
**IMPROVING COMMUNICATION BETWEEN
HEALTH AND EDUCATION FOR CHILDREN WITH
CHRONIC ILLNESS OR PHYSICAL DISABILITY**

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EXECUTIVE SUMMARY

Project aim

The overall aim of the project was to implement research recommendations on the need to improve communication between health and education staff about children with a chronic illness or physical disability. The project objectives were, in one site (the area covered by York NHS Trust and City of York education services):

1. To add to previous research carried out with young people, parents and teachers, by investigating health staff's perspectives on the difficulties of, and possibilities for, achieving good communication with education staff with regard to children with chronic illness or physical disability.
2. To share research findings on the perspectives of health and education staff, parents and children between all parties.
3. To develop and implement an action plan for the introduction of systems for ensuring good communication between health and education staff. Staff from health and education, and parents and young people, were to be involved in developing plans.
4. To draw up recommendations to guide other areas in implementing more effective inter-agency communication, and disseminate this information to other areas.

Factors of interest

The project was timely in view of the increasing numbers of pupils in mainstream schools who have a chronic illness or physical disability. It built on a previous research study, completed by the research team in September 1998 (for the NHS Executive R&D Programme: Mother and Child Health), on the service support needs of this group of pupils. The previous study gathered the views of young people, parents and teachers. The new project addressed a gap in existing research knowledge by investigating the views of health staff. The research findings were then used by an multi-agency group to inform the development of a model for improved communication between health staff and teachers in mainstream schools.

Methods

The project involved two main phases: a research phase and a development phase. The research phase lasted four months and took a qualitative approach, exploring the views of a range of health professionals with regard to communication with education staff. Semi-structured interviews were carried out with these staff. The development phase lasted 11 months. Informed by theories of change and literature on inter-agency collaboration, a multi-agency working group was formed and a staged approach was taken to the development phase: the research team made staff aware of the need for change, before assisting them in preparing for, and finally implementing, change. This was done through a series of workshops and meetings facilitated by the research team. The research team also recruited pupils and parents as advisors to the project, and acted as an intermediary between these advisors and local staff.

Participants

A purposive sample of 20 health staff, representing the range of professionals involved with pupils with a chronic illness or physical disability, were involved in the research phase. These staff were drawn from the York NHS Trust, which provides both acute and community services. In the development phase, a multi-agency working group of 13 staff was responsible for taking the work forward (seven representatives from health services, three from the Local Education Authority, and three from schools).

Outcome measures

The research phase provides qualitative data on: current practice in giving and receiving information to and from school staff; good practice and difficulties in communication about pupils with a chronic illness or physical disability, both within health services *and* between health services and schools; and recommendations for improving communication. The development phase produced a model for improved communication between health and education staff in relation to pupils with a chronic illness or physical disability. It also resulted in recommendations from project participants about how health and education staff should approach similar multi-agency development work in other areas.

Findings

The research data indicated that the information and advice health staff passed on to school staff, and how they went about this, varied widely. The flow of information to schools appeared to work best where individual staff had a keen interest, or where a specialist nurse was in post. Health staff experienced a number of difficulties, not just in communication with school staff, but also in communication with colleagues in health services.

Practice varied widely with regard to transfer of information among health staff, with protocols in place for few conditions. Practice by consultants was crucial since they were the primary source of much information. Lack of clarity about the role of school health staff caused variability in the flow of information from consultants through these professionals to schools.

Barriers to communicating with schools were: variation in school staff's attitudes and practice on health matters; health staff's concerns about the security of confidential health information in schools; lack of time for health staff and teachers to contact one another; and health staff's uncertainty about who was responsible in schools for this group of pupils.

During the development phase, health and education staff decided that in order to improve communication they needed to introduce a system which clarified who was responsible within health and education for passing on information about this group of pupils, what information they were routinely expected to pass on, and to produce a standard set of documents for collecting information. The model developed consisted of:

- A named teacher for health in every mainstream school;
- A named school medical officer for every mainstream school;
- A standard health care plan for every pupil with an illness or disability;
- A standard health register for all schools;
- The use of 'Smart cards' for pupils with an illness or disability. This was a laminated card which would be held by the pupil and include any information the pupil might want to pass

quickly and discreetly to teachers. Smart cards were added to model on the recommendation of pupils acting as advisors to the project.

The involvement of the research team terminated at the time of the initial implementation. Results of an audit of the implementation being carried out by staff in Spring 2001 will be published as an addendum to the report.

Conclusions

Data from health staff, while only from one Trust, were consistent with the earlier research into views of young people, parents and teachers, in finding that support for pupils is *ad hoc*, with a need for a more systematic approach to health-education communication. The model developed tackles key barriers to inter-agency communication identified in the research. In doing so, it also builds on existing national guidance for supporting pupils with medical needs. The model was developed to fit with resources and circumstances in York and so may need to be adapted in other areas.

Implications for future research

The approach the research team used in the development work to facilitate inter-agency working and implement research recommendations appears to have helped one area to achieve these aims. Such an approach may be useful for others wishing to carry out similar work.

CHAPTER ONE

INTRODUCTION

1.1 AIMS AND OBJECTIVES

This report describes a research and development project undertaken by a research team at the Social Policy Research Unit, University of York, in partnership with health and education staff within the City of York. The project was funded by the NHS Executive Research and Development Directorate, Northern and Yorkshire Region, between January 1999 and June 2000. The overall aim of the project was to implement research recommendations on the need to improve communication between health and education staff about children with a chronic illness or physical disability.

The project objectives were, in one site (City of York):

1. To add to previous research carried out with young people, parents and teachers, by investigating the perspectives of health staff on the difficulties of, and possibilities for, achieving good communication with education staff in relation to children with chronic illness or physical disability.
2. To share research findings on the perspectives of health and education staff, parents and children between all parties.
3. To devise and implement an action plan for the introduction of systems for ensuring good communication between health and education staff. Staff from health and education, and parents and young people were to be involved in devising plans.
4. To draw up recommendations to guide other areas in implementing more effective inter-agency communication, and disseminate this information to other areas.

It was clear in drawing up the research proposal that these objectives were inter-dependent and, in particular, that drawing up recommendations for other areas would only be possible if objectives 1 - 3 were met.

1.2 ORIGINS OF THE PROJECT

The increasing numbers of children surviving and managing chronic health conditions (Woodroffe *et al.*, 1993), together with a UK educational policy for inclusion (Education Act 1981; 1993) means that a growing proportion of pupils in mainstream school have a chronic illness. Some of the most prevalent chronic conditions among children are: asthma (12 per cent);

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

Between 1996 and 1998, the authors of this report carried out research into the support needs of pupils in mainstream school who have a chronic illness or a disability (Lightfoot *et al.*, 1998). One of the main findings was a need for improvements in communication between health staff and teachers. Towards the end of the project, workshops were held for health and education staff from three research sites to feed back the findings. These events were well attended and delegates were keen to take forward the recommendations.

At the same time there was a growing awareness among the research community that traditional dissemination methods, such as writing articles and presenting papers at conferences, rarely have an impact on professional practice. As a result, initiatives have been emerging to promote evidence-based practice in the fields of health and social care. For example, the NHS Centre for Reviews and Dissemination was set up to inform practice in health, and Research into Practice, at the Dartington Social Research Unit, informs social care services for children. We ourselves were also engaged in finding new ways of ensuring research influenced professional practice. For example, we had carried out a research-based development project aimed at implementing key worker services for families with disabled children (Sloper *et al.*, 1999; Mukherjee *et al.*, 1999). Experiences during this work had given us an insight into the value of researchers working alongside staff to facilitate the process of evidence-based service development.

One of the research sites for our study of pupils' support needs was York. Subsequent meetings with staff at the Department of Paediatrics at York District Hospital indicated that they were interested in taking forward the research recommendations, in particular to develop a new system for inter-agency communication between health and education staff. The research team and staff from the Department of Paediatrics prepared a joint proposal for a development project in which the research evidence would be used to inform the design of such a system. The previous study had collected data from pupils, parents and teachers, and it was agreed some further research was needed to gather the views of health staff on communication with school staff about pupils with a chronic illness or physical disability. Only then could a system be designed which took into account the needs of all involved. The project would therefore include both research and development work.

1.3 PROJECT DESIGN

The project was designed to last a total of 15 months and have four distinct phases:

1. Research	4 months	January - April 1999
2. Development	2 months	May - June 1999
3. Monitoring and Implementation	6 months	July - December 1999
4. Dissemination	3 months	January - March 2000

In practice, the development phase extended over a longer period than anticipated, because staff opted to defer some of the work scheduled for June 1999 until September, to avoid risking a loss of momentum over the school summer holidays when the teachers involved with the project were on leave. Our funders agreed that we could extend the overall timescale for the project to take this period of inactivity into account. In this way, we were still able to allow six months for the third phase. During phase three the staff continued to develop their plans, while our role changed from active facilitation to monitoring of this part of the process. Since staff themselves were engaged in development activity during phases two and three, throughout the remainder of the report we have collapsed these two phases together as the 'development phase'.

When the research team's monitoring role in the project ended, staff had 'launched' a model for improved health-education communications and were preparing for full implementation in the Autumn Term 2000. We have made arrangements with the working group responsible for implementation to follow up on their progress in Spring 2001, when they are scheduled to have completed an audit of the implementation. Results from this audit will be written up in an Addendum to the report and submitted to the NHS Executive Research and Development Programme, Northern and Yorkshire Region.

The research team are currently carrying out the final, dissemination, stage of the project. Instead of the series of short seminars originally planned, the research team have opted to hold a one-day workshop in September 2000. This will enable us to have an interactive event, with time spent both as a whole group and in smaller groups for discussion. The day will be facilitated jointly by the research team, and representatives from York NHS Trust and City of York Education Services who have been involved in the project. Time will be spent discussing:

- the research findings on why it is important for teachers to understand pupils' health-related needs, and the difficulties health and education staff experience in communicating;
- the model being put into practice to improve communication in York;
- the model for facilitating joint working between health and education staff used during the project.

Delegates will be encouraged to reflect on what the project findings suggest about how health and education staff might work better together in their local area and to identify ideas they wish to take forward.

1.4 CONTENT AND STRUCTURE OF THIS REPORT

This report summarises the first three phases of the project. The research team are currently carrying out stage four: dissemination of the project findings.

In Chapter Two we outline the background to the project. We begin by describing the *policy context*, discussing policy relevant to supporting pupils in mainstream schools who have a chronic illness or physical disability. Next we summarise *existing research evidence on communication between health and education staff* in respect of this group of pupils, including our previous research study, which points to the need for development work in this area. We then discuss *methods for putting research findings into practice*, drawing on theories of change, and the literature on facilitating stakeholder involvement in the change process. Finally, we provide *an overview of the project*, outlining our plans for each phase.

Chapter Three is devoted to the research phase of the project. We describe the research design and methods used to collect data from health staff, and report the findings.

Chapters Four and Five focus on the development phase of the project. Chapter four describes *how the research team worked alongside staff* to facilitate the process of developing a new communication system. This chapter includes recommendations for others seeking to undertake similar work. Chapter five gives *an account of the involvement of service users* in the development phase.

Chapter Six focusses on the outcomes of the development work, presenting the model health and education staff developed for improving communication, and their plans for implementation.

In Chapter Seven we draw together our conclusions from the project, reflecting on the strengths and limitations of the work undertaken, and passing on suggestions to others who wish to improve communication between health and education for children with a chronic illness or physical disability.

CHAPTER TWO

THE PROJECT: BACKGROUND AND OVERVIEW

2.1 INTRODUCTION

In this Chapter we first set out the background to the project, by summarising three areas of literature which informed us. First, we summarise the *policy context* relevant to supporting pupils in mainstream schools who have a chronic illness or physical disability - what we have termed 'special health needs'. Secondly, we summarise the *research evidence on communication* between health and education professionals in respect of this group of pupils, including that from our own earlier study (Lightfoot *et al.*, 1998). The third area of knowledge we summarise is that on *methods for getting research findings into practice*. In the final section of this chapter, we present an overview of the project along with the rationale for our chosen design.

2.2 POLICY CONTEXT

Inclusion in mainstream schools of pupils with a variety of special needs has been an explicit policy goal since the 1981 Education Act. Statistics point to the success of this policy: Norwich (1997) reports that, by 1996, the percentage of pupils aged between five and 15 being educated in special schools was 1.4 per cent, the lowest ever. In relation to pupils with special *health* needs, while it has long been the practice for pupils with some chronic conditions - such as asthma, diabetes and eczema - to be educated in mainstream schools, Botting and Crawley (1995) have shown that developments in medical technology now mean that a growing number of children are surviving with long-term and sometimes complex needs. It follows that, with a policy of inclusion, these pupils are now also joining their peers in mainstream schools. In May 2000, the Department for Education and Employment (DfEE) announced that £100 million will be allocated to mainstream schools between 2000 and 2002 to help them to 'improve further their facilities for children with disabilities' (DfEE, 2000).

Successful inclusion depends upon children receiving appropriate support for their special health needs. Many different types of education and health staff potentially have a part to play in supporting this group of pupils, including: teachers; Local Education Authority (LEA) learning support staff; school care assistants, administrative and catering staff; school nurses and school doctors; specialist nurses; therapists; and medical consultants. Collaboration is needed among these staff to ensure appropriate support is in place for individual pupils.

Pupils with a chronic illness or physical disability straddle the policy boundary between education and health: there is no single policy document which identifies their needs and gives

guidance on support. However, this group of pupils does feature in policy guidance in both education *and* health. Three guidance documents are particularly relevant: the *Code of Practice on the Identification and Assessment of Special Educational Needs*, issued following the Education Act 1993 by the (then) Department for Education and the Welsh Office (1994); guidance on *Supporting Pupils with Medical Needs*, published jointly by the Department for Education and Employment and the Department of Health (1996); and the Department of Health's (1996) good practice guide on *Child Health in the Community*. The following paragraphs outline the relevance of these documents to pupils with special health needs.

