAs and parents stayed in contact by writing notes to each other, passed on by the child. Another useful arrangement was for parents to carry bleepers so that they could be contacted in an emergency. More informal or personal relationships with some teachers were valued by parents:

> I make a point of calling them [teachers] by their first name... it's more personal, it's not a professional compromise, it's something we have in common. They supervise..... six hours a day and the rest of the time he's mine..... they started it [calling by first name]. It helped me approach them. I can have a laugh and a joke, it makes it easier to convey my problems or any difficulties or whatever, there's no figure of authority obstructing it.
> (Parent)

Some teachers saw themselves as a resource for parents - offering a sympathetic ear, and helping them to deal with NHS professionals, for instance by writing reports for parents to take to meetings. However, teachers also felt that some parents could at times be over-demanding. For instance, parents expecting to talk at length to teachers on a daily basis was inappropriate in a mainstream school setting.

Teachers described ways in which they had tried to improve their relationship with parents. One SENCO spoke of organising an open day for parents whose children had medical needs and were about to transfer to the school, and being inundated by parents anxious to discuss practical arrangements. The SENCO found the meeting invaluable in providing her with information about the children before they entered the school and in making her aware of parents' concerns. A SENCO from another school had arranged for parents to have the direct telephone number of the special needs department so that they could contact staff quickly.

The LEA as a source of information

Generally, teachers felt that it was easier to obtain information and advice from the LEA than from the NHS because they knew who to contact and most staff were quick to respond to requests for information. Some teachers felt that the LEA had been helpful in providing documents listing contacts. They also appreciated LEA training courses for SNAs, although they were sometimes difficult for schools to afford. However, teachers pointed out that LEAs were not always able to give them advice and information about medical conditions. Therefore, contacting the LEA was seen by some teachers as a waste of time, as the outcome was usually a referral to the appropriate health services. This additional layer of communication would not be necessary if school staff had better direct links with NHS professionals.

Health professionals as a source of information

Due to the difficulties in parents acting as information-givers, both parents and teachers argued for improved direct communication between health professionals and teachers:

> The health service sit in their little castle and school sit in their castle and it's Mum and Dad in the middle saying 'For God's sake, will you tell them what is happening and will you tell them what you need to know so that they can tell you what is happening.'
> (Parent)

and

> The paediatrician, he gets all the letters in from everybody else, well why can't a copy of everything go to the school, and like you say have a staff meeting. It would save hours of the parent's voice box.
> (Parent)

Teachers were concerned both about the *type* of information they received from health professionals and the *process* of communication. The main difficulty reported by teachers about the type of information received from health professionals was that it was not specific enough about the implications for school life of an individual child's condition. For example, the school might be told that the child should 'avoid strenuous exercise'. Teachers found such vague phrases difficult to interpret. It was important that information was clear so that teachers were neither over-cautious nor pushed the child to do too much. Details of the information teachers wanted are outlined under 'messages for health services' at the end of this section.

Teachers felt that communication between health and education professionals should be a two-way process. However, health and education were seen as two separate worlds. Teachers were concerned about the lack of opportunities for school staff to pass on relevant information to health professionals. They felt that their knowledge of the child in his or her everyday life was under-utilised by many health professionals who saw children in the less familiar context of hospital and clinic. In addition, they described as a constant struggle their efforts to obtain information from health professionals. Part of this struggle was due to confusion about the respective roles of health professionals in giving advice to school staff. For example, what is the role of the school doctor where a pupil has health needs but no learning difficulties? Should teachers be approaching GPs for advice? Questions such as these were common during focus group meetings.

Participants made specific comments about four sources of information involving health professionals: the school health service; therapists and nurses who visit school; hospital-based health professionals; and multi-agency meetings.

The school health service. For teachers, the school doctor was their first point of contact with health services and provided valuable input to Statementing procedures. However, discussion at teachers' groups brought out wide variations in the level of support offered by school doctors in relation to pupils with special health needs. Teachers described the service they received as dependent on the individual personality of the school doctor and the length of time they had known each other. For example, one teacher who went to her school doctor for advice on PE reported that she was refused help on the grounds that this information was confidential, whereas other teachers talked of their school doctor passing on any information made available to them, and about the valuable role their school doctor played in alerting schools about pupils with special health needs who were about to transfer to the school.

Overall, parents and teachers considered the school doctor's role in offering advice to school staff as limited, for three reasons. First, school doctors were not seen as having up-to-date medical knowledge on at least some of the health conditions now prevalent in mainstream school, for example, the medication regime for cystic fibrosis. Secondly, the school doctor might not have access to the child's medical records and so have little information about his or her condition and treatment. Thirdly, although school doctors could liaise between teachers and a child's consultant, delays were common:

> You go to the consultant and he writes a letter to the school doctor, the school doctor maybe gets a letter a fortnight later, she then writes to the school. Meanwhile four weeks have lapsed so it's easier to just come down to the school and tell them cos even then the class teacher isn't forced to know anything.
> (Parent)

Parents and young people also had concerns about school nurses' expertise in relation to their child's condition. There were also examples of school nurses being unaware that a child had special health needs, even if the child had a Statement. The provision of training sessions by school nurses in common conditions such as asthma, diabetes and epilepsy was mentioned in only one teachers' meeting, and by one parent. At one of the teachers' groups, there was an example of good practice with teachers talking positively about a change in role for local school nurses who had moved from a fixed-point inspection service to a more pro-active, co-ordinating role between families, school and NHS staff. A teacher in the group commented that this had been:

> ....one of the most supportive developments in the area recently. Prior to that [teachers] had much more of a struggle because the medical side, schools and parents were all separate.
> (Teacher)

Concerns about the support offered by the SHS led teachers and parents to call for more direct contact between school staff and the health professional with lead responsibility for the child's medical care.

Therapists and specialist nurses who visit school. Teachers reported that they were generally well supported by specialist nurses and therapists who visited the school. The fact that these people came into school regularly provided opportunities for developing a rapport, and made it easy to access specialist information and advice. Also, liaison between school staff and the therapist provided learning opportunities for school staff to carry on treatment regimes.

Hospital based health professionals. Both parents and teachers reported variation in the extent to which individual hospital based professionals passed on information, either directly or through parents, to school staff.

Teachers reported a number of reasons why they were dissatisfied with liaison with hospital based professionals :

- Teachers always had to be proactive in requesting information from hospital-based health professionals.
- Teachers did not always know who to contact for advice, particularly when the child did not have a Statement (which provides named contacts).
- Even if teachers managed to contact the appropriate health professional, information might be refused on the grounds of confidentiality.
- When teachers provided health professionals with information for assessments, they rarely received feedback.

In terms of good practice, teachers spoke about how useful hospital clinic open days were for overcoming some of these difficulties. Open days allowed teachers to establish contact with nurses and therapists whom they could approach in future if they needed advice. Another positive example of support was a multi-disciplinary health team which had prepared a letter and booklet for school staff explaining the support a pupil would need following surgery. This was given to the mother to pass on to the school. Young people were also appreciative of instances where health professionals updated school staff routinely on their progress. As one young man explained:

> He [consultant] was good... he wrote letters to the schools and informed them what was happening all the time. Just what he was telling me, every letter that he sent, he sent a copy to the school and so they knew what condition I was in.... so they knew what was happening.
> (Pupil, age 15)

Multi-agency meetings. When the child had a Statement, teachers had the opportunity to attend multi-agency annual review meetings. Although the school doctor's assistance in securing resources was valued, a number of teachers were unhappy that health professionals actually providing care for the child did not attend annual reviews. The school doctor was considered by teachers as a poor substitute as s/he often did not have access to the child's medical records. In one instance, the child's lead health care professional, a GP, had attended the annual review but had later sent the school a bill for the consultation. The LEA had since advised the school not to invite GPs to future meetings.

Teachers who had attended other multi-agency meetings were positive about the experience, describing the rare instances when they had taken place for non-Statemented children as 'amazing... brilliant'. Such meetings gave teachers a better understanding of the child's situation and uncovered inconsistences in approach between agencies. However, teachers reported difficulties in attending these meetings on account of their classroom responsibilities.

3.6.3 Communication systems within school

Young people, parents and teachers were concerned about the difficulty of ensuring that all staff were aware of the pupil's needs. Participants were particularly concerned about the difficulty of ensuring that new staff, supply teachers and students knew about a child's condition.

Teachers discussed the systems their schools used for passing on information about pupils' health-related needs. A wide range of approaches emerged. These approaches are outlined in Table 3.1, together with any advantages or disadvantages identified during the course of teachers' focus groups. There was a lack of consensus at meetings about the optimum approach.