2.2.1 Code of practice on the identification and assessment of special educational needs (DfEE/Welsh Office, 1994)

Although the focus of the 1994 Code of Practice is on special needs arising from *learning* difficulties, the legal definition of 'Special Educational Needs' (SEN) in the 1993 Act (Section 156) does include children with a disability 'which prevents or hinders them from making use of educational facilities' (now Section 312 in the 1996 Education Act). In addition, the Code draws attention to the *potential* impact which a child's medical condition may have for his or her education:

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

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

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

Although legislation imposes duties on agencies to help each other in respect of pupils with SEN, the provisions are weak. Under Section 166 of the 1993 Education Act (now Section 322 in the 1996 Act), health authorities must comply with an LEA request in connection with pupils with SEN, subject to 'the reasonableness of the request in the light of available resources' and unless they consider that the help is 'not necessary'. Nevertheless each health authority must have a 'designated medical officer' to lead the local NHS contribution to assessment of pupils with SEN.

2.2.2 Supporting pupils with medical needs (DfEE/DoH, 1996)

The growing number of pupils in mainstream schools with medical needs has exposed a 'grey area' as to the responsibilities of school staff at the boundary between education and medical care. In 1996, the DfEE and DoH issued joint guidance aimed at clarifying the situation through setting out the legal position and providing a Guide to Good Practice. The guidance was intended to assist schools in drawing up policies on managing medication and to put in place systems to support pupils with medical needs in school.

The guidance defines children with 'medical needs' as those with 'medical conditions which, if not properly managed, could limit their access to education' (Good Practice Guide para 7). The guidance cites the Health and Safety at Work Act 1974 as relevant law, which makes it clear that it is the employer - generally the school's governing body or the LEA - who is responsible for health and safety policy, which should include procedures for supporting pupils with medical needs. However, the guidance also makes it clear that it is parents who are responsible for their child's medication: there is no legal duty which requires individual members of school staff to administer medication; this is a voluntary role and the Head will normally be responsible for deciding whether the school can assist (para 11).

Drawing up clear protocols in the form of an 'individual health care plan' is recommended to identify and clarify the level of medical support needed at school (para 75). The Good Practice Guide includes a pro-forma plan which focuses on daily care requirements, what to do in an emergency, and follow-up care. In addition to the child, parents and school staff, NHS professionals (school health staff, GP or other health professional) may need to contribute to the plan, which should be reviewed annually (paras 75 and 77).

2.2.3 Child health in the community: a guide to good practice (DoH, 1996)

In 1996, the DoH issued a good practice guide in respect of all child health services, including the school health service (SHS) which has a range of functions in respect of the health of school aged children. One objective of the SHS is 'minimising the consequences of illness and disability in children for their education' (para 8.1). Inclusion of more pupils with disabilities in mainstream schools is cited (para 8.5) as one of the factors which has led to a shift in recent years from the traditional universal 'medical inspection' model of the service to a more selective focus. Within this more selective focus, the SHS is expected to provide information and advice to schools about individual pupils, and to make a contribution to the assessment and support of pupils with SEN and medical problems in school (para 8.6). However, communication between agencies is rendered complex by the requirement for health professionals to seek the consent of parents or, where judged competent, the child, prior to disclosing any information about a child's

health (para 2.9).

2.3 RESEARCH EVIDENCE ON COMMUNICATION BETWEEN HEALTH AND EDUCATION STAFF

Communication between health and education staff has not been the subject of a great deal of research. In this section, we first report evidence from a number of studies which have highlighted difficulties in communication and collaboration between these staff. We then go on to report detailed evidence from our own earlier study into pupils' support needs, since these findings informed the current study directly; indeed, they were presented to the participants.

2.3.1 Evidence from other studies

A number of studies which focus on teachers' knowledge about specific chronic illnesses (diabetes, cancer, leukemia, epilepsy, and asthma) have found teachers are ill-informed about the conditions and receive little professional advice and support to help them manage the education of these pupils (Eiser, 1980; Bradbury and Smith, 1983; Charlton *et al.*, 1986; Eiser and Town, 1987; Lynch *et al.*, 1992; Court, 1994). In particular, teachers report having difficulty knowing how to deal with emergencies, and how much to 'push' a child to keep up with school activities, both academic and physical. In several of these studies, teachers call for better collaboration between school and health staff (Bradbury and Smith, 1983; Charlton *et al.*, 1986; Eiser and Town, 1987). The implications of not providing guidance on the impact of a child's illness on their education are highlighted by Eiser and Town's (1987) study which found that teachers had low expectations of chronically ill children, believing they would not be able to participate fully in the curriculum. The authors call for health staff to provide guidance so that pupils are not restricted unnecessarily from school activities.

In a study carried out by Bolton (1997), 100 parents whose children had spent time out of school on account of a chronic illness or accident, and 40 children, were interviewed about education provision. The report highlights the importance of continuity in education for this group of pupils and that this can be difficult when a child moves between the hospital, home and school at different stages during their illness. Parents wanted a single person to co-ordinate education during this process. The author recommends the development of a model for liaison between hospital, home education services and mainstream school. Communication difficulties may not only exist between agencies however. In Larcombe's (1995) study of returning to school after treatment for cancer, she found difficulties in communication both *within* health services - between hospital and community services - and *between* health and education services.

Despite publication in 1996 of the joint DfEE/ DoH guidance on supporting pupils with medical needs, in a study of communication between school staff, health, and social services, teachers

continued to report a number of communication difficulties with health staff (Dyson *et al.*, 1998). Advice and information from consultants varied widely; although some gave prompt information which helped teachers to plan appropriate education programmes, others responded only after a considerable delay, or even not at all, on the grounds of confidentiality. Teachers also felt that health staff did not see them as partners, for example not asking teachers for information when pupils had medical assessments. Teachers argued that, although they did not have medical expertise, their knowledge of pupils in their everyday life at school could yield valuable information.

2.3.2 SPRU research

Aim and methods

The findings from our own research into service support in mainstream schools for pupils with special health needs both add weight to and extend existing knowledge about communication between school and health staff. The study was funded by the NHS Executive R&D Programme: Mother and Child Health, and aimed to identify needs for NHS support for schools as expressed by children with special health needs, their parents, and teachers. The research was undertaken in three local areas which, between them, included three Local Education Authorities (LEAs), three NHS Trusts and two Health Authorities. We carried out individual interviews with 33 pupils (aged 11 to 16) with a chronic illness or physical disability which had some impact on school life. A wide range of conditions - and, therefore, likely support needs - was represented in the study including, for example, severe asthma, cerebral palsy, cancer, cystic fibrosis, diabetes, haemophilia, juvenile arthritis, ME, renal failure, and spina bifida.

Data were collected from parents in a total of 58 families: 35 took part in focus group discussions (held separately by area and for parents with children in primary/secondary school); the remaining 23 families, who felt unwilling or unable to join a focus group, were interviewed at home. Data from 35 teachers were collected via focus groups (again held separately by area and primary/ secondary schools).

In a second stage of the project, we convened two joint workshops for invited health and education staff in each of the two Health Authority research areas. Nineteen delegates attended the first workshop, and a further 14 came to the second. The aim of these events was to disseminate the research findings and to encourage delegates to begin to think of issues they might wish to tackle to make any improvements to communication in practice. Full details of the research methods and findings from this study are reported elsewhere (Lightfoot *et al.*, 1998; 1999; and forthcoming; Mukherjee *et al.*, 2000). For the purposes of the current report we turn our attention to findings on communication between health and school staff.

Findings on communication between health and school staff

The central theme in our findings was the importance pupils attached to teachers having a good understanding of their health condition. Pupils felt that such an understanding meant that teachers were more likely to acknowledge their support needs in school, be flexible and take appropriate action to meet their needs. However, across our sample, pupils reported a wide variety of experiences in this respect. Taken together with teachers reporting receiving limited information about pupils' health conditions and their likely impact on school life, our research highlighted the need for improvements to communication between school and health staff.

This need stemmed from weaknesses in the traditional assumption that parents would act as the 'go-between' to ensure school staff had relevant information about their child's health-related support needs in school. Both parents and teachers argued that, for a variety of reasons, parents may not be able to meet the expectations placed upon them in this role. Instead, respondents urged more direct communication between school staff and health professionals. Currently, however, health and education were felt to operate largely as 'two separate worlds'. Teachers reported difficulties with both the *type* of information provided by health staff and the *process* of communication.

With regard to the type of information provided, the main difficulty reported by teachers was that information was not specific enough: for example being told that a child should 'avoid strenuous exercise' was too vague to help teachers avoid being either over-cautious or pushing the child too much. Teachers set out a range of practical health-related information needs, which covered: general information on the condition (especially when rare); details with respect to the individual child (symptoms, treatment, prognosis, and how to respond to the child's questions); and implications for school life (for example, likely absence, medical support needs, side-effects, limitations on participation in school activities).

Turning to the process of communication between school and health staff, teachers reported as a constant struggle their efforts to obtain information from health colleagues. Part of this struggle was due to confusion about the roles of different health professionals in giving advice; for example, can school staff approach GPs?

Teachers commented on four sources of information involving health professionals: the school health service; therapists and specialist nurses who visit schools; hospital-based health staff; and multi-agency meetings. For teachers, the *school doctor* was their first point of contact with health services. While school doctors were generally thought to provide valuable input to procedures leading to a pupil obtaining a Statement of SEN, discussion among teachers revealed

wide variation in the level of support offered by individual school doctors in respect of pupils with special health needs. Teachers thought that the service they received was dependent on factors such as the individual personality of the school doctor and the length of time they had known him or her, rather than there being a systematic approach for communication about these pupils.

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 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.

Parents and young people also had concerns about the expertise of the *school nurse* in respect of their condition, and about their awareness that they even had special health needs. The provision by school nurses of training sessions for teachers on common conditions such as asthma, diabetes and epilepsy was mentioned in only one teachers' meeting and by one parent. Positive comments were made by teachers in one of the three research sites mentioning a recent change in the role of the school nurse locally in which nurses had adopted a more pro-active stance, co-ordinating between families, school and health staff.

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

Turning to *therapists and specialist nurses who visit school*, teachers reported that they were generally well supported by these staff. As regular visitors, there were opportunities for developing rapport, and for easy access to specialist information and advice. Also, liaison between school staff and therapists provided learning opportunities for school staff to carry on treatment regimes. While these comments were positive, data from pupils in our study reveals that relatively few of them - six from 33 - were visited by these health professionals at school.

Both parents and teachers reported variation in the extent to which hospital-based health professionals passed on information, either directly or through parents, to school staff. Teachers reported four reasons for dissatisfaction. First, teachers always had to be proactive in requesting the information. Secondly, teachers did not always know who to contact for advice. Thirdly,

even if teachers managed to contact the appropriate person, information might be refused on the grounds of confidentiality. Fourthly, when teachers provided health staff with information for assessments, they rarely received feedback.

Against this general background of dissatisfaction, examples of good practice were reported. Teachers who had been to hospital clinic open days spoke about how useful these events were for establishing contact with health staff. Some health colleagues were good at providing written updates for schools on a child's condition, either directly or indirectly, via parents.

The final source of information - *multi-agency meetings* - was limited to certain pupils. Only where a pupil had a Statement was there a routine meeting - the annual review - for all the staff supporting the child to come together. Less than half (n=14) of the pupils in our study had a Statement. Although the school doctor's assistance was valued in helping to secure resources for the pupil via Statementing, some teachers expressed disappointment that health staff providing direct care for the child did not attend review meetings. The school doctor was considered a poor substitute as s/he often did not have access to the child's medical records.

In the workshops held in the second stage of the project, delegates identified two areas of good practice in existing inter-agency communication. The first was the system of liaison meetings held in schools, although these were for pupils with Statements only. The second area of good practice was felt to be the system of personal Child Health Records in NHS Trusts. These records were held by the family and completed by each health professional who met with the child. The rationale for developing the record was to overcoming confidentiality problems in sharing information among professionals, since the family was in control of the record. Delegates thought that there might be scope to extend the coverage of the record to include Statementing information.

Delegates identified two broad areas for improving health-education communication. The first was to develop the 'culture' of inter-agency working, which included: clarifying roles and responsibilities of health and education staff; knowing individual post-holders, so as to make connections between the work and interests of staff in different agencies; meeting more regularly for jargon-free and honest discussion about resources, constraints and criteria for service provision.

The second area for attention was to improve health-related information for schools. While health staff might be encouraged to prepare general leaflets on medical conditions, sharing information about individual pupils was more tricky, requiring a way of dealing with patient

confidentiality. One suggestion was that school staff might give parents a card with their contact name and address which, when handed to a health professional, signals parental permission to pass on information to that person in school. An alternative suggestion was that Trusts could develop a pro-forma to ask routinely for parental consent to pass information to schools.

The 'fit' between policy and practice

Policies relevant to supporting pupils with special health needs proved weak in practice. Application of the 1994 *Code of Practice on SEN* by SENCOs varied widely in respect of pupils who had special health needs but, as yet, no accompanying *learning* difficulties. In some schools, but not in others, these pupils were placed on the SEN Register. The significance of this for communication was that, if a pupil is *not* on the SEN Register, then they are outside the remit of the school's SEN Co-ordinator (SENCO) as the person with identified responsibility in school for co-ordinating support and liaising with staff from other agencies. SENCOs themselves reported being unsure as to whether their remit extended to this group of pupils.

The 1996 joint DfEE/DoH guidance on *Support for pupils with medical needs* appeared to have been poorly disseminated among the teachers in our study, many of whom said that they were not aware of it. These teachers suggested that working with families and health staff to design a health care plan would be a good idea, without being aware that this is a key element of existing guidance.

2.3.3 Summary of research evidence on communication

Research points to the need for school staff to have a good understanding of a pupil's special health needs if they are to provide appropriate support to enable the pupil to get the most from school life. Although some teachers report good liaison with health colleagues, others do not: despite national guidance intended to encourage good communication between health and school staff, practice appears to vary widely, as does pupils' subsequent experiences of support in school.

Evidence from teachers suggests that the following factors may constitute potential barriers to effective communication with health staff:

- confusion among teachers as to roles and responsibilities of different health staff and so not knowing who to approach for advice and information;
- lack of direct contact with a pupil's lead health professional: although the school doctor is the point of contact for school staff, s/he has to request the information, which results in delay;

- no system for multi-agency review meetings for pupils without a Statement of SEN.

In addition, teachers held the following beliefs about their health colleagues' attitudes which would affect the likelihood of communication taking place:

- some health professionals refuse to share information with teachers on the grounds of confidentiality;
- some health professionals do not perceive teachers as their partners in caring for children.

Research also suggests that, where health staff do pass on information, attention is needed to ensure that its content meets the needs spelled out by teachers in respect of: the medical condition generally; how it affects the child; and possible implications for school life.

The views of health staff are largely missing from studies carried out in this field to date. This was an important research gap we sought to fill for the current project. How we undertook the research and what we found out are reported in the following chapter. First, we review the literature on methods for getting research findings into practice.

2.4 METHODS FOR GETTING RESEARCH FINDINGS INTO PRACTICE

There is a growing awareness that while dissemination of research findings may raise awareness of the need for changes in practice, research recommendations alone are insufficient to bring about change. Senior management involvement in using that information, and good quality information to monitor its implementation, are also necessary (St. Leger and Walsworth-Bell, 1999). A systematic review of the effectiveness of research-based guidelines as a means of getting research into practice found that guidelines were more likely to be effective if they were disseminated by active educational interventions (such as targeted seminars, educational outreach visits and the use of professionals identified by their colleagues as influential opinion leaders), which require more active participation by professionals; and if reminders integrated into service delivery were used (Effective Health Care, 1994). More recently, a review of different dissemination and implementation interventions (for example, educational outreach, audit and feedback, reminders) found that interventions which used a number of these different strategies, and which identified potential barriers to change, were more likely to be effective (Effective Health Care, 1999). In summary, if research is to influence practice it is necessary to do more than produce guidance on what needs to change. Instead, a pro-active approach is needed in which interventions are devised which take account of the process of change, and involve local service managers and professionals.

A review of the extensive literature on management of change is beyond the scope of this report.

Instead we draw out key messages for planning interventions aimed at getting research findings into practice. We then go on to consider those likely to be involved in bringing about the change - professionals from different agencies and service users - and methods for facilitating their participation.

2.4.1 Facilitating change

Models of individual and organisational change can be used to guide interventions to bring about evidence-based change (Effective Health Care, 1999). In relation to individual change, theories of social cognition have played a role in the development of staged interventions, in which people are first made aware of *why* it might be necessary to change and *what* this will involve, and are then assisted in preparing for the change, before finally taking action.

These staged approaches to changing individual behaviour are parallel to models for organisational change: both stress the importance of guiding people through the change process. For example, ‘the cycle of innovation’ (West, 1997) suggests that organisations need to pass through four phases in order to implement change in services. First *initiation*, in which problems are identified, the need for change is recognised and the agenda is set. The second is the *planning* phase, in which what needs to change is clarified and matched with what fits with the needs of the various stakeholders involved. This is a complex phase which involves thinking both about what is to change and how this will happen. Once this is done, the organisation can move on to the *implementation* phase in which plans are put into action. This phase also involves looking at the successes and failures in implementation, and reflecting on these before considering the future of the service. Finally, there is the *routinising* phase, in which a shift is made from a pilot approach (where the service is closely monitored and evaluated) to a mainstream activity. Another model which follows the same underlying approach of making people aware of the need to change, before expecting them to make the change is the ‘unfreeze-change-refreeze’ model (Effective Health Care, 1999).

2.4.2 Overcoming barriers to change

During the various stages of implementing change, it is likely that people driving the process will encounter barriers. During the early stages, when the focus is on convincing people of the need for change, one way of making progress is to focus on getting endorsement for the broad direction of the change, rather than consensus on the finer details of the plan (Effective Health Care, 1999) or to encourage a search for mutually agreeable ways forward by talking about ‘shared futures’ (Gray, 1985). It has also been suggested that it is better to work with people who put themselves forward as wanting to be involved in the process, since those who are not keen to be involved will simply drop out (Effective Health Care, 1999).

Once in the planning stage, in addition to clarifying the nature of change by considering both what needs to change and what needs to stay the same, it is suggested that time should be spent preparing for potential difficulties. For example, Smale (1996) suggests considering the following:

- Who will be affected by the change?
- What resistance is likely to be encountered?
- How can such obstacles be overcome?
- Who needs to support the changes?
- How should these people be brought on board?

During planning, it is important to be clear about who is going to do what and by when. A recent Social Services Inspectorate report on services for disabled children and their families identified lack of agreed objectives and time-scales as barriers to inter-agency planning and cooperation (Social Services Inspectorate/Gooding, 1998). Research on staff involved in a multi-agency development project found that detailed action plans played a key role in keeping them to schedule, being used as a means of monitoring progress with the work (Sloper *et al.*, 1999).

The literature on organisational change stresses the importance of ensuring that all stakeholders are supportive of the changes proposed (Beckhard and Harris, 1987). In practical terms, this means specifying in action plans details of who needs to speak to whom, about what, and by when (Sloper *et al.*, 1999). It is crucial that all those affected are clear about what is happening, why and how. Methods of communicating this information should be appropriate to the audience (Effective Health Care, 1999).

2.4.3 Working with multi-agency groups in developing services

In seeking to implement change involving more than one agency, as was the case in our project, the process becomes a great deal more complex, involving collaboration among a wide range of staff. Multi-agency planning groups usually come together when those involved appreciate that they need to solve a set of problems which they cannot solve individually. Often groups come together because of an external mandate. While this may help to maintain the activity, it is not thought to be enough to guarantee successful collaboration. Forming a group is not a straightforward process and consideration needs to be given both to group membership and the way group meetings are run (Gray, 1985).

The importance of group membership

First, in terms of group membership, it has been suggested that for collaboration to occur, it is vital that those on the group are seen as legitimate members; that is they have the right and

capacity to participate (Gray, 1985). A person's capacity can stem from having expertise, financial control, access to information or being in the position to block implementation. It is useful to have both managers and practitioners involved in multi-agency planning groups since the work can be informed by their different perspectives, making it more likely that the change will be accepted and appropriate to the roles of staff at different levels within the organisation (Sloper *et al.*, 1999).

Care is needed in bringing together individuals with very different levels of power since this can have a negative impact on groups, particularly if weaker members do not feel free to put forward their views (Gray, 1985). Anyone facilitating change should take time to understand the organisations they are working with, and which individuals have the power to bring about change. St. Leger and Walsworth-Bell (1999) warn that individuals with line management responsibility may not be the only people to have power within a group.

Facilitating inter-professional collaboration

In order for the group to plan change it is crucial to form a multi-agency group with members who work well together. This is not a straightforward process. The literature on group dynamics suggest that all groups go through a similar cycle (Clarkson, 1995; Kent 1997). They begin by 'forming', in which the major focus of attention is on understanding what needs to be done and getting to know each other. Then they tend to 'storm', experiencing a period of conflict and competition between group members. Only then does the group 'norm', where group members listen to each other and value each other's contribution. Having done this they can 'perform', or get on with the task.

When the group is comprised of staff from different agencies, the potential for 'getting stuck' in the storming phase is greater. Each agency has its own ways of working, and uses its own language, making communication more complex. Agencies may also have different and, on occasion, competing agendas and funding arrangements. Furthermore, people may not know each other or have worked together before. The success of inter-professional collaboration is said to depend on maintaining the balance between each profession having its own identity within the group and group members merging to fulfil a shared objective (Biggs, 1997).

The complexity of multi-agency group working means that a neutral facilitator can be extremely valuable (Sloper *et al.*, 1999). Such a person can offer assistance in ensuring the process of decision-making is fair to all by facilitating communication within the group and ensuring that all members contribute to discussions (Schuman, 1996). In addition, a facilitator can: foster participation of individuals who feel intimidated within the group; help the group come to a

shared understanding of the problem to be tackled; intervene when there are rivalries or distrust between members; and speed up the process of decision-making.

Even if a professional taking part in the group had the requisite skills to deal with these issues, it is unlikely that s/he would have the capacity to pay attention to such matters and take part in the group. When facilitating any group there are two main types of process to attend to:

- *Social* - interpersonal interactions, group dynamics, and communication patterns which play a part in the solving of complex problems.
- *Cognitive* - analytical or intellectual factors which shape ideas and decision making.

When facilitating a multi-agency group, there are also 'political' processes to consider. Political process is described as a sub-set of social process, concerned with who exercises power and is able to participate in decision-making (Schuman, 1996).

Care is needed in deciding who should be appointed as facilitator. Gray (1985) notes that anyone taking on the role of facilitator needs to be seen as having legitimate authority to do so, particularly if they are also convening the group, otherwise stakeholders are likely to withdraw from the process.

In addition to having a neutral facilitator, findings from our own previous multi-agency development project (Sloper *et al.*, 1999) indicated that staff felt it more efficient to have blocks of one or two days away from everyday work, rather than a series of short meetings, in order to:

- establish relationships;
- ensure shared understanding;
- build a team;
- plan the service development.

They also reported that holding such meetings in a neutral venue, away from the distractions of everyday work, facilitated the process. Once the steering group was formed and action plans developed, participants found it valuable to be monitored by a member of the research team. They reported that the presence of an outside observer provided the impetus to stay committed to the project during the implementation phase.

2.4.4 The role of service users in development work

Reasons for involving service users

Service users' involvement in the development of service plans is increasingly being encouraged, not only in the NHS, but in other public services, such as housing and social services (DoH, 1998 and 1999; DETR, 2000). In response to public policies such as the Children Act 1989 and

Children (Scotland) Act 1995, there has been a move towards consulting children, as well as adults, about the services they receive. The concept of the service user has shifted from a passive recipient of services to one of an active co-worker. As such, users have a legitimate 'stake' in the shape of services, both at the 'micro' level of their own situation and at the 'macro' level of service development more generally (Myers, 1996).

There are two major arguments which underpin this trend for increased service user involvement, one focussed on principle and the other on practice. In terms of principle, citizens have rights to a say in a democratic society. Promoting citizenship helps to counter challenges faced by modern-day public service organisations (PSOs), such as the perceived lack of democracy and - in the case of unelected bodies such as health authorities and NHS Trusts - concerns about their limited responsiveness and accountability to their local populations (Barnes, 1997; Milewa *et al.*, 1999; Sanderson, 1999; The Commission on the NHS, 2000). From the PSO point of view, arguably there is a complementary need to secure public confidence in and support for likely radical changes in future patterns of health care and welfare (Barnes, 1997).

The second - practical - argument for increased involvement is that services will be provided more efficiently and/or effectively as a result of taking into account the expert knowledge of service users about their needs and appropriate ways of meeting them. The acknowledgement that users have 'crucial' information and experience (Beresford and Croft, 1993) - which, without asking users, cannot be known to service providers, managers or commissioners - represents a considerable shift from the traditional approach to public service planning and delivery, which has placed a premium on professional knowledge and expertise and on managerialism (Beresford and Croft, 1993; Barnes, 1997; Harrison and Mort, 1998; Sanderson, 1999).

Methods for involving service users

Research on methods of consulting service users notes that researchers and planners of services may be asking people to take on an unfamiliar role when they consult with them (Robertson, 1995; Tozer and Thornton, 1995). It is suggested that lay people should be prepared for this new role by meeting as a service users' group, giving them an opportunity to acquire skills and knowledge before meeting with staff. Group members may also gain confidence through the development of a cultural identity and peer support. These considerations are particularly important when consulting with children and young people (Doorbar and Associates, 1995). Members of service user groups themselves highlight the importance of being given feedback about any changes made as a result of consultation if they are not to feel exploited (Lindow, 1999).

2.5 OVERVIEW OF THE PROJECT

The overall aim of the current project was to implement research recommendations on the need to improve communication between health and school staff about children with a chronic illness or physical disability. In planning the project, we drew on the literature reviewed in this chapter. It was clear that we would need to address the research gap in respect of the views of health staff on communication between health and education. Knowledge of the difficulties of getting research recommendations into practice suggested that the research team would need to work actively with service providers in order to bring about change, and that we should take an active role in facilitating the process of change and in forming a multi-agency group of staff and service users to take the work forward. As a result, the project was designed as follows.

2.5.1 Stage one: research phase (4 months)

Semi-structured interviews would be carried out with health staff working in or from the Department of Paediatrics at York NHS Trust. These interviews would cover: the needs of chronically ill or physically disabled children and young people in school; their role in meeting these needs; the difficulties they experience in achieving good communication with their colleagues in education; and their experience of good practice. This stage would build upon the authors' previous research on pupils' health-related support needs.

2.5.2 Stage two: development phase (2 months)

It was proposed that a multi-agency working group (including parent and pupil advisors) would be set up to develop and oversee the implementation of improved communication to meet the needs of chronically ill or physically disabled pupils.