Table 3.1: Communication systems in schools for pupils' special health needs

No system	Some teachers said that their school had no system, describing it as 'hit and miss' or at the discretion of the head teacher to decide whether information should be passed on.
Word of mouth	All primary schools and some small secondary schools talked about passing on information verbally to any member of staff who needed to know. This could happen informally at break times or at staff meetings.
Incorporate information into other systems for all pupils	Other schools reported using established information systems to circulate information about special health needs. These included class lists, pastoral care records and annual requests for information from parents. *Disadvantages* Difficult to ensure the child's needs were noted among the mass of information.
Adapting existing systems	
a) using the SEN register	In some schools, the SEN register was used to raise awareness about a child's special health needs. In some cases, a formal decision was made to include any pupil on the register who had needs which had an impact on school life. In others, entry on the register was *ad hoc*, based on whether the SENCO thought other staff should know.
b) using the individual education plan (IEP)	Two SENCOs mentioned that they had adapted the child's IEP record so that all staff teaching the child were required to comment on how they would meet the child's health-related targets. *Advantages* This systematically ensured that all staff were aware of the child's needs. In addition, the records could be used to reassure parents that all staff had been informed about their child's condition.

Dedicated medical register	A number of teachers reported having a dedicated medical register. These lists were considered highly confidential so were either held centrally or circulated to those who 'needed to know'. *Disadvantages* It was difficult to ensure that all those who needed to read the register did so. Some teachers reported that their school had decided not to employ such a system because of concerns about confidentiality.
School notice boards	Some schools used staff notice boards to display information and photographs of pupils with special needs. *Advantages* Useful in large schools as enabled teachers to put a face to a name. *Disadvantages* Some teachers were concerned that this was breaching confidentiality as such rooms were used by school visitors.
Special training events	For children whose needs were less obvious, special training events could help to refresh memories and inform new staff. Where provided, these were usually run by specialist nurses and therapists.
Empowering the child	Due to difficulties in ensuring staff read written records and remember the information they were given, some teachers considered it good practice to help the child inform others directly about their special health needs. One way of doing so was to give the child a laminated card with details of any special arrangements approved for them. This was shown to any teacher who needed to know about these arrangements. In addition, one teacher talked about encouraging children to feel confident to enough to tell school staff about their special health needs. *Advantages* Such approaches were considered particularly helpful when the child was being taught by a supply teacher or student, who might be particularly unlikely to be aware of the child's condition.

One of the reasons why awareness-raising seemed to be difficult for this group of pupils was that, when pupils did not have a Statement, there was no clear policy in schools about which teacher was responsible for their needs. In most schools, SENCOs took responsibility by default, because other staff assumed it was the SENCO's responsibility. Comments such as the following were not uncommon:

> I'm not sure whether or not I'm that responsible person. I think it's the pastoral care side of school and I know some SENCOs take that on board, but I do tend to get landed with a lot of stuff. And that's bad in itself, that I'm not clear as to whether I am properly responsible or not.
> (SENCO)

The SENCOs involved in our study had concerns about taking on responsibility for this group of pupils. They pointed out that most SENCOs were also class teachers and so had limited non-contact time, which made it difficult for them to liaise with people outside school. In addition, they felt that colleagues had unrealistic expectations: often they assumed SENCOs had medical knowledge and could deal with any health-related problem that arose. Often SENCOS felt they had not been trained to take on such responsibilities. As one SENCO commented:

> People assume you're an expert. It's a quite unbelievable job in that sense... people expect you to be aware almost like a medical person of what [condition] involved and how to treat it and how it's going to affect the child in school.
> (SENCO)

In summary, ensuring that teachers have a good understanding of pupils' special health needs is multi-faceted, requiring attention to the quality of information made available to school staff, the systems in place for passing information on to schools, along with the systems *within* school for circulating information to staff. Project participants' suggestions about improving practice in these three key areas are outlined below. As for previous themes, messages for education and health services are presented separately.

An Understanding Teacher: Participants' Messages for Education Services

Communication between schools

- Teachers recommended that it should be compulsory for schools transferring pupils to draw attention to special health needs and any special arrangements in place. It was suggested that this might be done by appending details to the child's file on transfer.

Communication within school

- Young people, parents and teachers all recommended action to raise awareness among staff, especially for non-Statemented pupils where systems are not necessarily in place. It was suggested that every school should have an information system which ensures that all school staff know about the pupil's health condition, its likely impact on school life, and any special arrangements that have been made.

- Young people, parents and teachers all commented that, whatever the information system, some teachers might refuse to believe that a pupil was ill. Young people said that someone was needed in school to act as their advocate.

- Parents and teachers recommended that schools clarify who is responsible for co-ordinating special arrangements for pupils with special health needs and making sure that other staff know about such arrangements.

- Teachers recommended that whoever takes responsibility for coordinating support within school for this group of pupils needs sufficient non-contact time and training.

Communication between parents and teachers

- Prior to school entry, teachers urged the introduction of a model of good practice in which a member of staff sets up a meeting for parents of incoming pupils with special health needs.

- Parents recommended close liaison after school entry, through regular meetings between the pupil, parents, and school staff responsible for the pupil's welfare to discuss how the child was managing in school.

- Parents suggested that, where a child received help from support staff, these people could act as a link between home and school.

- Parents wanted teachers to respect their expertise about their child and to take seriously their requests to school staff.

An Understanding Teacher : Participants' Messages for Education Services (continued)

LEA as a source of information

- Teachers wanted LEAs to inform schools clearly about any relevant health-related responsibilities held by LEA officers so that teachers would know who to approach for advice.
- Teachers said LEAs could have a particularly valuable role in collating information on contacts in other agencies, including the NHS.
- Teachers felt it more useful for school staff rather than for LEA officers to have skills and knowledge about pupils with special health needs. Therefore, it was recommended that resources be directed towards training school staff rather than LEA officers.

An Understanding Teacher: Participants' Messages for Health Services

Types of information health professionals should provide

Teachers were very clear about the information they needed from health professionals:

General information on the condition

- Considered particularly important when the condition was rare.
- Teachers need advice on how to explain the condition to sceptical colleagues.

Details of the condition with respect to the individual child

- Symptoms, treatment and prognosis.
- Teachers need advice on how to respond to the child's questions about their condition.

Implications of the condition for school life

- Is any treatment planned that might lead to school absence?
- What medical support is needed in school?
- Is there anything which the child needs to avoid in order not to put their health at risk, for example knocks to parts of the body, being outdoors in cold weather?
- What side effects are to be expected from the child's medication?
- What impact is the child's condition or medication likely to have on the child's behaviour?
- Will the child's condition have any impact on ability to keep up with school work?
- Will the child's condition have any impact on ability to take part in physical activities?
- Do any special arrangements need to be made for school trips?
- Do any special arrangements need to be made for exams?

An Understanding Teacher : Participants' Messages for Health Services (continued)

The role of health professionals in providing information to school staff

- Parents and young people wanted health professionals to act as advocates in providing written or verbal 'back up' when school staff were sceptical about families' views of a pupil's needs in school.
- Teachers wanted clarification about the roles of different medical professionals in providing advice for school staff.
- Teachers recommended more direct contact between school staff and a pupil's lead health professional.
- Teachers felt that therapists and specialist nurses were useful in passing on information and advice to school staff.

Improving the process of communication between health professionals and school staff

- Teachers wanted health professionals to be more proactive in communicating with school staff:
  - to pass information routinely to school;
  - to overcome difficulties in passing information to schools on grounds of confidentiality by developing a system along the child protection model. Here the consultant, parents and child agree what information will not be passed on, rather than assuming that *no* information would pass routinely between professionals;
  - to invite teachers to visit hospital facilities, establishing face-to-face contacts.
- Teachers recommended that a named health professional was needed for each child with a chronic illness or physical disability, regardless of whether they had a Statement.
- Parents and teachers recommended that a single named professional should take responsibility for co-ordinating health-related information about the child.
- Teachers wanted to work in partnership with health professionals. They would welcome being approached by NHS staff for advice as fellow professionals. When they do provide information for assessments, they want feedback from health professionals on the child's progress.
- Teachers felt that health professionals should make efforts to include school staff in multi-agency meetings for pupils with complex needs, including bearing in mind teachers' time commitments.

3.7 MEDICAL CARE

3.71 Responsibility for medical care

Medical care was not an issue raised by young people but was of concern to parents and teachers. Parents reported wide variation both within and between schools in how much responsibility individual members of staff were prepared to take on. This is not surprising given that there is no legal duty which requires school staff to administer medication; this is a voluntary role. However, some parents and teachers felt that LEAs did not wish school staff to take on such responsibilities, which seems contrary to the spirit of formal guidance (DfEE/DoH, 1996). For example, one parent spoke of how her child's teacher had been advised not to get involved in giving her daughter injections while on a school holiday:

> They wouldn't let [her] go on holiday because of her injections. Her own teacher offered to learn to do injections and the education department wouldn't let him. He was upset that she'd never been on a holiday with the school... so he actually took her on holiday and every morning she had to walk five miles with the teacher to a little rural doctor to give her an injection. He said it was ridiculous because he offered to do the injection but he walked with her which was nice. Every morning she had to trail in and out and she said she's never going again.
> (Parent)

When school staff were not willing to provide medical support, parents talked about the inconvenience of permanently having to be 'on call'. Parents of primary school aged children with asthma felt that schools panicked and called them to take their child home unnecessarily, disrupting the child's school life. Parents regularly called in to school reflected on the fact that this was only possible because they did not work and wondered how schools coped when parents did work:

> She was on an extra course of steroids and I'd have to go at dinner time and give her medication. They don't give medication. I'm lucky in the sense that I can go, but parents with both of them working, that must be a problem. It would be nice to know there was someone there, maybe a school nurse or someone, that could give medication.
> (Parent)

and

> No sooner do I get to school than I'm back home with him again. One Christmas I'd gone shopping and I said I'd be back about twelve o'clock and actually it was one o'clock and school had been trying to get hold of me. He'd gone into one of

> his minor fits. I felt so guilty I never moved out of the house for four months, just
> in case they needed to get hold of me.
> (Parent)

Aside from advice given by the LEA, teachers pointed out that their reluctance to get involved with medical regimes was often due to lack of expertise in medical matters and concerns about being held to account should anything go wrong.

3.7.2 Practical arrangements for medical care

Medications and medical emergencies

Although there is guidance on how teachers should deal with access to medication in school (DfEE/DoH, 1996), many teachers reported that they were unaware of it. Teachers and parents reported a wide range of approaches for dealing with access to medication. Pupils having easy access to their medication was important to parents but presented a dilemma for teachers. Teachers felt that, on the one hand, giving children control over their own medication would be positive for the child, increasing their independence and minimising disruption to the school day. On the other hand, however, they were concerned that other pupils' health might be put at risk if they got hold of medication. Parents of primary school children with asthma were concerned that their child was not allowed to carry their own inhaler. They pointed out that even when medication was not locked away, access could be limited by a teacher taking charge of it. A few parents overcame this problem by giving their child an inhaler to carry with them without the teacher's knowledge. Parents of secondary school children thought it ridiculous when children who regularly took medication had to telephone home to get permission to take pain killers. While they appreciated teachers needed to be cautious with primary school children, they felt the same level of care was unnecessary with older pupils who could manage their own medication.

Primary school teachers reported particular difficulties in dealing with medical emergencies due to not having another adult to call upon. In large secondary schools, greater numbers of non-teaching assistants gave more scope for responding in an emergency.

Medical equipment

There was concern about the availability of medical equipment within the school setting. Teachers felt the situation was exacerbated by a lack of clarity between the NHS and the LEA about who was responsible for the purchase and maintenance of equipment and the disposal of clinical waste.

Space requirements

There was also concern about how appropriate school buildings were for pupils following medical regimes in school. Space was needed for storing equipment and medication. Teachers spoke of needing somewhere private and hygienic for pupils to have treatment. Such space was not always available. For example, a teacher spoke of a boy with severe eczema locking himself in the boys' toilet to apply ointments in private; another teacher mentioned tracheostomy tubes being cleaned and stored in staff toilets; and one school mentioned having to stop a child's physiotherapy because the room was needed for other purposes.

Medical Care in School: Participants' Messages for Education Services

- Parents wanted schools to have a clear policy about medications and the level of support staff were prepared to offer pupils, and to communicate this policy to families.
- Parents wanted school policy to support the child as a manager of his or her own care.
- Teachers urged that a clear protocol be drawn up for every pupil with medical needs in school, with details about medication and what staff should do in an emergency.
- Teachers recommended that a member of staff within every school should be identified as responsible for medical issues and receive appropriate training.
- Primary school teachers recommended that primary schools should have more non-teaching support to deal with medical emergencies.
- Teachers pointed out that school buildings need to have adequate storage space for medication and equipment.
- Teachers called for schools to have a private and hygienic room in which pupils can have treatment and therapy without interruption, and to allow them to have time out of class when unwell.

CHAPTER FOUR
WORKSHOPS

4.1 INTRODUCTION

The workshops constituted the second stage of the project, which was more developmental in character, the aim being to consider the implications of the stage one research findings for service development. Ultimately, services are developed by those with knowledge and skills in managing and providing support, in this case for pupils with special health needs. As researchers, we wished our final recommendations to be informed by such knowledge and skills. To achieve this, we convened two separate one-day workshops (one for each research site) for invited delegates working in health and education services. At these workshops we disseminated the findings from the research phase. We then asked delegates to work together, reflecting on these findings and using their knowledge and expertise to identify good practice locally and to develop ideas for improving services.

Details of the recruitment and characteristics of the delegates, along with the organisation of the day, were set out in Chapter Two. Both workshops followed the same format: presentation of research findings; initial reflection by the delegates on these findings; identification of local 'good practice'; discussion about what needs to change - and how - in supporting pupils with a chronic illness or physical disability; and messages for national policy-makers. In their discussions, delegates were encouraged to draw on their own expertise to develop recommendations which might be generalisable to services in other geographical areas. Feedback sessions from both workshops were tape-recorded and initially analysed separately, providing two sets of information. Similar themes emerged in both events and are brought together in the results reported here. At the end of this chapter we report the feedback from delegates' formal workshop evaluation forms.

The workshops were valuable in two ways. First, they validated many of the suggestions made by research participants in the research phase, and generated ideas about how these might be put into practice. Secondly, the workshops added new data, both from health professionals (who were not involved in stage one) and from delegates' discussion of issues which concerned them, some of which had not been highlighted in the research phase.

4.2 REFLECTION ON THE RESEARCH FINDINGS

The research findings were seen by delegates as consistent with their own experience. Delegates raised an additional concern about differences between health and education professionals' definitions of 'chronic' illness - health staff meaning 'long term' and education staff meaning 'severe' - which could pose problems in understanding and organising appropriate support. Health professionals attending the workshops were also able to contribute their own perspectives to the issues identified in the research. This added valuable data, since the research phase had been concerned with the views of service users; that is, children, parents and teachers. In particular, health professionals added to an understanding of inter-agency communication difficulties by commenting on their own experiences: they reported problems in finding out who would be the best person to liaise with in an individual school about children with a chronic illness or physical disability; and practical difficulties in managing to speak with teachers who are in the classroom for most of the day.

4.3 EXAMPLES OF GOOD PRACTICE

The workshops identified a number of aspects of current local service provision which were believed to be working well and/or were thought especially supportive and so might constitute 'good practice'. Such examples both underline and supplement aspects of service provision which were valued by participants in stage one of the study.

4.3.1 Good practice by NHS staff

In relation to the NHS, most examples of good practice identified concerned liaison:

- Specialist liaison nurses offering outreach services to schools (for example, diabetes and epilepsy nurses).
- Therapists working in schools, since contact between staff improves liaison (although there can be conflict over the preferred timing of sessions between preferences of pupils, teachers and therapists).

- School nurses acting as link between NHS, school and family, particularly when this is systematic (for example, regular meetings between the school nurse and SENCO).
- School doctors attending annual reviews of pupils with Statements.

Other examples of good practice concerned training and medications:
- NHS staff (for instance, school nurses) providing training for teachers and SNAs (PSAs).
- Doctors avoiding prescribing medication doses unnecessarily during the school day.

4.3.2 Good practice by school staff

Delegates identified the following examples of good practice in relation to schools:
- SNAs (PSAs) taking a holistic approach to the child's care; that is, beyond the child's learning needs. For example, accompanying the child to a clinic can improve liaison between staff and allow for better understanding of the child's situation. (However, some Heads do not allow the school's resources to be used for such an extended role.)
- Action to address problems with peer relations (for example, through 'buddy' systems).

4.3.3 Good practice in inter-agency liaison

Experience of multi-agency meetings concerning an individual child were cited by delegates as an excellent means of working together. Unfortunately, only pupils with Statements were part of a system in which such meetings (in the form of annual reviews) were convened routinely. For other children, it was felt that meetings were convened only in a time of crisis.

Personal child health records were mentioned as a potentially useful new development for school age children. These are held by the parent or child and filled in by different professionals in contact with the family. Hopefully these records could improve sharing of information, and so help to overcome confidentiality problems. They will be especially useful if they can be extended to include Statementing information.

4.4 LOCAL POLICY AND PRACTICE: WHAT NEEDS TO CHANGE AND HOW?

In this part of the workshop, delegates discussed a wide range of issues relating to the need for change, which fell into four broad themes: direct support for pupils and parents; clarification of roles and responsibilities; improving health-related information for schools; and improving ways of working together. In echoing the issues which emerged from the research phase, these themes both validate and seek to take forward many of the areas for action suggested by the young people, parents and teachers who took part in the study. Here we report on delegates' views of policy and practice which can be developed by agencies and professionals primarily at a *local* level. Delegates also identified a number of areas in which they thought action was needed at *national* level. These suggestions for more strategic change are recorded in the next section.

4.4.1 Improving direct support for pupils and parents

Much of the debate about what needs to change concerned improving the ways in which professionals work together. A couple of points were, however, made about supporting pupils and their families.