All health staff interviewed in the research phase would to be invited to attend a one day workshop, along with representatives from York Local Education Authority (LEA) and Special Educational Needs Co-ordinators (SENCOS) from schools in York. This workshop would be facilitated by the researchers and a consultant specialising in group process. It would involve: i) learning about research findings, from both the previous research study and from interviews with health staff carried out during stage one; ii) consideration of the implications of the findings for local practice; and iii) identification of the ways in which professional practices or organisational structures needed to change to improve communication between health, education, and families. The workshop would allow a range of relevant staff to have an input at an early stage to plans for change, thus bringing them 'on board' with the project. At the end of the workshop, professional members of a working group would be identified. This working group would have the task of developing and overseeing detailed plans for changes in practice.

During the early stage of the project, two advisory groups would be established and facilitated by the researchers: one of parents and the other of young people of secondary school age with a range of chronic health conditions. Members would be recruited from families already known to the researchers through their participation in the earlier study.

Once professional members of the working group were identified a second, one and a half day, workshop would be held to bring health and education staff together with the parents' and young people's advisory groups. The aims of this second workshop would be: i) to review the conclusions from workshop one about the specific aspects of practice that need to change, or be introduced, to improve inter-agency communication; and ii) to draw up detailed action plans and allocate responsibility to ensure that these changes would be implemented and maintained. In addition to planning, this workshop would also help the group to get to know each other and work together effectively. The delegates would decide at this workshop how they wished to work during the remainder of the project, in particular, whether to continue to meet as three separate groups or to merge.

In addition to facilitating the workshops, the research team would observe and record the content, process and outcomes of these events.

2.5.3 Stage three: monitoring and implementation (6 months)

During this phase the working group would continue to meet on a regular basis to lead and monitor the implementation of action plans. These meetings would be observed by one of the research team. If the parents' and young people's groups decided to continue to meet separately, the researcher would also observe these meetings and, if required, facilitate meetings and act as 'go-between', passing information between the three groups.

The researchers would draw up reports on all meetings, recording the processes involved in implementing action plans, including difficulties or barriers to change in improving inter-agency communication. Recommendations from the project would then be drawn up in collaboration with the working group.

In this final stage of the project, researchers would gather parents' and young people's views on their experience of involvement in the project and draw up recommendations for user involvement in service planning.

While acknowledging that the group's work might take longer than six months, we anticipated that the initial implementation would be underway within the timescale for which we were

funded to work with the group.

2.5.4 Stage four: dissemination (3 months)

In addition to traditional methods of disseminating research findings, such as writing articles for academic and trade journals and presenting papers at conferences, we proposed to run seminars for health and education staff within the Northern and Yorkshire Region. The purpose of these seminars would be to promote an understanding of ways in which agencies can communicate more effectively about this group of children, enabling replication of the project in other areas.

CHAPTER THREE

RESEARCH PHASE

3.1 THE AIM OF THE RESEARCH PHASE

As we noted in Chapter Two, the existing research literature includes the perspectives of young people, parents and teachers on communication between education and health staff in respect of pupils with special health needs. However, the views of health staff are largely missing. Therefore, in advance of working with all concerned to draw up plans to improve communication in York, we sought to fill this gap in knowledge through investigating health professionals' views on their experiences of communicating with school staff.

In this chapter, we report on the research methods for and findings from data collection from health staff in York NHS Trust. We then set out conclusions from these data and their 'fit' with existing research evidence from other sources. In a final section, we explain how the research evidence on communications informed the development work that we describe in the remainder of this report.

3.2 RESEARCH METHODS

We carried out 20 semi-structured interviews with health professionals working for York Health Services NHS Trust, which provides acute and community health services. Our recruitment criteria were to include as wide a range of staff as possible, and that all those interviewed carried (or were likely to carry) some responsibility for meeting the health needs of children with a chronic illness or physical disability. A list of individual staff to approach for interview was compiled with the advice of the Consultant Community Paediatrician, who was our co-applicant for project funding.

Interviews were carried out with the following staff in Spring 1999:

- Consultant Paediatricians (n=4)
- Consultant Community Paediatrician
- School Doctors (n=5)
- School Nurse
- Specialist Epilepsy Nurse
- Diabetic Specialist Nurse
- Health Visitors (three present, treated as one joint interview for analysis purposes)
- GP
- Speech and Language Therapist
- Paediatric Occupational Therapist

- Paediatric Physiotherapist
- Clinical Psychologist
- Consultant Psychiatrist.

For most categories of staff we interviewed a single professional to obtain a perspective from that professional group. In the case of health visitors, the initial respondent opted for a joint interview in which two colleagues were present for part of the time. For analysis purposes, we have treated this as a single interview. In the cases of hospital-based paediatricians and school doctors, we interviewed all the local staff, since these professionals are the main holders of medical information which research suggests would be of use in supporting pupils at school.

The interview topic guide (see Appendix One) was developed from existing evidence about communication between health and education staff and covered: their role and practice in giving and receiving information to and from school staff; examples of good practice and difficulties in communication; and any recommendations for improvement. Two members of the research team took responsibility for the interviews, which were carried out face to face and tape recorded. We were interested both in responses to the *a priori* issues in the topic guide and to other, 'emergent', issues raised by respondents. Qualitative interviews can produce a mass of data, and the analyst must follow a transparent, systematic and defensible process of reducing these data without losing a sense of its richness (Miles and Huberman, 1994). We used the *Framework* approach for analysing qualitative data (Ritchie and Spencer, 1994).

Since our interviews were quite structured and we were not seeking to analyse the responses in depth, we did not transcribe the interviews verbatim. Instead, the interviewer in each case took responsibility for preparing notes of the interview, using the topic guide as a template, and incorporating any 'emergent' issues.

To promote reliability, all three members of the research team read all the notes and agreed a suitable thematic framework for allocating the data systematically across a series of 'charts', which is the method used in *Framework*. Each chart is a matrix for displaying data on a particular theme. Each respondent is allocated a row and sub-themes are organised in columns. Charts are useful in allowing the themed data to be read both respondent by respondent (by reading across a row) and by sub-theme for all respondents (by reading down a column). The work of charting was carried out by two members of the research team, each taking responsibility for a number of charts. The researchers wrote a short prose summary of each of their charts and then discussed these with each other. In turn, these discussions allowed us to reduce the data further by identifying a smaller number of over-arching themes. In writing up

our findings, the *Framework* approach allowed us to refer back to the charts and, when necessary for clarification, to the original notes from the interviews, in order to verify the conclusions that we were drawing from our analysis.

3.3 FINDINGS

First, we describe current practice in communication between health and school staff, including the types of information passed on and unmet information needs of health staff. We then outline health professionals' examples of good practice and the difficulties they face in communication with school staff. We conclude with their recommendations for improvements.

3.3.1 Current practice

Giving and receiving information

Health staff were asked both about information they pass to school staff and *vice versa*. Ten of the 20 respondents saw themselves as having a role in passing on *general* information to schools about health conditions. Such information was passed on in a variety of ways: in writing; over the telephone; and/or via training events for school staff. One person expressed concern that information leaflets were only currently available in York for a small number of health conditions.

Health-related information about *individual pupils* was given by health staff to school staff and *vice versa*. All 20 respondents mentioned having given specific information about an individual child directly to schools, whether through a visit, in writing, over the telephone, through training or in liaison meetings.

Fourteen respondents also talked about receiving information from school staff. Sometimes this information was received as a result of a request for information by the health professional, for example to assist in making a health assessment (n=7), or in taking decisions about on-going case management (n=3). On other occasions, teachers might volunteer information, for example when attempting to access services or support from health staff (n=4). Four respondents also noted that occasionally teachers chose to pass on information to a health professional about a child's progress in school without any clear rationale for doing so.

Generally health professionals were satisfied with the information they received from teachers. Five commented that teachers were prompt to respond to their requests, although two mentioned that they could be slow to provide written reports. One person noted that written reports usually came from head teachers when it would have been more appropriate to receive information from the class teacher, who was in day to day contact with the child. Six said that the quality of the

information they received was satisfactory. However, seven respondents did identify unmet information needs, relating both to an awareness of the child's health-related needs at school and to build up their overall picture of the child. Unmet health-related information needs were: the level of school absence; symptoms experienced by the child in school; and the teacher's views on whether the child needed any additional support in school. The speech therapist also said that it would be useful to know the pupil's educational targets for each term so that she could work on appropriate vocabulary with the child. The more general unmet information needs were: the child's social relationships in school; any educational difficulties (two respondents said they would welcome knowing whether a pupil had a Statement); and the family's circumstances.

Direct and indirect communication

Communication between health and school staff could take place either *directly* or *indirectly*, through either another health professional or a parent. Direct communication included face to face contact, telephone conversations and written reports. Variation in the pattern of communication was apparent both between respondents in the sample and within accounts of an individual's own practice.

Of the 20 respondents: five reported that they *always liaised directly* with the school (a mental health professional, two of the school doctors, a school nurse and one of the therapists); seven said that they *usually liaised directly* with the school (three of the school doctors; a specialist nurse, a mental health professional, and two therapists); and eight said that they *usually liaised indirectly* through a third person (the GP, all the consultants, a specialist nurse and health visitor). This latter group included categories of staff who are least likely to visit schools: GPs and consultants. The health visitor talked of liaising with school nurses. The specialist nurse worked part-time in this role and so had opted for a model of using her scarce resources to educate school nurses. Health staff who said they would 'usually' liaise directly appeared likely to take a pragmatic approach to passing on information. For instance one therapist mentioned that she would liaise indirectly if she knew another health professional would be visiting the school in question before her own next visit. School doctors in this category reported liaising through school nurses, who were more frequent visitors to schools.

Practice varied among respondents as to whether they would liaise with school staff via parents. Eight respondents mentioned doing so, six of whom passed on information verbally. The other two respondents said that they would pass on written information to schools via a parent, one adding that she would also telephone the school herself.

Four respondents said that there were certain types of information that they assumed parents

routinely passed on to schools and so would not take this task on themselves. The circumstances under which parents were assumed to take the initiative included: when the child did *not* have a Statement of SEN; when the condition was ‘mild’; or, for children with diabetes, when it was assumed that hospital clinic staff would have asked the parent to pass on information to school.

Commenting on different ways of communicating with school staff, direct face to face contact was thought best, for a number of reasons: ease of explaining the issues; seeing the child in the school setting; and getting a better knowledge of each other’s roles so, for instance, a teacher can understand other ways in which the health professional might be able to help. However, routine face to face contact was often unrealistic, given that teachers far outnumber health staff and that health staff must balance their time for liaison against that for direct care of their young patients.

3.3.2 Good practice and difficulties in communication

Respondents were asked about any local examples of good practice in communication with school staff and about any difficulties they experienced. The data indicate three areas for attention to communications - *within health services*; *within schools*; and joint work *between health and education* - and the findings are structured accordingly.

Good practice and difficulties within health services

Respondents drew attention to the following communication issues within health services: the flow of information; use of the parent-held Child Health Record; meetings among health staff; and clarity of professional roles.

Flow of information: comments were made about information flows among the following groups of health colleagues: from consultants to school doctors; from school nurses to school doctors; from health visitors to school nurses; from specialist nurses to school nurses; and between consultants, school nurses and specialist nurses. While examples of good practice were reported, a general difficulty raised was the lack of systematic protocols for passing on information, which meant in turn that practice varied widely between individuals. Where information was not passed on between health staff, this posed difficulties for communicating with schools.

School doctors drew attention to differing practices among consultants in the likelihood of them providing school doctors with information relevant for school staff. School doctors said that, owing to their involvement in Statementing procedures, they could only be confident about receiving information from a consultant for Statemented pupils. For pupils without a Statement,

the decision to inform a school doctor at all - and, if so, what information to pass on - was at the discretion of the individual consultant, and practice varied widely. School doctors said that they felt embarrassed when teachers asked them for advice on pupils whom they were unaware had a medical condition. It was also then impossible for them to give the advice needed without the delay involved in going back to the consultant to request information.

Consultants themselves acknowledged that they held differing views about passing information routinely to school doctors. Two consultants said they were unhappy with the idea of routinely copying their letters to GPs on to school doctors. For one person this was due to concerns about maintaining patient confidentiality. The other consultant thought that copying letters would simply be increasing paper work, which would not be read.

Where consultants did copy GP letters to school doctors, one school doctor reported that it could be difficult to know exactly what part of the content the consultant expected them to pass on to schools. This respondent had found it very helpful that one consultant was in the habit of appending a note for the school doctor to make explicit what should be passed on and that parental consent had been obtained. For school doctors, a key issue was being careful not to pass on information which might be deemed confidential. However, two consultants expressed the view that it was the professional responsibility of the school doctor to decide what information needed to be passed on to the school.

Both school doctors and consultants mentioned that these communication difficulties had now been acknowledged within the Department of Paediatrics and that improvements were being made. School doctors, however, remained concerned about information transfer from other consultants, who were also thought less likely than paediatricians to have in mind the likely consequences of illness for a young patient's life in school.

School nurses were seen as a potential source of information for school doctors. Again, practice varied, although it was hoped that the flow of information would improve following recent moves in York to clarify and standardise referral procedures from school nurses to school doctors, and when school entry health interviews by school nurses were introduced later in the year.

Turning to the flow of information between health visitors and school nurses, health visitors commented that, since the two groups of staff were now managed separately, it had become more difficult to maintain links. While all health visitors passed on their case notes to school health, practice varied as to whether a health visitor would actively seek out a particular school

nurse to discuss an individual pupil. This meant that there was not a system to guarantee that any health-related needs of new pupils would be flagged up for the school nurse to raise with school staff.