In respect of *pupils,* there is a need to improve inclusion in after-school activities, for example by changing taxi collection times. Teacher delegates noted that this difficulty affects a much wider group of pupils who have a variety of problems in staying behind after school - for example, children in rural areas who travel by school bus - and is an increasingly important issue to tackle, given an increase in after-school activities. Teachers also wanted to offer *parents* better support: it was thought good practice to invite parents routinely to school to talk through any health concerns they may have about their child in relation to school life.

4.4.2 Clarification of roles and responsibilities

Overall, there is a need to clarify roles and responsibilities of school staff and health professionals - especially the school health service - for pupils with chronic illness or physical disability, both in terms of co-ordination and hands-on care. A number of elements of the need for change and possible ways forward were identified.

In relation to the roles and responsibilities of *school staff,* fundamentally it was thought that pupils with health conditions needed a higher profile in school. Individual schools can help to ensure this happens by allocating clear responsibility among school staff for identifying and co-ordinating support. For example, it was recommended that the role and responsibility of the SENCO should be clarified in respect of pupils with medical conditions *per se* since, at the moment, SENCOs may not routinely have information about these pupils, nor do they have sufficient time and training for this role. Delegates thought that there was possibly a case for an LEA officer with identified responsibility for this group of children.

It was considered that the roles and responsibilities of *school health* staff required clarification, so that school staff and families could make better use of their service. Suggested ways in which awareness might be raised included putting information about school health staff in the school prospectus, and preparation of an annual report by school health staff (on health needs in school and the work of the service) for both governors and parents. School nurses could help to begin to focus services on needs in a more targeted way, by 'profiling' special health needs and existing support facilities in schools. School nurses could also help to keep schools up to date with advice on specific medical conditions by liaising with specialist nurses.

4.4.3 Improving health-related information for schools

Delegates thought that teachers in mainstream schools needed a better understanding of health conditions and their impact on school life. At the local level, ways of improving teachers' level of knowledge might include using local special schools as centres of expertise, and giving a greater emphasis during in-service teacher training to the impact of health conditions on life in school. Approaches such as these were also considered to be possible ways of beginning to change attitudes of teachers who are potentially sceptical or apathetic in relation to complying with special arrangements for individual pupils.

Delegates agreed that school staff need better information, both about health conditions in general and health information specific to individual pupils. In relation to *general* information, it was suggested that the NHS should provide summaries for schools of information and advice about individual conditions. Although such summaries were thought to exist for some conditions, they were poorly disseminated. An additional strategy could be to compile a local directory of people with expertise in particular health conditions, which would be an efficient way for schools to access advice. A directory would also be useful for finding people to run training sessions in schools when needed.

In terms of accessing health-related information for schools about *individual pupils,* the main problem identified was confidentiality. Delegates discussed possible ways of making parental permission more explicit for information to pass from health professionals to school. For example, a school might give parents a contact name and address on a card which, when handed to their health professional, signals permission for the health professional to pass information to school. Alternatively, local NHS Trusts could develop a pro-forma for written parental permission.

4.4.4 Improving ways of working together

Most of the discussion by delegates was on issues related to the need to improve ways of working together, primarily between workers in health and education, but also including social services. A general need for a culture of inter-agency working was identified, the achievement of which would require action in several areas. First, professionals need to meet on a more routine basis: the concept of local 'families of settings' was suggested (building on the idea of 'families of schools') in which workers in health, education and social services in a small geographical area could meet to discuss issues of common interest in supporting local children and families. Secondly, professionals need to be more alert to connections between their work and that of other agencies so that when, for instance, one agency is organising training events or developing local policies, people from other agencies with related interests and/or whose work would be affected, could take part. A practical example in one workshop was that delegates from the LEA reflected that they had in the past been 'short-sighted' in excluding school doctors from the revision of criteria for statutory assessment of children with physical and medical difficulties. It was agreed that local school doctors would be consulted in future.

Delegates felt that underpinning the ability to work together is the need for clear understanding about each other's roles and jargon, along with open and honest discussion on matters such as resources, constraints and criteria for service provision. Even more basic is the need to know the identities of professionals working locally in other agencies: simple sharing of lists of named school nurses and SENCOs was thought to be a useful starting point, and delegates at one workshop agreed to exchange this information routinely in future.

4.5 NATIONAL POLICY: MESSAGES FOR THE DEPARTMENT FOR EDUCATION AND EMPLOYMENT AND THE DEPARTMENT OF HEALTH

Throughout their discussions, delegates were clear that, while there was much they could do 'on the ground' to improve support for pupils with a chronic illness or a physical disability, attention was also required at the more strategic level of national policy-making. Delegates had separate and joint messages for the DfEE and DoH.

4.5.1 Messages for DfEE

- Special educational needs policy is too narrowly focused on learning, and fails to address the wider range of needs of some children which affect their education and life in school. The 'profile' of the group of pupils with a chronic illness or physical disability needs to be raised nationally if LEAs and, in turn, schools are to give this group of pupils the higher priority they need. The Code of Practice on SEN should be reviewed to provide advice on how their needs will be identified, assessed and met, in particular for pupils unlikely to have a Statement.

- A commitment is needed to ensure that school buildings are appropriate for including as many children as possible in academic and social aspects of school life. Guidance recommending that appropriate space is set aside for health-related work in schools needs to be strengthened.

- To improve understanding by school staff of special health needs in school, more 'medical' sessions are needed in both initial and in-service teacher training programmes.

4.5.2 Messages for DoH

- NHS Trusts should be considering the implications of education 'inclusion' policy for their services. Therapy services appear especially under-staffed to work peripatetically, and liaison nurses in more specialties could be beneficial in providing advice and information to schools.

- A more targeted use of school health resources is needed. While routine health surveillance of school children is reducing, school health staff can offer other services needed in school, including support where pupils have a chronic illness or physical disability. Such support may be difficult to find from other sources, for example, GPs may be unwilling to take on a support role in relation to special health needs at school. A strategy is needed to raise awareness of the role of the school health service. School staff and parents need to know that they can turn to the SHS for advice. National prescription is undesirable since it could stifle local creativity, but the DoH could act as advocate, for example by pressing the DfEE to recommend incorporating school health staff in school prospectuses.

4.5.3 Joint messages for DfEE and DoH

- The two departments need better dialogue with one another, so as to prevent education or health policies being developed and implemented in isolation.

- The departments should work together to raise the profile of health issues in school. One practical idea would be to pilot joint-funding of school nurses in large secondary schools and evaluate the outcomes for users.

- Current arrangements under the Code of Practice on SEN fall short of placing a statutory responsibility on the NHS to provide a prescribed level of support. This weak position should be re-considered.

- The joint guidance *Supporting pupils with medical needs* should be revised, building on the concept of the individual health care plan to (a) extend its coverage beyond medications; and (b) clarify who is responsible for managing these plans. Dissemination of the guidance should be improved, perhaps through distribution directly to schools.

- Clarification is urgently needed for funding special equipment in schools for disabled pupils: perhaps pooling arrangements between health and education for funding and joint stores could be explored.

- Common definitions of children 'in need' should be developed at national level: the Children Act, Code of Practice on SEN and WHO definitions all vary.

- Resources are genuinely insufficient to support this group of pupils, yet the economic argument alone for investment is strong, given the long-term costs in adulthood of underachievement at school and psychosocial problems.

- In relation to children as a client group more generally, there might be benefits from fundamental structural change in favour of 'joint children's services' whereby health, education and social services for children were brought together organisationally and financially. Experience of developing Children's Services Plans, while helping to bring professionals together, suggests that without a common organisation and budget, it is genuinely difficult to work together fully.

4.6 EVALUATION OF THE WORKSHOPS

Delegates were asked to complete an evaluation form at the end of the workshop (see *Appendix 9*). Analysis of their responses shows that workshops appeared to work well as a means of disseminating the research findings to key health and education staff in the study sites and in generating - through small group discussion - ideas for service development.

In addition to this outcome for the project, analysis of the evaluation forms reveals that participation in a multi-agency workshop *in itself* could bring benefits for improved collaboration. In their comments on the small group work, delegates mentioned the workshop as an opportunity to meet people from other disciplines face to face, so establishing links, and the value of taking time out together to reflect on issues concerning a group of pupils whose needs are rarely highlighted. Delegates also found that workshops allowed them access to a range of views in group discussions, so developing a better awareness of other perspectives, sharing knowledge and good practice and understanding each other's constraints. One delegate wrote about a new awareness that health and education are on the 'same side' and that 'perhaps I will see it as less them and us in the future'.

Delegates also mentioned two other important outcomes of the workshop for them. First, some delegates wrote about new knowledge they had gained from listening to the research findings, such as: the role of the school health service; what users think; and the impact of absence on pupils. Secondly, from dissemination of the findings and from the small group discussions, delegates mentioned having plenty of 'food for thought'. Delegates wrote that they had clear practical ideas to take back for implementation. One example given was for school staff to maintain contact with pupils who are absent by visiting them, not just by sending work.

Other comments made by delegates suggest factors which contribute to a successful workshop:

- *The size of groups*: delegates liked working in small groups (between six and eight people) since this gave everyone a chance to speak and the atmosphere felt 'comfortable', not intimidating.

- *The composition of groups*: delegates appreciated the range of perspectives in the workshops. However, a few delegates drew attention to the fact that (in both workshops) one or two senior staff had been unable to attend and that this was a pity since their commitment was important in taking forward ideas for service development.

- *The structured approach:* delegates commented positively on the structure of the day, in particular a clear presentation of the research findings (with handouts), together with the value of questions to focus the subsequent group discussions. Although two delegates suggested that the small groups might have benefited from facilitation by a researcher to keep the discussion moving and make sure that everyone's opinion was valued, most feedback on small group work was positive.

CHAPTER FIVE

DISCUSSION AND IMPLICATIONS

In this final chapter, there are three sections. We begin by discussing the results of the two phases of the study in the context of the research and policy literature, highlighting what the findings add to current knowledge. In the second part of the chapter we review the research methods used, including comments on the strengths and limitations of the study. Finally, we outline the implications of the study's findings for future practice, policy and research.

5.1 DISCUSSION OF THE FINDINGS

Our research revealed that young people valued both academic and social life in school and were making efforts to actively manage their own condition. However, there were aspects of school life which concerned pupils, parents and teachers and where support was needed. All three groups of participants were concerned about: the implications of school absence; exclusion from school life; the need for emotional support for pupils and teachers; and the impact of the child's condition on their relationships with peers. An issue for parents and teachers, not highlighted by young people, was the need for medical care in school and the resources necessary to provide such support. The issue of most concern to all participants was the importance of school staff being aware of a pupil's condition and understanding its implications for school life. Parents and teachers felt that improving teachers' understanding requires attention to both the *quality of information* provided and the *process* by which it is communicated: within schools, within health services, and between school staff and health professionals.

Workshops with health and education managers revealed that the research findings were consistent with their own experiences. Health professionals added to the data on communication between school staff and health services by describing the difficulties they encountered in attempting to liaise with teachers.

In discussing the study's findings, it is important to make clear that our sample is not necessarily representative either of young people with a chronic illness or physical disability more generally or their parents and teachers. For example, the importance which we found that young respondents attached to school may well be more likely for these pupils who were sufficiently interested to take part in research about school life. However, as a result of the study, we do have new insights into support needs expressed by pupils themselves. Likewise, the views of parents and teachers are drawn from those motivated to take part in research on this theme.

Overall, our findings suggest that pupils with chronic physical conditions need support in a number of different spheres in order to have a positive experience in mainstream school. They need direct support for themselves, indirect support for those who interact with them on a daily basis - parents, teachers and pupils - and improvements in communication between health professionals, teachers and parents. Recommendations made by project participants also highlight the importance of local and national health and education policies in guiding changes to practice.

We now go on to assess how the findings of our study fit with the research literature on the support needs of pupils with a chronic illness or physical disability. This assessment is followed by reflection on health and education policies relevant to this group of children in the light of our evidence.

5.1.1 How do the findings fit with existing research knowledge?

Children 'at risk'

In Chapter One of this report, we reviewed the literature indicating that this group of pupils are 'at risk' of developing emotional and behavioural problems, difficulties in their relationships with peers and academic problems. Given limited existing research in which young people have been asked about their experiences in school, we could only speculate as to why such problems might arise. The results from this study begin to give us a picture of what life in school is like for young people who have a chronic physical condition.

Our research reveals a number of aspects of school life which were distressing for these pupils, including: not being allowed or not being able to take part in school activities; being forced to take part in activities they felt unable to manage; school staff not believing a pupil was suffering from symptoms or had special health needs; and problems with peer relationships. While such experiences may not in themselves cause emotional or behavioural problems, it is likely that they would contribute to low self esteem and, if continued over long periods of time, exacerbate feelings of anxiety or depression.

The findings with regard to peer relationships are particularly interesting as they suggest young people's experiences are more complex than is suggested by studies which focus solely on investigating whether pupils are 'at risk' of having peer difficulties: many young people spoke of being bullied, while at the same time having very close friendships.

Young people and parents reported that many pupils received little support from school staff in catching up with work missed through school absence and that there were often no systems in place for passing work between the school and the home or hospital. These difficulties were also highlighted in a recent study on the needs of pupils absent from school (Bolton, 1997). Such findings may help to explain why young people with chronic physical conditions are at risk of developing academic problems despite their condition not resulting in cognitive impairment.

Service support

Some of the concerns raised by young people confirm findings from previous research. Common concerns include: falling behind with school work; not being able to take part in school activities; being teased by peers; and PE teachers reacting inappropriately to their symptoms (Lynch *et al.*, 1992; Henning and Fritz; 1983; Freudenberg *et al.*, 1980). In terms of teachers' support needs, in common with earlier research we found that teachers want access to information about a pupil's special health needs, particularly how the condition impacts on school life (Court, 1994; Lynch *et al.*, 1992; Johnson *et al.*, 1988; Eiser and Town, 1987; Charlton *et al.*, 1986; Bradbury and Smith, 1983; Eiser, 1980). We found difficulties in communication between parents, school staff and health professionals which are similar to those reported in other studies. For example, the results indicate that parents are the most frequent source of information for teachers, but that teachers have concerns about the accuracy of information provided by parents and want more contact with health professionals (Court, 1994; Johnson *et al.*, 1988; Eiser and Town, 1987; Charlton *et al.*, 1986; Bradbury and Smith, 1983). Parents themselves want better liaison with schools (Lynch *et al.*, 1992).

Our findings are also consistent with previous studies in respect of communication and collaboration between health professionals and school staff. In particular, consultants varied in the advice and information they offered to teachers, there were delays in schools receiving information, some health professionals refused to provide information on grounds of confidentiality; and teachers felt that they were not being treated as partners by health professionals, for example they are not asked to contribute to a child's assessment (Dyson *et al.*, 1998; Larcombe, 1995). In addition, our findings support the recent Ofsted report (1997) which suggested that school staff are unclear both about who to contact for support within the NHS and about the nature of parents' responsibilities for communication.

The findings from this study also *add* to the research literature, in particular in respect of young people's views on service support and the processes of communicating health information, including communications between the NHS and schools, from one school to another, and within a single school. Details of this new knowledge are given below.

The young person's perspective. By including the views of young people themselves, our study provides a new source of information about the support needs of pupils with a chronic illness or physical disability. Importantly, we found individual differences in the type of support young people wanted. Furthermore, comparison of teachers' and young people's data revealed differences in perceptions about how best to support pupils. For example, young people felt most comfortable talking to a teacher about health-related concerns, whereas teachers thought young people might prefer to seek such support from a school nurse. This difference was most striking in the emphasis given by workshop participants to the development of the role of the school health service, as compared to young people's and parents' views that school health staff were not appropriate sources of support. It follows that it is crucial for professionals and managers to consult with young people, both at the level of individual support and at the general level of planning service development. Such consultation is consistent with the rights of the children and young people to have a say in decisions which affect them (United Nations, 1989).

Our findings from young people suggest that the pupil's experience in school is largely dependent on the people who surround them during their everyday life: parents, teachers and friends. Young people spoke positively about having a parent who was willing and able to act as an advocate for them and about having a sympathetic teacher who understood their needs and acted on this knowledge. There were numerous examples of friends helping pupils with their condition, which is in keeping with research by La Greca (1990) on friends of pupils with diabetes which found that peers provided emotional support, companionship and assistance with day-to-day management of their condition. Our study adds to this knowledge about support from peers, first by finding that they are a resource for pupils with a wide range of conditions. Secondly, our study adds to knowledge on the types of support offered by peers. Young people in our study reported help from peers in respect of bullying, various forms of practical assistance associated with their condition, and help with keeping up with school work. In summary, parents, teachers and peers all make a difference to whether the pupil is able to keep up with and take part in the social and academic aspects of school life. It follows that ensuring these people are able to take on such roles will help indirectly to support the child in school.

The process of communicating health information to schools. Our study highlighted the importance of the process by which health information is passed to schools. In doing so, our evidence supports previous research, indicating that teachers are dissatisfied with receiving health information through parents and want better communication between health and education services. Our study provides further details on teachers' concerns about systems for communication, including: dissatisfaction with using school health services to access information directly; not knowing who to contact; and dissatisfaction that health professionals rarely initiated contact with school staff.

By including the views of parents, our research provides evidence that parents have similar concerns to those of teachers about school staff relying on parents for health information. Like teachers, parents in our study also wanted health professionals to be more proactive in passing information to schools. Parents provided details of two types of difficulty they experienced in liaising with schools. First, parents sometimes had difficulty getting school staff to take their views seriously and so to act on the information they provided. Secondly, in large secondary schools many parents experienced difficulties with information not being passed on to staff who needed to know.