By contrast, specialist nurses took on a more pro-active information-giving role with school nurses. The diabetes specialist nurse said that she made a point of telling the appropriate school nurse at the point of a pupil's diagnosis. The epilepsy specialist nurse was training school nurses and setting up a resource library to help ensure that all school nurses could deliver a good standard of service. A consultant talked about copying letters directly to the epilepsy specialist nurse since she has 'a pivotal role' for these children. In turn, consultants reported receiving useful information from nurses: about children's needs from school nurse 'drop-ins'; and about teachers' gaps in knowledge from the diabetes specialist nurse.

Use of the parent-held child health record: health visitors reported that this record had been set up so that a central note of health professionals' interventions with a child could be kept by parents, for reference by all those working with that child. However, health visitors reported that they seemed to be the only professional group routinely making entries in the record.

Meetings between health staff: the weekly meeting between child and adolescent mental health and paediatric staff was felt to be helpful for sharing information about complex cases.

Professional roles: there was some uncertainty among health professionals as to the current and/or developing roles of school health staff. Three consultants felt that the role of the school doctor needed to be clarified. Evidence also emerged of variation among school nurses in their support for pupils with chronic physical conditions, despite them being well placed as a link between health and school staff. A consultant drew attention to this variability, as did a specialist nurse. However, the school nurse discussed the wide remit the school nurse role in York, which meant that there was little time for focussing on children with chronic conditions. Both the school nurse and consultants felt that a focus was gradually developing within the role of the school nurse on providing support for pupils with mental health needs.

Good practice and difficulties among school staff

Health staff mentioned examples of what they considered to be good practice by school staff in respect of communications. They valued 'good' SENCOs, who: ensured messages were passed on to relevant staff; persuaded reluctant teachers to do something for a child (when they might

not listen to a health professional); and kept an overview of a child's progress through their school career in a way that year teachers cannot do.

Health staff were appreciative of school staff who prioritised communications by creating time to talk with them. Being pro-active in asking a health professional for advice was also valued, as was taking the initiative in organising health-related training. An example was given by a school doctor of a group of Personal Support Assistants (PSAs) in one school asking to borrow a training video on administering rectal diazepam. A therapist talked positively about a head teacher who had allowed a PSA paid time to accompany a pupil to clinic appointments, so learning more about the child's condition and how to support the child in school.

Health staff reported wide variation in the ethos of schools with respect to supporting pupils with special health needs. Where the ethos was unsupportive, respondents identified three problems for communication stemming from unhelpful attitudes of some school staff. The first problem - raised by all three therapists - was that often the information they gave to the school was not passed on to the members of staff who could best use it to support the child. In these cases, information typically stayed with the head teacher or SENCO, when it was intended for the class teacher.

A second difficulty with attitudes arose where teachers appeared unwilling to meet with health professionals when they visited the school:

Staff don't appear to have time to see me, they're reluctant when I offer to visit. There's nowhere private to talk and no protected time, the teacher is always distracted. I wish teachers were more welcoming.
(Specialist nurse 1)

and

The ethos of schools varies regarding medical matters, it can be difficult to get your foot in the door with some schools.
(Specialist nurse 2)

The third difficulty was with non-teaching staff, and was raised by a therapist. She reported that, despite taking care to inform school secretaries in advance when she was planning to visit, secretaries frequently failed to let teachers know that she had made an appointment to see a child in school. This put a strain on the relationship with teachers as it meant the therapist appeared rude by arriving unannounced at the classroom to see a child.

Good practice and difficulties in joint work between health and school staff

Examples of the following areas of good practice were given: joint meetings; policy

development; shared documentation; and training.

Joint meetings: the Child Health and Education Assessment Forum (CHEAF) meets every two months. It was felt useful for facilitating discussion among health and education staff about children whose condition is difficult to diagnose and/or manage, for example chronic fatigue. Meetings are attended by the educational psychologist, paediatricians, school doctors, child and adolescent psychiatrist and psychologist, and the community psychiatric nurse. The Autism Spectrum Group, also meeting every two months, was a valued opportunity for discussion among relevant health and education staff about pupils with this condition. Health staff also valued the system of liaison meetings which some - but not all - schools have organised to discuss all pupils on Stage 3 and above of the Code of Practice on SEN. Health visitors commented on the usefulness of termly meetings in nursery schools in one part of York in which nursery staff, therapists and a health visitor discuss any issues about the children's development likely to have an impact when they start school.

Policy development: the school nurse spoke about the anaphylaxis policy in York as an example of good practice in policy development. The need for a policy had arisen owing to teachers' concerns in using Epi-pens when pupils had experienced anaphylactic shock. A policy on authorising what to do in such cases was developed to apply to all schools in York and is signed in each pupil's case by the child, a parent and the GP. The policy is backed up by a protocol in which the consultant informs the school nurse on diagnosis. The nurse then visits the school to inform, train and reassure teachers.

Shared documentation: the epilepsy specialist nurse reported that she was piloting health care plans for pupils with the condition. She would use the pilot to check that she was not asking teachers to duplicate records they already keep and to find out from teachers any ideas they have for managing epilepsy in school. One therapist spoke about valuing those school staff who were prepared to use the system of the school/therapist message book passed via the parent between the two professionals. This therapist also saw as good practice a book used in some schools for all visiting professionals to record for each other what had happened on their visit to a pupil.

Training: the occupational therapist spoke about the potential value of a study day being organised to increase teachers' understanding of the needs of pupils who have developmental co-ordination difficulties. Due to caseload pressures, occupational therapists were unable to work with children who are mildly affected, but they could be helped in school provided teachers could identify their needs and know how to support them. School nurses could also take on a more pro-active role if they saw these pupils at their 'drop-in', and it was hoped that some school

nurses would also attend the study day.

Health respondents also raised a number of difficulties in working with school staff: practical difficulties; parents as a conduit of information; confidentiality; and knowledge of respective roles.

Practical difficulties: six respondents drew attention to difficulties for health and school staff in finding a good time to contact each other, when teachers were in classes and health staff in clinics. It was also thought difficult, owing to their sheer numbers, to work with all school staff who have contact with pupils who have special health needs.

Parents as a conduit of information: in practice, parents were often a conduit of information between health and school staff. However seven respondents expressed concerns about this: that parents may be reluctant to pass on some information; that they may not remember all the details; that they may not see the relevance of the information for schools; or that they might seek to 'twist' what a health professional had said to try to get what they want from school staff.

Confidentiality raised a number of concerns among health staff about passing on information to school staff, with the dilemma well summarised by the following:

It's a minefield: on the one hand everything should be confidential and on the other we should all be working together.
(School nurse)

Respondents' accounts revealed different approaches to dealing with family consent in relation to passing information to school staff. Six said they always asked for parental permission, while another four said that parents were always aware that information was passed on. Here health staff told parents what information they felt the school needed and would be passing on. However, eight respondents said that, in some circumstances, parents might not always be aware that information is being passed on to the school. Although not routine practice, examples of these circumstances included: if the health professional considered passing on the information to be in the best interests of the child; where the information was not considered sensitive; or where they were passing on a subjective opinion rather facts.

Five respondents commented that having to seek out parental consent delayed the speed at which they could pass on information to teachers. A school doctor and school nurse felt that, although they sought parental consent for passing on the results of routine assessments - such as hearing tests - this was probably 'going overboard' since teachers needed such information to educate

the child. A consultant reflected on the cumbersome nature of the current system for dealing with teachers' requests for information:

If the teacher asks me, it takes me two weeks to write to the parent to ask for permission, then two weeks to wait to see if the parent objects, then two weeks for me to write back to the teacher. I do try to remember to copy my letter to the parent to the teacher, so that the teacher knows what I am doing about it. But it's a frustrating way to pass information to teachers. It's quicker if the teacher routes the query via the parent, so the parent and I can be clear what can be passed on at the same time.

(Consultant)

Although seven health staff mentioned the difficulty they faced when parents refused permission for information to be passed on to the school, they said this rarely happened. When it did occur, they would make efforts to persuade reluctant parents that passing the information was in the child's best interests. Nevertheless, the right of the parents to refuse meant that passing information from health staff to schools could not be automatic.

Children appeared to be given much less say than their parents in consenting to information being passed to schools. Instead, health staff spoke in terms of the child being aware of what was being passed on, since they were present during the discussion between health professional and parent. Only one respondent (a consultant) mentioned routinely writing directly to the child after each clinic appointment, explaining who would be receiving what information. Another respondent (a specialist nurse) talked in terms of empowering children by asking them what they thought should be passed on to school staff.

Ten of the 20 respondents had concerns that, since NHS staff adhere to a stricter code of confidentiality than do teachers, the latter may not keep confidential the information they were given:

Education is a more open environment in terms of passing on information. They find it difficult that we don't just tell them, and we find it difficult because we're not sure who they might tell.

(Therapist)

Three of these respondents mentioned that the more open approach in schools meant information risked being shared within the school community against the wishes of the child or parent. Five respondents felt that teachers could behave inappropriately by expecting them to pass on everything they knew about the child and family. These health staff argued that the appropriate response was to tell school staff only what they needed to know.

Knowledge of respective roles: Three respondents said they had difficulty knowing which

member of staff to liaise with in schools. For two school doctors, confusion arose around the role of the SENCO where pupils have a medical condition but are not on the school's SEN Register.

Seven respondents also reported as problematic school staff's lack of understanding of their own role as a health professional, mentioning that some teachers did not ask for help and advice when health-related problems arose and/or under-utilized their scope to assist with aspects such as advice on classroom activities, home visits, and annual reviews.

3.3.3 Respondents' recommendations

We asked each respondent whether they had any recommendations for improving communications between health and school staff in York. We have included all the suggestions here although, since respondents were interviewed individually, they do not necessarily indicate a consensus view. Recommendations are categorised according to where responsibility would lie for their development: health; education; or joint work.

Recommendations for health

Flow of information

- as the link health professional with schools, the school doctor needs copies of consultants' letters to GPs, and to know what information parents have consented to be passed on to schools.
- occupational therapists should probably work more with school nurses, advising them about support in school for the considerable number of pupils with mild developmental co-ordination problems.

Roles

- to be helpful to school staff, the school doctor needs to be able to answer teachers' queries and have an educational role in respect of health conditions and school policies. In future, the school doctor might usefully practice as a 'developmental paediatrician' in a Primary Care Group (PCG)-matched locality, taking referrals from GPs, school nurses and school staff. The school doctor would refer on more complex cases to paediatricians. The school nurse would be the main link with individual schools.
- to overcome variability among school nurses and a lack of paediatric training, a small number of posts for nurses with a generic community children's nursing role could be developed. Each nurse would have a special interest and be able to support school nurses,

who would be carrying out health promotion and ‘drop-in’ work in schools.

Recommendations for education

Flow of information

- communication would be improved if teachers could commit just a small amount of time (10 minutes) without distractions to discuss a child’s case with a visiting health professional.
- mainstream school staff could use the system in special schools of completing periodically a short pro-forma for health staff about the child’s progress and whether the teacher thinks that they need any help.
- support for pupils from PSAs is likely to be enhanced if more head teachers would allow PSAs to accompany children to clinic appointments.

Joint recommendations

Flow of information

- a staged Statementing system for pupils with medical needs might be a useful parallel to the SEN system, including regular inter-agency reviews.
- a medical register in each school would provide a central source of information: if consultants were given responsibility for sending updates, it could encourage them to consider what school staff need to know and to ask for parental consent more routinely.
- more teacher training sessions on health issues would enable health staff to inform greater numbers of teachers.
- the model of joint nursery and health staff meetings could be extended to other areas in York.
- with regard to family consent for passing information to school staff, the current system could be ‘turned on its head’ by health professionals making clear to parents an expectation that information will be routinely passed on unless they - or their child - indicate otherwise.

Roles

- a written agreement about how to meet a pupil’s health needs at school would be useful,

signed by a member of school staff, a health professional and a parent. Such an agreement would clarify the role of school staff and reassure them that the parent had authorised them to take action.

- leaflets about the roles of different therapists could be developed and passed to school staff on a visit, along with the therapist's contact name and telephone number. Such a leaflet might help school staff to understand the range of issues about which therapists can advise.
- two respondents wondered whether a 'key worker' was the best solution to communicating about the needs of this group of children. Such a worker would: hold all the information about the child and disseminate it; see the child regularly; and be a focus for liaison.

3.4 CONCLUSIONS

Clearly, health staff in York are involved, whether directly or indirectly, in giving and/or receiving health-related information to and from teachers about pupils with special health needs. In doing so, health staff experience a number of difficulties, not just in communication with school staff, but also in communication among health staff working for the Trust. With few protocols for transfer of information among health staff, practice varies widely and a number of communication 'blocks' are apparent. Since consultants are the primary source of much of the information, their practice is crucial to its subsequent flow. Information flows appear to work best where individual staff have a keen interest, or where the child has diabetes or epilepsy for which there are specialist nurses in post and staff work to information protocols. Lack of clarity about the roles of school health staff could be a factor limiting the flow of information.

In their work communicating with schools, health staff identified a number of examples of good practice in respect of joint meetings, policy development, documentation and training. Health staff valued efforts made by some school staff to pass on health-related information to their colleagues and to ease arrangements for visiting schools. However, as among health staff, attitudes and practice varied between schools and individual teachers on health matters. Health staff had particular concerns about the security of confidential health information in schools. A practical problem was getting in touch, with teachers and health staff having little time to contact one another. Health staff were also unsure who had responsibility for this group of children, especially in secondary schools, and so who they should contact.

The flow of information and clarifying roles were two key issues about which health staff subsequently made recommendations. Some of these recommendations built on existing models of health-education communication, for example the Code of Practice on SEN and practice in

special schools.

3.5 CONTRIBUTION TO EXISTING RESEARCH EVIDENCE

The findings of this research both complement and add to the existing research evidence in this field reported in the previous chapter. It is clear that communication practices between health and school staff are not standardised, but left to the discretion of individuals in both agencies, which has resulted in wide variation in practice. When practice is good, pupils can be well-supported, but current arrangements do not guarantee, or even foster, good communications.