Comparison of teachers' and parents' views on liaison between parents and teachers revealed differences in opinion. While parents wanted to meet teaching staff on a more regular basis, teachers found it difficult to express their concerns about a pupil in front of his or her parents and were also reluctant to risk over-burdening parents with meetings. Having both parents' and teachers' views on this issue is valuable since it reveals tensions which exist between different groups of service users and which need consideration when developing ways in which all people supporting the child can work together.

Participants in our study suggested two possible approaches to resolving difficulties in providing school staff with health information. The first was to improve direct communication between health and education professionals. Many teachers and parents in our study had concerns about the school health service as means of accessing information and therefore suggested ways of improving direct communication between the school and the health professional with the lead responsibility for the child. However, teachers attending one focus group meeting spoke positively about school nurses due to a change in their role locally. Here, school nurses had become more proactive, co-ordinating support between the family, school and NHS for pupils with special health needs. It is possible that this 'link' role of school health staff could be strengthened although, if school nurses were to devote more time to pupils with special health needs, such a change could have implications for resourcing the service. During the course of the study, we did hear about a service set up in another area in which a secondary school and the local NHS Trust joint-fund a nurse for the school on a full-time basis to act as a home/school liaison health co-ordinator. While such an approach might improve communication between school and parents, systems which involve intermediaries may not overcome teachers' concerns about delays in receiving information which does not come directly from the child's lead health professional. Given young people's reluctance to access support from school health professionals, consultation with young people is clearly vital when considering any development or evaluation of the service.

The second approach suggested for improving communication was to improve support to parents in their role as 'link' between health and education professionals. Examples of good practice included a current initiative to set up multi-agency parent-held child health records for disabled children, and consultants providing written summaries of meetings for parents and acting as their advocate in times of difficulty liaising with the school. This emphasis has been adopted in the United States where programmes have been set up to 'support parents in their natural role as primary providers for their children'. The aim of such programmes is to develop partnerships between professionals and families in all aspects of planning and service provision (Lehr, 1990). Since parents and teachers both thought that parents are likely to differ in the extent to which they wish to be involved in liaison between health and education services, it follows that proposals for information systems need to be negotiated with the individual family. Whichever approach is adopted, what is crucial is that health professionals, school staff and parents are clear as to how information will be passed on.

Although we did not interview health professionals as part of the study, discussion with health professionals during the workshops suggest that they experience similar communication difficulties to those reported by teachers. For instance, health professionals did not know who to contact in schools and had difficulty arranging to speak with teachers owing to their limited non-teaching time. Further research is needed to explore health professionals' experiences in relation to supporting this group of pupils so that any changes to services and systems of communication take health professionals' needs into consideration.

Our study also revealed the needs of teachers for general information about the range of health conditions which they might come across among their pupils. This finding supports earlier studies which have investigated the level of teachers' knowledge about childhood chronic conditions (for example, Court, 1994). Teachers in our study wanted general information on health conditions to be available to schools routinely. Although such information does exist (for example, NACC, 1998), not all conditions are covered and dissemination is not necessarily widespread. Recent research into the quality of health information leaflets written for patients on ten common conditions found that most of the information was of poor quality, inaccurate, misleading or biased, even when written by doctors (Coulter *et al.*, 1998). Such evidence suggests a need for better co-ordination and vetting at national level of the production of information leaflets.

The process of communicating health information between and within schools. Unlike previous research in this field we gathered data on methods used to pass health information within and between schools. This work highlights a number of areas where improvements are needed, particularly: a system for transferring information about special health needs between schools; effective systems within large schools for passing on information to all members of staff; greater clarity within schools about who is responsible for pupils with special health needs, particularly in relation to pupils who do not have a Statement; and sufficient non-teaching time for teachers to liaise with parents and with other professionals.

Taken together these findings on communication highlight roles for both health and education services in ensuring that teachers' understanding of pupils' special health needs and their impact on school life is improved.

5.1.2 How do the research findings fit with health and education policy?

The issues of concern to young people, parents and teachers were identified through examples of good practice and from descriptions of difficulties with service support. However, there were wide variations in the service which participants received from health and education professionals. These variations did *not* reflect differences between the sites involved in the project. Instead, the way in which professionals responded to the needs of this group of young people, their parents and teachers seemed to differ *between* individual professionals. For example, young people reported teachers within the same school responding differently to their requests to have work sent home during periods of absence; teachers working within the same area of the NHS trust reported some school doctors providing advice on this group of pupils while others refused on grounds of confidentiality; and parents reported consultants differing widely in the extent to which they liaised with school staff. In summary, the service provided at present is inequitable, reflecting a lack of clear policy guidance for this group of pupils. Our evidence suggests that there are four main reasons why services are so 'patchy': pupils with chronic physical conditions are 'hidden' within existing policy; agency responsibility for this group of pupils is unclear; roles and responsibilities are ambiguous; and the onus of responsibility for information-giving is on parents, who may not be able to meet the expectations placed upon them.

The 'hidden' group

Variation in service support reflects the lack of clear policy guidance for this group of pupils. First, pupils who have a chronic physical condition are a 'hidden' group within education policy. At national policy level, the fact that relevant guidance is spread among a number of documents in itself obscures clear definition of the support needs of this group of children. Straddling the remit of two government departments - education and health - may also serve to weaken their identity as a group.

The main way of accessing support for pupils with special health needs is through the SEN system. Our research indicates that this system was advantageous for a pupil in terms of raising awareness about his or her needs within the school: once a pupil is placed on the SEN register, the SENCO takes responsibility for ensuring that his or her needs are meet. However, in practice, interpretation of the Code varied widely between schools as to whether - and if so, where - to place children with chronic physical conditions on the SEN Register. It followed that there were also variations in the extent to which SENCOs were taking responsibility for this group of pupils.

Some of the pupils in our study had a Statement, while others did not. Statementing brought potential advantages in raising the profile of the pupil's needs, not least through improved opportunities for inter-agency communication. This is not to say that communication between teachers and NHS professionals was entirely problem-free for the Statemented pupils in our study, rather that these were the only pupils for whom a formal communications system was in place.

At LEA level, it became clear to us during our initial contact with the research sites that the group of pupils with chronic physical conditions could be hidden *even* when they had a Statement. Although LEA databases did record whether a pupil had a Statement owing to a physical disability, Statementing for other health-related reasons was not recorded. LEAs in the study did not have formal systems for collating information on non-Statemented pupils with a chronic illness or physical disability. Although one LEA was able to collate this information manually on request, these LEAs had very little routine information about the size of this population, which schools these pupils were attending, or what their special needs might be.

Disputes over agency responsibility

A second reason for variability in support is that LEAs and the NHS were reported to have difficulty reaching agreement about who should fund equipment in cases where it was difficult to determine whether the resource is for heath or education purposes. Such difficulties lead to delays in children receiving the help they needed. Recent research by Dyson *et al.*, (1998) suggests that this is a difficulty in other areas in the UK.

Ambiguity in roles and responsibilities

The third reason for variation in support for this group of pupils is that health and education policies are often vague about the roles of specific groups of professionals and of parents. In practice it often appears to be up to the individual professional to decide what type and level of support they want to offer, with parents expected to fill gaps in support.

In relation to medical care at school, national guidance suggests that schools should have a policy with regard to storage of and access by pupils to medication, but that it is up to individual teachers to decide whether to volunteer to provide medical care for pupils (DfEE/DoH, 1996). It follows that children attending the same school may receive different forms of support, at different times in their school career, according to the willingness of individual teaching staff involved with the child to volunteer. For their part, while some teachers in our study were willing to take on a voluntary medical role, reasons for not volunteering included lack of clarity as to whether they were insured to do so, along with pressure from their LEA not to offer such support. Teachers were generally unaware of the existing guidance, which states that LEAs (or governing bodies in the case of grant-maintained schools) 'should ensure that their insurance policies provide appropriate cover for staff willing to support pupils with medical needs' (para 13).

When teachers were unwilling to get involved in medical support, parents who participated in our study spoke of being required to come into school throughout the day, for instance to give medication, apply ointments and deal with asthma attacks. Parents' views that such a role is inappropriate are consistent with that of the Health Select Committee who recently stated:

> We do not believe that it is reasonable to expect that parents should, other than in exceptional circumstances, be called to school to help with their child's clinical

> needs. In many cases this would impose an intolerable burden on parents, especially those in full-time employment or who have responsibility for caring for their small children.
> (House of Commons Health Committee, 1997, para 90).

In practice, while teachers' involvement in medical care remains a voluntary responsibility and alternative sources of support are not available within school, parents are faced with little option but to go into school to assist their child.

The Code of Practice on SEN suggests that school staff should approach health professionals directly for advice and information. In this situation teachers are effectively service users, seeking out help for themselves from health professionals. However, there is little consideration in the Code of the practical difficulty school staff may face in tracking down the appropriate health professional, which was one of the obstacles to liaison highlighted by our research.