As with school staff, health staff have a number of unmet information needs. Barriers to effective communication suggested by teachers - confusion about professional roles and responsibilities; lack of information from consultants; concerns of health staff about confidentiality; and staff from different agencies not perceiving each other as partners - are supported by data from health staff.

Some of the communication difficulties health staff experience can only be alleviated through action within their own agency, for example, agreements about information to be passed from consultants to school doctors. This finding parallels that from teachers, who report difficulties with information flows within and between schools. Therefore it is clear that improving communications requires attention not only to joint work *between* health and education staff, but also to practices *within* each agency.

Aside from wide variation in practice in passing on information, a second key stumbling block to consistently good communication appears to be the lack of clarity and understanding of respective roles. This poses both practical problems in knowing who to liaise with, but may also result in under-use of colleagues' information and expertise, thereby limiting the support available for pupils.

In turn, these findings point to the value of health and education staff developing jointly a more *systematic* approach to communication if the support needs of pupils with special health needs are to be met. It is this work which the development project sought to address in York and which is described in the remainder of this report.

3.6 HOW THE RESEARCH DATA WERE USED TO INFORM THE DEVELOPMENT WORK

In Chapter Two we reported that the literature on management of change suggests the value of a staged model of development work, in which the first step is for those involved to acknowledge the *need* for change. In York, key professionals had already declared an interest in making

improvements to communication between health and education staff based on evidence from our earlier research into pupils' support needs. After carrying out the research into the views of local health professionals, we used all these data - from young people, parents, teachers and health professionals - to inform the participants at the first development workshop.

We used the data in two ways. First, we presented a summary of the research findings in order to demonstrate evidence for the need for change. Secondly, we made available as a resource (see Appendix Two) the examples of good practice cited and recommendations for improvement. Participants drew on this resource when asked to consider their priorities for making changes to health-education communications in York.

CHAPTER FOUR

THE DEVELOPMENT PHASE: WORKING WITH HEALTH AND EDUCATION STAFF

4.1 INTRODUCTION

In this chapter, we describe how we approached the task of working alongside health and education staff to develop plans for improving communication. We begin by describing the methods we used for monitoring the development work. We then explain the research team's role during the development phase and the support we offered to health and education staff. Next we describe the phase, outlining the various events held and what happened as a result. The chapter ends with reflections on the development work from both the research team and the working group, along with recommendations for others undertaking similar work.

4.2 METHODS FOR MONITORING THE DEVELOPMENT WORK

During the development phase, multiple methods were used to collect data. The aim in doing so was to ensure that we had a record of the process of the project. In addition to this, we were also interested in tracking the impact of the research team's input on the project.

Observational methods are favoured for researching process because they are good at answering 'how' questions and for exploring what is 'going on'. They also provide a record of what people do, rather than what they say they do (Robson, 1993). The type of the observational method, particularly the degree to which the data collected are pre-determined, varies according to whether the observer is participant or non-participant in the process. During the early phase of the development work, members of the research team were acting as facilitators of staff workshops and service users' meetings. This meant that we were automatically participant observers. Participant observers usually adopt an unstructured approach. Texts on using observation methods suggest that the researcher begins with a broad 'descriptive observation' - including the physical setting, the group members and key events - which can be used to write an initial narrative account (see for example, Robson, 1993). Then, the researcher can move in to more 'focussed observation' attending to some aspects of what is going on but not to others, according to the particular research questions.

What is striking about the literature on research methods for investigating process (both in methodological texts and in empirical research papers) is a consensus that a multi-method approach is appropriate (Davis, 1997; Torres and Deschenes, 1997; Robson, 1993; Rhodes *et al.*, 1991; Jorgensen, 1989; Chadwick *et al.*, 1984). There appear to be two reasons for this: first, to compensate for a weakness in any one method for capturing all the relevant data. For

example, observation may be the best way to collect data on actual process, but would not capture other useful data, such as participants' perceptions of the process (Weingart, 1997). Secondly, using a range of methods is a strategy for promoting internal validity through triangulating the data (Rhodes *et al.*, 1991).

Reports were prepared on each stage in the development phase of this project. These reports included observations of:

- contextual information - where the event was held, who attended, which members of the research team were involved;
- social process - the group dynamics.

Also included were researchers' records of:

- the input provided by the research team;
- the outcome of the event;
- discussion on the reasoning behind decisions made;
- their own reflections on aspects of the input which had worked well and what, with hindsight, we might have done differently.

In practical terms, we made notes during events when we could (that is, when a researcher was not actively involved in facilitating a session), otherwise we wrote up observations after events. During the later stages of the development work, when one of us was attending meetings in a monitoring capacity, it was possible to record observations while the event was in progress. These notes were also used to write minutes of each meeting which were distributed to all those who attended.

These data were supplemented by collection of documents, including correspondence and reports of other meetings not attended by the research team. Staff views on the process were also collected at various points during the development work. Views on the input provided by the research team at the first workshop were collected through an anonymous questionnaire at the end of the day. The working group were asked for their reflections on the project through an anonymous questionnaire sent to them towards the end of our funding period, followed by a focus group discussion to develop recommendations for others wanting to carry out similar work.

4.3 THE ROLE OF THE RESEARCH TEAM

In designing the development phase, we gave careful consideration to the support we could offer to managers and staff. The research team could provide evidence about the need for improvements in communication between health staff and teachers. However, there were limitations as to how much input the research team could have in the change process. First, we did not have research evidence about *how* communication between health and education staff should be improved. Secondly, we had no authority to impose action. Thirdly, we had no in-depth knowledge about the local area and what changes would be appropriate. Local health and education staff did have detailed knowledge of local services, including the resources that were available locally for making changes, and the constraints under which staff work. Therefore, it was more appropriate that they made decisions about what changes would be put in place in their area.

It was decided that the research team would facilitate change by:

- Providing input on research evidence.
- Setting up and running service user advisory groups.
- Acting as neutral facilitators for a multi-agency working group.
- Monitoring progress.

Health and education staff would be responsible for:

- Making decisions about what needs to change and how it should be changed.
- Implementing the changes.

Bearing in mind that the researchers' involvement was temporary, we took steps to help ensure that the staff would have a sense of ownership of the project and the changes being introduced. The research team would assist staff in deciding what they wanted to do, but as far as possible would not express personal opinions or try to direct the decision-making process. In addition, we structured the development work so that the research team would withdraw gradually over the course of the project. All members of the research team would be involved in facilitating the initial planning through a series of workshops. However, the research team would then reduce their involvement to one researcher, who would be in contact with staff only for the purposes of monitoring their work.

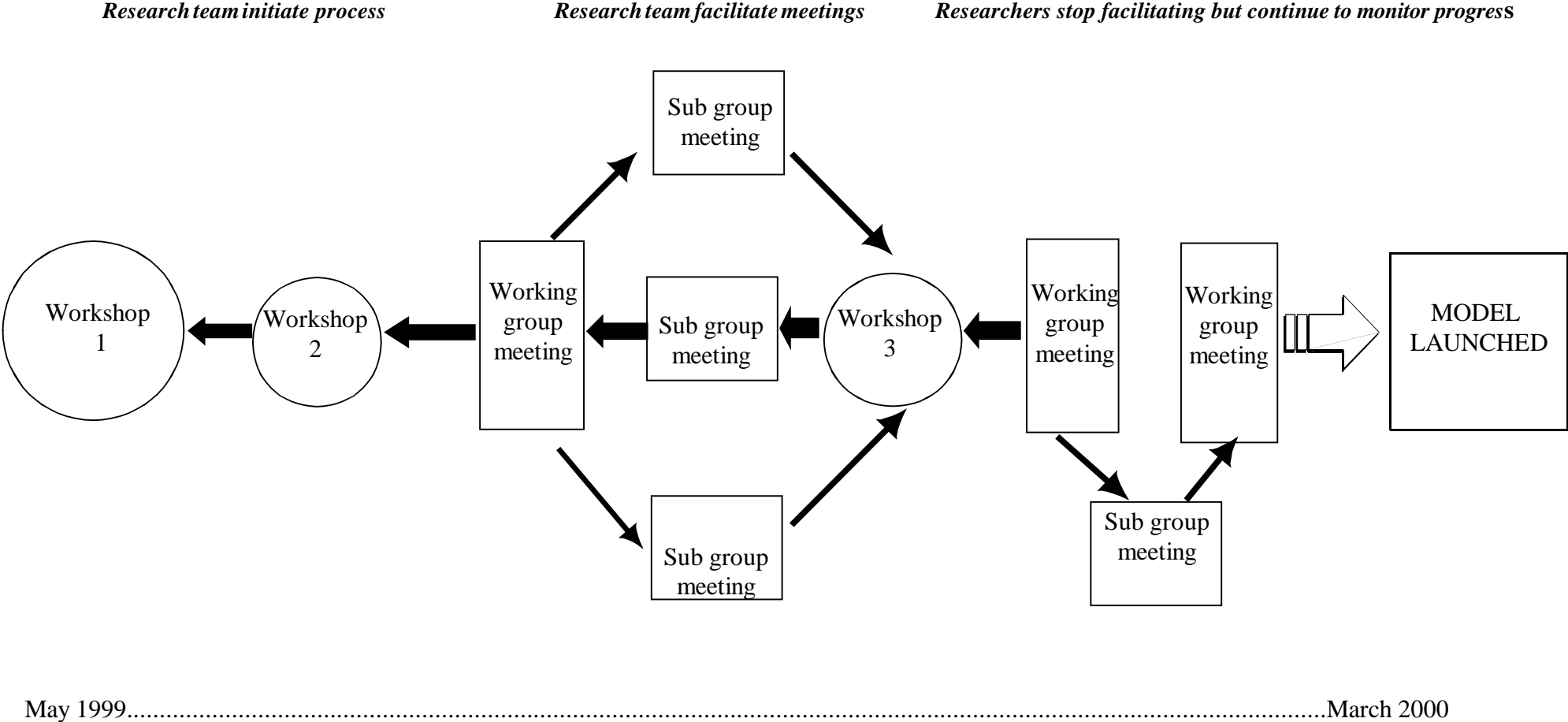
4.4 DESCRIPTION OF THE DEVELOPMENT PHASE

Informed by the theories of change, we designed the development phase according to a staged approach, beginning by making people aware of the need for change, before assisting them with preparing for change, and finally taking action. As outlined in Chapter Two, it was intended that the research team's involvement with initiating and planning would last two months and involve

two workshops. In practice, this phase of the work extended over five months to accommodate the staff's wishes. Taking into account the six months spent monitoring the project, the research team were involved with the development work for a total of 11 months. Figure 4.1 depicts the various meetings held during this 11 month development phase, and the changes to the research team's role over this period.

In this section, we provide an overview of what happened during the development phase. We begin with the preliminary work undertaken by the research team, then outline the events during the initiation and planning stage, before finally describing the last six months of the project in which a researcher monitored progress.

Figure 4.1: The development phase



4.4.1 Preliminary work

As explained in the introduction, this project arose from a joint proposal between the research team and the York Health NHS Trust, so the idea of change was initiated before the project began. Once funding for the project had been secured, key representatives within the LEA were approached about the project. All were keen to be involved and were aware of the findings from the previous research study, which formed the basis of the project.

Separate meetings were then held with consultant paediatricians and an officer from the LEA to discuss the project and to identify other staff who should be involved. At these meetings, consultant paediatricians said there was already an awareness of the need to improve links between local health services and schools and a feeling that participating in the project fitted in with this agenda. The LEA officer reported that there were a number of local projects aimed at improving inter-agency working. However, a distinctive and favourable feature of this project was that we intended to involve service users, with parents and pupils acting as advisors to the project.

Next we recruited other relevant staff to take part in the project. Our aim was to include representatives from services within health, the LEA, and mainstream schools, who had a role in supporting pupils with a chronic illness or physical disability. Having worked in the area previously, we had some local knowledge of people it would be useful to involve. Aside from approaching teachers who had taken part in the previous research study, we worked with our key contacts within the Trust and the LEA to identify people who should be invited to a workshop about the project.

After this point, the process began to ‘snowball’, with each new contact nominating other people who should attend. Once it seemed that we had a comprehensive list which included a lead representative from each of the relevant disciplines within health and education, we stopped recruiting. Invitations to the workshop were sent out and individuals were asked to confirm that they would be attending. Those who were unable to attend were asked to nominate someone else to take their place.

In inviting participants to the workshop, the research team tried to ensure that the number attending from health and education services was equal, and that the various disciplines who might be involved in supporting pupils with special health needs were all represented. We also gave some consideration to the role people might play in developing and implementing plans. We wanted to include both practitioners, who might be expected to carry out the changes in their every day work and would have an insight into whether the plans developed were realistic, and managers with sufficient authority to give the go ahead for any changes proposed.

4.4.2 Initiation and planning

Workshop one

The first workshop was organised and run by the research team in May 1999 as planned. This was attended by an invited group of 21 health and education staff (see Table 4.1). The greater range of disciplines within health who needed to be represented at the meeting meant that slightly more health staff than education staff attended.

Table 4.1: Participants at workshop one

Health Trust	Consultant Community Paediatrician Consultant Paediatrician Clinical Medical Officers (n=2) Epilepsy Liaison Nurse Development Manager, Healthy Young Minds Health Visitor Nurse Manager, Children's Services Physiotherapist School Health Nurse Coordinator Senior Clinical Medical Officer Senior Paediatric Occupational Therapist Speech and Language Therapist
LEA	Assistant Director, Pupils, Students and Parents Learning Support Teacher
Schools	Primary Schools: Deputy Head Teacher Secondary Schools: SENCOs (n=4); Deputy Head Teacher

The first workshop was a one day event and represented the first meeting of staff recruited to take part in the project. As such it was a significant event, with the future of the project depending on what happened during the course of the day. The aims of the workshop and the programme for the day are given in Table 4.2.