Guidance from the Department of Health suggests school health staff should seek to 'minimise the consequences of illness and disability in children for their education' (DoH, 1996; para 8.2). Findings from our study indicate that there is a wide variation in how school health professionals interpret such guidance - even within the same NHS Trust - and so service users are left unclear as to what to expect from the SHS.

To fulfil their obligations under the 1993 Education Act and the 1994 Code of Practice, Department of Health guidance urges child health professionals to be alert to possible SEN and - with parental consent - to communicate these swiftly to the LEA (DoH, 1996 para 1.43). Furthermore, GPs and doctors working in any part of the child health service are advised, with consent from parents, to respond promptly to request from schools or LEAs for information about the children who may have SEN. Since in practice the SEN process focuses on the needs of pupils with a learning difficulty, the guidance potentially does not cover all pupils with a chronic illness and physical disability. It follows that teachers' health-related information needs are unlikely to be met fully through guidance intended primarily to support identification and assessment of SEN.

In practice, there appears to be wide variation in teachers' access to information. Teachers reported that the best information came where pupils had conditions for which the NHS provided specialist clinics, or where health professionals such as therapists and specialist nurses visited schools to provide treatment, information and advice on the premises. However, since there is no general requirement for NHS Trusts to provide specialist nurses or peripatetic support, provision among the NHS Trusts in our study varied.

In summary, our findings support the Health Select Committee's view that there is still a great deal of confusion about professional responsibility for pupils with medical needs, despite the 1996 DfEE/DoH guidance. While accepting that policy and guidance can never ensure that all service users receive an optimum service, and that there will always be variation due to the personality of the individual professional, there is scope for guidance in this field to be clearer about the minimum level of service which can be expected from health and education professionals.

The information-giving role of parents

The findings from this study indicate that the onus is placed upon parents to provide school staff with information on their child's health needs, an approach which is endorsed by existing guidance (DfEE/DoH, 1996). However, young people, parents and teachers in our study drew attention to variation in the extent to which parents are able to fulfil these responsibilities which, in turn, has an impact on the support pupils receive. Children whose parents were assertive and articulate, and were prepared to pursue professionals, were thought to receive higher levels of support. Children within our study attending the same school and with the same condition, noticed that they received different levels of help, which they attributed to their parents' respective abilities to fight for support.

5.1.3 Summary

For schools to operate as a setting for pupils with a wide range of health-related needs, systems and lead responsibilities are required to put support in place. In addition, close co-operation is needed between school staff and NHS professionals. Analysis of existing guidance and of the data from our study suggests that children with a chronic illness or physical disability are a somewhat hidden group, with their support requirements being weakly defined. The boundary between professional responsibilities appears particularly difficult. For school staff, children are essentially *pupils* for whom learning takes priority. For health professionals, children are essentially *patients* for whom hands-on NHS care does not extend to school. So, despite the increasing numbers of pupils with health-related needs in school, support for them by individual school staff is provided on a voluntary basis, with health professionals in an advisory role. Relying on parents to fill the gap is at best unrealistic given the circumstances of many families: more fundamentally it flags up the failure of policy to address growing demands on those professionals acting in *loco parentis* for this group of children in the school setting.

5.2 DISCUSSION OF THE RESEARCH METHODS

In this section, we reflect on the research methods used in the project. Our aim in doing so is to share our experiences with other researchers who may be considering similar approaches. We used three research methods: semi-structured interviews (with young people and with some parents), focus groups (with parents and with teachers), and workshops (with health and education staff). Details of these methods were set out in Chapter Two. In this discussion, we reflect on these methods according to the type of respondent.

Young people

The rationale for semi-structured interviews with young people was to allow young people to raise issues of concern to them. This rationale stemmed from both the research argument - that there was little previous research knowledge in this field - and also the principles that we as researchers wished to adopt; that is, acknowledging young people as experts on their own health needs, and avoiding a focus on asking only about 'problems'. We also decided to use a variety of techniques: question and answer; mapping with discussion; and sentence completion. Reasons for such variation were to make the interview a potentially more interesting experience for participants and to offer them some control over the content and pace of the interview.

This approach appeared to work well. In particular, incorporating mapping appeared to have a number of advantages. For those young people who were reticent in the question and answer format, mapping allowed them to express themselves non-verbally. The resulting maps of support enabled some young people to express sophisticated relationships among the network of people who helped them. The process of drawing a map also gave young people an opportunity to slow down the pace of the interview, giving them time to think before responding. Arguably, including a mapping exercise made the interview less intimidating, since respondents did not have to make eye contact with the researchers throughout. Young people's behaviour became more relaxed when drawing, for instance in adopting a more informal position by moving from a chair to work on the floor. Some young people entered into a dialogue with the researcher whilst drawing the map, in contrast to the more formal pattern of a verbal interview.

Interviews with young people took between one and one and a half hours to complete. It was our experience that young people needed up to a third of this total as thinking time: longish silences were not uncommon before respondents replied or appeared to be drawing a map rather than doodling. Unfamiliarity with being asked for their opinion, particularly on this subject, may have accounted for the need for so much thinking time: a couple of older respondents remarked that they were pleased to be asked for their views, but unaccustomed to it. Whatever the reason, we learned that it was important to be patient and not to be anxious to move the interview along.

Parents and teachers

Focus groups were chosen as the method of data collection with parents and teachers since the aim was to develop recommendations for service development through discussion among people with differing experiences. There were similarities and differences between group work with parents and teachers. Similarities included: incorporating some 'social' time over refreshments at the beginning of the session to allow participants to talk informally and so ease any anxiety; adopting strategies for moving the discussion on; and making sure quieter members had their say.

There were also some differences - both in planning and process - between running groups for parents and for teachers. These differences meant that extra time was needed both in planning and running meetings for parents. First, in respect of *planning*, it was easier to recruit and plan meetings for teachers than for parents. One reason seemed to be that teachers were coming in their role as professionals as part of their earmarked working day. The project also funded supply cover. By contrast, parents had many and varying commitments on their time, which made organising meetings more difficult. We needed to offer parents a choice between day or evening meetings and we also had to hold meetings much more locally than for teachers. Although we paid for travel costs, including taxis, the amount of time required was the main difficulty for parents.

A tricky practical problem for the researchers was parents' uncertainty until the last minute as to whether or not they would be able to attend, depending upon family commitments. Having offered a choice of time of day and our commitment to very local meetings, inevitably some of the planned sessions were for small numbers (as few as three). It followed that any non-attendance risked having to cancel the session on the grounds that it would not constitute a 'group'. We made sure that we re-contacted parents the day before the scheduled meeting, to check that they were still able to attend. Often this acted as a useful reminder for parents, some of whom said they would have forgotten to come otherwise. Nevertheless, one parents' meeting was rearranged three times and a couple of planned meetings proved no longer viable since insufficient parents were available at the same time. In addition, a couple of parents said that they would be too anxious to come to a meeting, but were prepared to be interviewed. As a result we revised our research design to include individual interviews for parents unable or unwilling to attend a meeting.

Turning to differences between parents' and teachers' groups in terms of *process,* although the broad framework of the two sets of groups was similar, we found important differences in behaviour between parents and teachers. While parents openly displayed nervousness, anger and distress, teachers did not. Nervousness about being part of a group discussion was expressed in various ways, for instance by bringing a friend to the meeting and by sitting aside from the rest of the group. A few parents became upset during focus group meetings, being angry or tearful about their family's situation. When this happened, we allowed time for the person to compose themselves and, rather than the researchers intervening, we encouraged the rest of the group to support the upset person, for instance by talking about any similar experiences of their own.

Focus groups appeared to meet well their aim of fostering discussion about differing experiences, leading to general recommendations. Comparing the data collected from parents' groups with those from individual interviews with parents reinforces our initial preference for group work where potential solutions to difficulties are needed. Drawing on discussion of their experiences and knowledge of different services, parents in groups were much more able to move on to consider recommendations than were individual parents in interviews. Despite the fact that focus groups appear to be more productive for research concerned with service development, our experiences in this study suggest that it is not realistic to plan solely for group work to collect data from parents, on the grounds that it risks excluding many parents.

5.3 OVERALL STRENGTHS AND LIMITATIONS OF THE STUDY

As with other research projects this study has particular strengths and limitations. One strength is what we have learned about service support from young people themselves, which was a particular gap in existing knowledge. Including children with a variety of health conditions and needs was also a gap in previous research. The themes which emerge from our study are not necessarily condition-specific and so can be used to develop ideas about supporting children with chronic illness or physical disabilities more generally. In looking at the needs of these children as a *group*, the study can also help to make more explicit service support issues for them which have hitherto been somewhat hidden in policy terms.

In addition to the views of young people, a further strength of the study is its inclusion of the perspectives of other potential users of NHS support - parents and teachers. Data from these groups of respondents served both to amplify the young people's accounts and to add issues which concerned adults but which were less problematic from the pupils' point of view, such as medical care. In addition, comparison of the views of these three groups of service users enabled us to identify differences in opinion about service support, and so draw attention to the importance of consulting with service users.

Since we chose to focus the research on the users (or potential users) of NHS support, we did not set out to explore support issues from the perspective of health professionals. Given that communications between NHS staff and teachers emerged as a key theme, it is important to acknowledge that our research has only captured the issues in detail from the perspective of teachers. However, it is clear from comments by health professionals at the workshops that they also experience difficulties in communicating with school staff, and further research is needed on their perceptions of their role. Similarly, an important source of support that emerged from the results was that of peers, particularly the child's friends. However, we have no information on the views of peers themselves about their own roles and associated support needs.

The second, workshop, stage of the project was a strength in four ways; first, in validating the research findings by local professionals and managers. Secondly, the workshops were an opportunity to influence local practice, through dissemination of the research results and group work to develop ideas for service development. Thirdly, local experts in this field drawing up recommendations has helped to ensure that such recommendations are securely grounded in the realities of practice. Fourthly, delegates felt that the workshops had provided them with a positive experience of inter-agency working.

As with all research projects, the scope of our work was constrained by resources available, and so we had to take a number of decisions about how best to use these to answer the research questions. Although we sought children's views, we only did so for secondary school pupils. Views on the needs of younger pupils were expressed by adults only: parents and teachers. The initial decision to interview only secondary school pupils was premised on the plan to recruit from key transition points in a child's school career; that is, school entry, transition to secondary school and leaving school. This approach meant recruiting families with children aged 5, 11 and 16. Ideally we would have sought the views of the very young children. However, given the resources available, we restricted data collection to the older age groups on the grounds that they would have a more developed sense of the meaning of service support. When it became apparent that sufficient numbers of children of these three ages would not be available, the decision was made to extend the age criteria and thus include families with older primary school children. However, by this stage of the project there was insufficient time for either further methodological development for work with very young children, or for extending the recruitment period to include larger numbers of older primary school pupils.

We recruited rather fewer young people to the study than we would have liked: 33 as opposed to a target of 40. Nevertheless, this total was sufficient for qualitative research of this type. Furthermore, we managed to recruit families and teachers involved with 39 schools. Given the scope of schools to manage their own affairs, it was useful to draw on the experiences of people involved with a large number of schools.

Initial recruitment of schools was more difficult than expected. Many schools we contacted claimed not to have any pupils with a chronic illness or physical disability, while others said that they were too busy to take part. It may be that the schools who did agree to take part had a more positive attitude and active interest in supporting pupils with special health needs. A further factor to bear in mind when interpreting the results is that we recruited families to the study via teachers. Sometimes teachers took on a very clear 'gatekeeping' role, saying to the researchers that they had only put forward families who they judged would be 'interested' in taking part. It is difficult to assess the likely impact of this judgement on our findings: certainly it was not the case that only families with positive experiences of support were selected by teachers. A final concern about recruitment is that no families from ethnic minorities participated, despite our selecting a research site in which the population of ethnic minority groups is relatively high. Further research is needed on the support needs of pupils from ethnic minority families, for whom there may be additional dimensions to the evidence raised by our study of difficulties with communications and the parent's role as information-giver.

5.4 IMPLICATIONS OF THE FINDINGS

In this section we draw on findings from all stages of the project, including recommendations made by young people, parents, teachers and workshop delegates, to outline the implications of the study. The implications fall into three types: implications for practice, for policy and for research. Practice and policy implications are categorised according to whether they are relevant to education services, the NHS or both.

5.4.1 Implications for practice

Education Services

- A member of staff is needed within schools to take responsibility for pupils with a chronic physical conditions, irrespective of whether this child is on the SEN register. This person should:

- Listen to young people about what they are able to manage in school, taking into consideration symptoms, treatment and absences.
- Make arrangements for maintaining contact during periods of absence, including provision of school work.
- Organise adaptations to school activities and make arrangements for additional support so that the pupil can participate as much as possible, including school trips and after school activities.
- Ensure the young person has emotional support.
- Help resolve difficulties with peers.
- Help resolve difficulties with school staff.
- Ensure the pupil has an individual health care plan covering the implications of the condition for school life and any special arrangements needed in school.
- Liaise with other staff from other schools when the child is transferring schools.
- Liaise with parents.
- Liaise with health staff and other professionals.
- Pass on information about the pupil's special health needs within school.

Staff taking on this role need sufficient non-contact time and appropriate training.

- For pupils known to have a chronic condition, systems need to be in place so that home tuition can be accessed quickly.

- Every school should have a clear policy about medication and the level of support on offer. This policy needs to be communicated effectively to parents.

- Counselling should be available to teachers working with pupils with terminal or life-threatening illnesses.

- LEAs need to ensure that schools are aware of the existing guidance on supporting pupils with medical needs (DfEE/DoH, 1996), that they understand its implications and are implementing the guidance.

NHS

- During consultations health professionals should discuss the following issues with children and parents:
    - School life, in particular how they want to timetable treatment, medication, therapy and clinic appointments.
    - Clarification of which school activities are appropriate for the child.
    - Any assistance needed from health professionals in raising awareness and improving understanding among peers and teachers of the child's condition.
    - What information should be passed to schools by health professionals, to whom and how.

Health professionals should offer to copy letters, summarise meetings, and to speak directly with school staff.

- Teachers should be treated by health professionals as part of a team responsible for supporting the child. Subject to parental consent, health professionals should approach teachers for information about the child, provide feedback when teachers contribute to an assessment, and invite teachers to multi-agency meetings for children with complex needs.

- A local directory of health professionals with expertise in particular conditions would be useful for school staff.

5.4.2 Implications for policy

Our study has a number of implications for national policy. The findings point to a need both to *strengthen* existing policy guidance, and to consider *new* areas of guidance. Taken together, these recommendations are designed to help ensure that the needs of pupils with a chronic illness or physical disability can be more clearly identified and more equitably addressed. Throughout, the DfEE and DoH should ensure that they work closely together, for example through representation of both Departments on working groups developing policy recommendations.

Education

- *The Code of Practice on SEN* requires review so as to make more explicit:
    - How this group of pupils 'fit' into the staged approach when they do not have learning difficulties.
    - Whether SENCOs have overall responsibility for this group of children.

- Every school should be required to have a lead person with overall responsibility for pupils with a chronic illness or physical disability.

- Initial and in-service teacher training should include a greater focus on special health needs of pupils.

- All schools need to provide sufficient private and hygienic space for therapy, treatment and storage of medical equipment, and a minimum of basic adaptations, such as handrails, ramps and disabled toilet facilities.

- Schools transferring pupils should, with the consent of the child and parents, be required to pass on information about their pupils' special health needs and existing special arrangements in place.

Health

- *DoH Guidance on Community Child Health Services* requires strengthening to ensure that inclusive education is taken into account in the work of health professionals. In particular:
    - Greater clarity is needed for school staff about the respective roles of different medical professionals in providing advice about pupils with a chronic illness or physical disability, irrespective of whether pupils have been placed on the school's SEN Register.
    - The responsibilities of the school health service in respect of pupils with a chronic illness or physical disability require review. A national description would be useful, both to clarify service users' expectations and to secure more equitable support across the country.

  - Therapy services require review to enable in-school provision where possible.

Health and education jointly

- *The joint DfEE/ DoH guidance 'Supporting Pupils with Medical Needs'* requires review to:
  - Indicate who is responsible for medical care during the school day, should teaching staff be unwilling to volunteer.
  - Extend the scope of individual health care plans to cover the range of ways in which a health condition may affect school life, and to indicate special arrangements in place.
  - Improve dissemination of the guidance to schools.

- Health and education professionals should be encouraged to listen to children, allowing them to express their needs and service preferences and, where possible, tailoring services accordingly.

- Health and education professionals should be encouraged to support parents in their key role as information-giver and acknowledge their expertise about their child.

- There is a need to provide accurate, standard, information on medical conditions for schools. National co-ordination of such information could perhaps be secured through the Centre for Health Information Quality. Collaboration between DfEE and DoH is needed to ensure that high quality information is then disseminated to schools.

- Health and education professionals should be encouraged to take a holistic approach to supporting the child, working collaboratively and proactively with others. Such an approach includes having systems for the routine exchange of information and advice to fellow professionals.

- Joint guidance is needed to avoid inter-agency disputes over funding, for example of specialist equipment to allow pupils to access their education. Where it is particularly difficult to determine responsibility, a system of joint funding might be developed.

5.4.3 Implications for further research

Our study points to a number of avenues for further research, in particular:

- Views of younger pupils on their needs for and experiences of service support in relation to school.
- Views of pupils from ethnic minorities on their needs for and experiences of service support in relation to school.
- Views of health professionals on their roles in, and experiences of, working with school staff.
- Views of friends who actively support the ill or disabled child in school on their role and on their own support needs.