Table 4.2: Workshop one - aims and programme

Aims: to secure support from local staff for taking the project forward; identify priorities for change, based on the research evidence; and obtain nominations for a multi-agency working group.

Programme:

- Introductory ice-breaker;
 - Input from the research team on the research evidence;
 - Multi-agency group work to identify local priorities for change;
 - Single agency group work to:
 - consider what the changes prioritised would mean for their agency
 - nominate people from their agency to be on the working group;
 - A short working group meeting to make practical arrangements for taking the project forward.
-

Although there were a number of specific aims for the day, the main purpose was to secure support from local staff for taking the project forward. It was essential that delegates responded positively to the research evidence and the suggestion that there was a need for change. Since this was a multi-agency event, we chose a neutral venue in a local hotel. The day was facilitated by three researchers. A consultant in management of change chaired the day. This person was able to take on a neutral role, facilitating discussions between the research team and health and education services.

Process

The day got off to a good start with participants finding it easy to talk to others during the ice-breaker session. When people were asked to speak about what they hoped to get from the day, many mentioned having the opportunity to network. Others spoke of the difficulties they experienced in supporting pupils with a chronic condition and the importance of good communication. It seemed at this stage that many in the group were already convinced of the importance of communication. When the plans for the project were outlined by the research team, some members of the group challenged the idea that a working group could take responsibility for implementing changes. It was suggested that the most that could be expected to come out of such a group was a set of recommendations. This was a time of some tension as the research team explained that they hoped that the working group would move beyond recommendations to try to introduce changes, seeking approval and assistance as necessary from others within their respective agencies.

As the day progressed, the group became engaged in the discussions, taking notes throughout the presentation on the research evidence and asking questions. They worked energetically on the tasks they were asked to complete and by the end of the afternoon had achieved what the research team hoped they would in the time available: the identification of priorities for change (using resources from the research - see section 3.6 and Appendix Two) and 13 nominations for a core working group of staff to take these priorities forward (see Table 4.3). This meant that the afternoon ended with a sense of achievement.

Table 4.3: The working group

Health Trust	Senior Clinical Medical Officer
	Consultant Community Paediatrician
	Health Visitor
	Development Manager, Healthy Young Minds
	*General Practitioner
	Physiotherapist
	School Health Nurse Coordinator
LEA	*Education Advisor, Special Needs
	*Assistant Education Officer
	Learning Support Officer
Schools	Primary School: Deputy Head Teacher
	Secondary School: SENCOs (n = 2)
* = members of the working group not invited to the first workshop	

Outcome of the event

By the end of the day the delegates had identified the changes they wanted the working group to prioritise in York. In the short term, they recommended that the working group focus on:

- A named teacher for health in each mainstream primary and secondary school in York.
- A named health professional for each mainstream primary and secondary school.
- The development of a system of health care plans, to be drawn up jointly by health and education.
- The introduction of Smart cards for pupils with special health needs - a plastic card given to a child which summarised their health needs, the aim being to empower the child to pass on information about their health when they needed to in school.

Less of a priority, but things to be considered in the longer term were:

- The production of a leaflet explaining the different roles of all staff within health and education services.
- Multi-disciplinary meetings to include children with health needs but no Statement of SEN.
- To have a trained person in each school responsible for health care plans, who would link with a network of named people and ensure that health care plans were kept up to date.
- The development of a system for seeking family consent to pass on information from health staff to schools.

At the end of the workshop members of the working group who were present were asked to stay behind to make practical arrangements for future meetings. This was a difficult session as people were tired at the end of busy day and apprehensive about what they had taken on. It was difficult to reach a consensus about issues. However, there was evidence that the group were keen to take the work forward, since they were animated when talking about concrete short term issues, such as who should bring what as a resource to the next workshop.

The initial intention of the research team was to set up a one and half day workshop soon after the first event, to allow the working group to refine their ideas and draw up action plans for implementing changes. However, the working group felt it would be more useful to split the time available into two events, having a one day workshop approximately one month later (in June), followed by a half day workshop in the Autumn. There were a number of reasons for this suggestion. First, many staff felt they could not take a block of one and a half days out from work in order to attend a workshop. Secondly, staff argued that the project needed to go ‘on hold’ over the summer since the teachers on the group would be on annual leave. It was argued that a half-day event in the Autumn would help to revitalise the group. Finally, the LEA representatives felt they could not proceed with the implementation until they had sought managerial approval. It was envisaged that this might take some time. Having considered these factors, the research team agreed to change their plans and the remaining one and a half days of workshop time was split into two events, a one day workshop held in June 1999, followed by a half day workshop in October.

Workshop two

The research team’s role at workshop two was somewhat different from that at workshop one, where they were responsible for providing a substantial amount of input on research findings. At workshop two, their role was primarily to facilitate the planning process. It was therefore thought unnecessary to have the consultant in management of change present as a neutral chair. The aim and programme of the workshop are described in Table 4.4.

Table 4.4: Workshop two - aim and programme

Aim: to clarify the remit of the proposed changes and begin planning the implementation.

Programme:

- Group exercise on experiences of working in a multi-disciplinary group: what works well and why;
 - A presentation by the research team on expert advisors' views (see Chapter Five for further details);
 - Group work to clarify the remit of the changes being taken forward;
 - Discussion on the scale and timing of implementation;
 - Presentation on understanding change and securing commitment of key stakeholders;
 - Arrange future meetings.
-

Participants

Twelve of the 13 people nominated to the working group were able to attend the event (see Table 4.5 for details). However, three people, all representatives from health services, had to leave the workshop at lunch time.

Table 4.5 : Attendance at events by working group members

<i>Agency</i>	<i>Job title</i>	<i>Workshop 1</i>	<i>Workshop 2</i>	<i>Meeting 1</i>	<i>Workshop 3</i>	<i>Meeting 2</i>	<i>Meeting 3</i>
Education	* Education Advisor (Special Needs)	O	X			X	X
Education	Assistant Education Officer	O	X		X	X	X
Education	Learning Support Officer	X	X	X	X		X
Education	Primary school representative (Deputy head teacher)	X	X	X	X	X	
Education	Secondary school representative 1 (SENCO)	X	X	X	X	X	X
Education	Secondary school representative 2 (SENCO)	X	X	X	X	X	X
Health	* Consultant Community Paediatrician	X	X	X	X		X
Health	Senior Clinical Medical Officer	X	X	X	X	X	
Health	Health Visitor	X	X	X	X		
Health	Development Manager	X		X	X		
Health	General Practitioner	O	X		X		X
Health	Physiotherapist	X	X	X	X	X	X
Health	School Health Nurse Coordinator	X	X	X	X		X

* = lead decision maker in agency

O = not invited to workshop one

Process

There were three new members of the group who had been nominated but not present at the previous workshop: two from the LEA and a GP. All three participants contributed fully to discussions. However, the two LEA representatives were slightly hesitant about the project, expressing concerns about it becoming another ‘talking shop’ and uncertainty as to how the LEA would react to the proposals. Despite this, there seemed to be a lot of energy in the group, there were lively discussions around multi-agency working and the researchers were asked a lot of questions following their feedback on meetings with expert advisors. By the end of the morning, the group had made a substantial amount of progress, preparing notes clarifying the remit of the changes they were taking forward and a sequence for implementing these changes.

While the morning discussion was dominated by health staff, at lunch time three health service representatives had to leave and as a result there was shift to education dominating discussions. The group began to think about the resources they needed to implement the changes, and concluded that it was essential to have LEA backing for the work. The group then seemed to get ‘stuck’, suggesting that there was nothing more they could do until they were certain of LEA support. At this point there was a definite loss of enthusiasm within the group. Lack of time in the afternoon, due to lengthy discussions about the resources needed to implement change, meant that sessions planned had to be reduced. A session in which participants discussed codes of confidentiality within education and health services had to be cut, as was a session on how the group had worked together during the day. Instead a concluding session on what members of the group needed to do next was run. Sub-groups were set up to take the forward the work that needed to be done before the next workshop. Since it was unclear by the end of the workshop what these sub-groups were proposing to do by the Autumn, the research team persuaded the group to have a short meeting one week later to sort out these details.

Outcome of the event

By the end of the day the group had produced the following statement:

Our aim is that each school in York will have the following:

- *A named teacher for health in each school.*
- *A named health professional for each school.*
- *Individual health care plans in respect of pupils with an illness or disability.*
- *Individual Smart cards for pupils with an illness or disability.*

The group did some work on defining the roles and responsibilities of the named teacher and named health professional, and the purpose of the health care plan and Smart card, but agreed

they needed to do further work on this before they could proceed. They concluded that these changes were part of ‘a system’ for improving communication between health and education staff. They drew up a sequential plan of action as follows:

- Seek LEA approval for the changes and obtain a policy statement to this effect.
- Identify an LEA named person who will act as an advisor on the changes.
- Clarify the role of the named health professional.
- Clarify the role of the named teacher.
- Devise a special health register.
- Devise the individual health care plan.
- Devise a Smart card.
- Run system for a pilot period, then review/evaluate.

Three sub-groups were set up: for health representatives; for LEA representatives; and for school staff. Each sub-group agreed to undertake work on one or other of the items in the plan and report back on progress at the third workshop scheduled for the Autumn. It was agreed that both the health and the school staff sub-groups should work on the health care plans, Smart cards and named health professional, so that the final remit took into account the needs of both groups.

Working group meeting one

One week after the second workshop, there was a short working group meeting chaired by one of the research team. The purpose of this meeting was to clarify what the sub-groups would be doing over the summer months. Attendance at the meeting was relatively low (see Table 5) and the discussion was short. However, it did allow people in sub-groups to arrange dates to meet over the summer months, agree on venues, and decide what they would do at these meetings.

Workshop three

This half day workshop was the final event to be facilitated by the research team. On this occasion only two researchers were involved in the event since most of the time was to be devoted to the working group completing action plans without outside assistance. In addition, the research team wanted to signal the beginning of their withdrawal. The aim and programme of the workshop are given in Table 4.6.

Table 4.6: Workshop three - aim and programme

Aim: to draw up detailed action plans for implementing the changes.

Programme:

- Clarification of the working group's statement of aims;
 - Feedback by research team on further meetings with expert advisors (see Chapter Five for details);
 - Brief progress reports by the sub-groups;
 - Presentation on key issues to consider when developing action plans for implementation;
 - Group work to prepare action plans on: the production of materials; securing commitment of senior managers; promoting change among colleagues and users; training and support for staff; monitoring progress;
 - Arrange future meetings.
-

Participants

Only one member of the working group was unable to attend, but unfortunately this person was leading the implementation of changes within education services (Education Advisor, Special Needs). In addition, the person taking the lead within health services (Consultant Community Paediatrician) was unable to be present for the first half of the morning.

Process

To ensure that participants developed comprehensive actions plans in the time available, the research team organised and ran a fairly structured event. To help the group focus on their task, we produced 'action plan templates' based on our experience in a previous development project (Sloper *et al.*, 1999). An example is given in Appendix Three. There was a template for each of the following:

- Producing materials, for example, model 'Smart' card, model health care plan, remit of named teacher, remit of named health professional.
- Securing commitment from senior managers.
- Promoting the change among:
 - colleagues
 - pupils and parents.
- Training and support for staff.
- Monitoring progress.

On arrival people were relaxed, but enthusiastic to get on with the work. The first task was to look over the statement of aims for the working group. This proved to be very useful, both in

focussing the group on what they were trying to achieve and revealing areas where there was a lack of clarity, which needed to be resolved before the group could proceed. Feedback from sub-groups revealed that both health and school staff had drawn up templates for a health care plan. These were somewhat different, but this did not cause a problem, with the group discussing the elements of each plan which they favoured and agreeing to put these together in a single document. There was a clear sense at this stage of people coming together to work as a group.

The person taking the lead for much of the decision-making within health services arrived mid-way through the morning. To minimise disruption one of the researchers took this member out of the group to update her on what had been happening during the morning. Up to this point, much of the discussion had been dominated by the work that needed to be done within education services. However, with the arrival of this health representative the focus of the discussion shifted and the group was able to clarify what would be happening within health services to ensure the implementation of the changes. There were a few periods of tension between colleagues within agencies during the course of the morning, due to misunderstandings or confusion about arrangements. Overall the group worked hard during the session and managed to complete the task of drawing up action plans.

Outcome of the event

The group decided what needed to be done in relation to each of the action plan templates. They did not, however, have time to decide who would take responsibility for each of the tasks. In brief, it was decided that the best way to proceed was to produce a single document offering guidelines on good practice in relation to pupils with a chronic illness or physical disability. The document would outline the remit of the named teacher, the named health professional, the health care plan, and the Smart card.

It was agreed that the guidelines would be launched in schools through the next Head Teachers' conference (in Spring 2000). The lead representatives from health and education would approach the Director of Educational Services to ensure that he was supportive of the guidelines and to secure a slot at the conference. This launch would be followed up with a training event for teachers, to which all primary and secondary mainstream schools in the area would be invited to send a representative.

The launch of the guidelines in health would be organised through a series of meetings for the different professional groups. School medical officers would be invited to the teachers' training event, but would also have their own training event. It was agreed that an audit would be carried out some months after the initial launch to monitor progress in implementation.

At the end of the meeting the group arranged to meet again within a month since it was important to maintain some momentum in the project and to complete the action plan.

4.4.3 Monitoring

After October, the working group continued to hold meetings to plan the implementation. However, only one researcher attended meetings for the purposes of monitoring progress; researchers did not facilitate the process. The researcher continued in this monitoring role for six months, until April 2000.

Working group meeting two

This meeting was attended by eight of the 13 working group members. Those able to attend were predominantly from education. Despite the fact that the research team had reminded the group at all workshop events that they would be withdrawing from the facilitator role after the third workshop, there was a clear expectation at this first meeting that the researcher would be chairing the meeting. Some negotiation with the group was necessary about handing this role over to one of the group.

The discussion focussed on what needed to happen within education services, since there were only two health representatives present. The lead education representative had been unable to attend the previous workshop, so had not been party to the plans for implementation. She expressed concern that the plans were not wholly realistic in the current climate within education, where school staff are being expected to make a great deal of changes and are under substantial pressure. More specifically, it was considered unrealistic to expect teachers to attend a training event which would have to be organised after school hours. After some tense discussions, the lead education representative took a decision to remove training for teachers from the action plan.

In relation to implementation within health, there was a lack of clarity within the group as to how to proceed and the group seemed reluctant to make decisions without the lead health representative being present.

By the end of the meeting the group had decided who should take responsibility for the tasks outlined in the action plan. It was notable that there was an uneven dispersal of work with the lead representatives for health and education services being nominated as the people to take on the bulk of the work, since they were considered to have the skills and status necessary to take on the tasks. While it had at times been a fraught meeting, people said at the end of the session that they felt a great deal had been done in the short time available.

Outcome

It was agreed that the proposed changes should be put together in a single document referred to as 'guidelines on good practice'. The guidelines would be produced by combining and editing the work that had already been done by the various sub-groups over the summer months. It was agreed that the most efficient way to take forward this work would be for the lead representatives from education and health to meet as a sub-group to draft the guidelines. Once the text of the guidelines was agreed, the research team would provide some administrative support, taking responsibility for typing up the document. The lead representatives from education and health subsequently held a lengthy sub-group meeting to work up a detailed draft of the guidelines.

Working group meeting three

This meeting was attended by ten of the 13 members of the working group. There was a more even balance of agency representation on this occasion, with two people present from health who had been unable to attend the last session. It was clear from the beginning who would be chairing and an agenda for the session was drawn up in advance.

The agenda for the meeting was:

- The guidelines for good practice - agree on a final version.
- The printing options for the guidelines.
- Update on the research team's plans.
- Review and update of the action plan.

The mood of the group was positive from the outset and people were clear about the agenda. The two lead representatives had done a considerable amount of work since the previous meeting, putting together the draft guidelines. This document had been sent out to all group members prior to the meeting for comment and there was a clear sense of achievement within the whole group at having something tangible to show for their efforts. Much of the meeting was spent checking the guidelines and everyone made a contribution to this task. Half an hour before the end of the meeting, the lead representative from health had to leave. This did pose a difficulty as there were a number of issues for discussion outstanding. It was agreed that the group should go ahead with making plans and that the lead representatives from health and education services would meet at a later date to sort out any remaining issues.

Outcome

By the end of the meeting the group had agreed on the final wording and format of the guidelines. There was a small amount of money within the research budget which would cover the cost of printing the guidelines, and after consulting with the group about design details, the

researcher offered to take responsibility for organising printing. It was agreed that the lead representatives from health and education would present the guidelines at the Head Teachers' Conference and that copies of the guidelines would be included in the delegate packs. Further copies would be posted to the Head Teachers of all schools. The group agreed to meet again in July 2000 to discuss the monitoring and evaluation of the implementation.

In May 2000, the research team arranged a meeting to draw the research project to a close. The agenda for the meeting allowed time for the working group to update each other on progress with the project, and for the research team to clarify with the working group what part they would play in disseminating the project findings. However, the primary focus of the meeting was for the research team to facilitate the group in reflecting on the project and drawing up recommendations for other areas who want to carry out similar work. These reflections and recommendations are reported at the end of this chapter.

At the time of the final meeting, the working group had launched the model for improved communication between health and education staff. It was anticipated that the model would be fully implemented within health and education services in Autumn 2000. An audit of the implementation was scheduled for Spring 2001. The model for improved communication and the approach to implementing the model are described in Chapter Six.

4.5 REFLECTIONS ON THE DEVELOPMENT PHASE: VIEWS OF STAFF

Staff views on the development work were collected at two points in time: following the first workshop and at the end of the phase, when the research team had completed their work on the project. The purpose was to assist the research team in disseminating findings from the project about how other groups might go about carrying out similar work.

4.5.1 Evaluation of workshop one

At the end of the first workshop, staff were asked to evaluate the event, with the focus being on the input provided by the research team. Eighteen of the 21 delegates returned an evaluation form. The form consisted of three open questions, asking people about: the input they had received on research findings; the group work sessions; and anything the research team could have done to have improved the day (see Appendix Four).

In relation to the input on research findings, almost all comments were positive. Participants said that the data presented were interesting, and that the content was relevant to practice and highlighted areas for development. They also found it useful that the data included the views of parents and young people. The only criticism was the small sample size. One of the delegates

would have liked the work to have been replicated using a larger sample to investigate whether issues raised were related to specific conditions and/or to whether children were receiving health care from secondary or tertiary services.

In general, the group work sessions were described as ‘well facilitated, comfortable, and relaxed’, ensuring that people stuck to the time and targets set out for the day, without being obtrusive. One person commented that it been excellent to have a facilitator to help the group remain focussed and pull out what changes need to be made to local practice. People said that the discussions had been informative and interesting, and that it had been helpful to have the opportunity to spend time in both single agency and multi-agency groups. The only concern raised by one delegate was that there should have been more representatives from education services.

Four people made suggestions for improvements to the day. These were: to have been given more detail on the structure of the day prior to the event; more active management of the discussion to stop people talking at once; to have been asked to bring documentation on local policy and practice; and to have had a more even representation of services.

4.5.2 Working group views on the development phase

Views were collected at the end of the development phase in two ways. First a questionnaire (see Appendix Five) was posted out to all members of the working group asking them to reflect on their experience of participating in the project. Secondly, members of the group were invited to attend a final meeting with the research team to draw the project to close and to ask them to develop recommendations for other areas. We opted for a discussion group to draw up recommendations because such work is reported to lead to the formation of new ideas through giving participants an opportunity to share experiences and exchange different perceptions (Vaughan *et al.*, 1996).

Questionnaire

The purpose of the questionnaire was threefold: to ensure that all members of the group had an opportunity to contribute their views, even if they were unable to attend the subsequent meeting; to allow them to feed back on the project anonymously, thereby making it easier for them to make honest comments; and as a ‘warm up’ to the meeting, asking people to think about the issues we would be discussing. The questionnaire asked people to reflect on: how the project had been organised by the research team; how they worked together as a group; and the personal advantages and disadvantages for them in taking part. Ten of the 13 members of the working group returned the questionnaire.

How the project was organised: In terms of how the project was organised, staff were asked to reflect on aspects of the project that the research team had taken responsibility for, in particular: how the events were organised and run; and how the time was structured. It was clear from their responses that members of the working group had valued the researchers' input in organising and facilitating events. Aside from general chairing skills, having a facilitator from 'outside' was thought helpful because: it was clear they would have no loyalties to any particular agency; and they would not have the practical difficulty of attempting the dual role of chairing and taking part- in the discussion. The negative side was that the level of the researchers' input was reduced part way through the project and so the group had to adapt their way of working. One person commented that it might have helped the group to have spent some time explicitly planning for this change. Venues used for workshops were reported to be accessible, pleasant and conducive to good working; and dates were arranged well in advance.

Overall, people felt that the working group had sufficient time to do its work. They were asked what had worked well and what had been problematic in the *use* of time. It was clear from the feedback that people have different preferences - for example, during workshops there was quite a lot of time available for open discussion. While some people felt that this was good, as it had meant discussions were not cut short in favour of pressing on to action, others thought the opposite: that some of this time was rather unfocused and could have been better spent moving on to take action. However, there was some sense from the responses that a balance is appropriate - and so the mixture of longer and shorter meetings had been useful.

Only three people made any suggestions for changing the use of time: sticking to start and finish times; agreeing in advance how much time to spend on what type of activity (initial discussion versus drafting and reviewing guidelines etc.); a slight preference for weighting time a little more on producing/reviewing the guidelines.

In response to being asked whether they would change anything about how the project was organised, one person said that they would have liked to meet with the parents and young people who had been involved with the project to discuss how agencies were meeting their needs.

Working together: The questionnaire asked staff in what ways the working group had worked well together and/ or experienced difficulties. Three themes emerged about how the group had worked well together. First, having a common aim, so that from the start everyone agreed there was a need to do something and people could see that there would be benefits from what the group was doing. Secondly, the group was thought to have been good at sharing information and differing perspectives. People felt they had been able to share openly and honestly insights into: how agencies worked; what examples of good practice already existed; what was problematic

about communication; and to say which ideas for change would or would not work for them and why. There were some comments that being able to talk and be listened to had made for a good atmosphere and helped group members to develop respect for one another. Finally, a variety of comments were made which suggested that people felt that a high level of commitment had been given to the group, for example, that despite the fact everyone was so busy, real efforts were made to attend meetings; and that the group made deadlines and shared responsibility for moving things forward in smaller groups between working group meetings.

When asked about any difficulties experienced by the group in working together, finding time when everyone can meet was mentioned most often. It was also suggested that sometimes the timetable for the multi-agency group could conflict with particularly busy periods in your own agency. Finally, one person mentioned that agencies need to take care to appoint members from the outset of the project (so that they can participate fully) and to ensure that the mix of members fits the task in hand, for example, with hindsight should the group have included teaching staff from a wider range of positions within schools?

Staff were asked whether they thought there was anything about the context in which the project was carried out which had a bearing on the way the group worked together. Carrying out the work in a small geographical area was thought helpful as it meant that people had short travelling distances to meetings, and it was likely that at least some people would know one another. Knowing people was felt to 'break the ice' and was the basis for mutual trust and respect. Another helpful factor in York was existing experience of and willingness to work in partnership across agencies.

Personal advantages and disadvantages to participating in the project: Staff reported three types of personal benefit in taking part. The first was better knowledge of other services: how they work; their constraints and pressures. The second theme was better knowledge of individual staff: developing a relationship with people only previously known by name; and making links with people which then make it easier to contact them again about issues outside the remit of the project. Thirdly, three people also commented on satisfaction from being part of the project as a whole: that it had been 'gratifying' to see the group work together successfully over a period of time; that it had been a 'real bonus' for them to be involved in a project from start to finish; and that it was good to feel you had 'made a difference' to be able to support pupils better from now on.

As for disadvantages, competing priorities for their time was the only issue mentioned, but was widely felt, being raised by six people. This included two people mentioning that the work of

the group made demands on time outside their normal working hours. One person said that, ideally, dedicated time would be available to carry out this type of project work.

Group discussion on recommendations

Seven members of the working group attended the final meeting. At the meeting, the group were presented with a short summary of the results from the questionnaires and then asked to consider the following question:

‘If you were now advising staff in another area who wanted to improve communication between health and education staff, what guidance would you give?’

Staff who attended the meeting were positive about their experiences during the project: they were pleased with the outcome of project and said that being a member of the working group compared very favourably with their experiences in other multi-agency planning groups. As a result, most of their recommendations were made after reflecting on why they felt the project had worked well (see Box 1).

Box 1: The working group's recommendations for managing multi-agency change

Aims and ways of working

- Keep to a realistic outcome.
- Set a timescale with an end point.
- Break down big tasks so you can tackle one thing at a time and people can see end points.
- Whoever is facilitating the group needs to give individual members ownership: don't do things for the group, but give out tasks so that people have a part to play.
- Make sure that people come to every meeting.
- Select your chair carefully: an external expert is valuable but, if not available, consider having two chairs (one from each agency) to share the role.
- Use pleasant venues (and not always the same one).

Resources

- Think about resources early on, or the work will not be able to progress.
- Projects which are resource-neutral are easier: ie the focus is on changing ways of working, restructuring systems rather than major changes to staffing.

Group membership

- Keep the group small (10 to 12 people).
- People with power to take action should be on the group.
- Group representatives are needed from all agencies involved, to show commitment.
- It is important to have primary care 'on board'.
- Make sure one agency or professional group is not over-represented.
- Make sure the representation fits the focus of the group.

4.6 REFLECTIONS ON THE DEVELOPMENT PHASE: VIEWS OF THE RESEARCH TEAM

In this section, the research team reflect on the development phase, including how it was organised and facilitated, and the way in which the working group worked together during the course of the project. The section ends with our recommendations to other researchers wishing to engage in similar work.

4.6.1 How the development phase was organised and facilitated

At a practical level, it is important to note that work on the project was completed three months later than planned, owing to spreading the workshops over a longer period than originally proposed. While there were very sound reasons for staff wishing to ask for the change (see Chapter One), this did have implications for the research team, who were funded to work with the group over fixed period of time. In this instance, the project funders agreed that the research team could postpone the submission of this final report to accommodate these changes. However, the flexibility in timescale required does draw attention to the potential practical difficulties in funding time-limited development work.

Our prior knowledge of group process and management of change, together with experience of applying a staged model for development work, was important in helping the research team to organise and facilitate the project. From the outset, we considered it important for local staff to have ownership of the project. To achieve this, we made efforts to ensure that the plans drawn up were based on the ideas of staff, with the researchers facilitating this process. We also encouraged staff to take responsibility for any work that needed to be done in order to produce the model for improved communication or to implement it. However, at times it seemed that we might not transfer ownership of the project from the research team, who had initiated the project, to local staff. Members of the working group often referred to the project as the 'SPRU project'. However, by the end of the development phase the working group decided that it was important for the product of the development work - the guidelines for health and education staff - to be seen to be their work and not the result of a research project. They took pains to make this clear in the content of the guidelines - explaining that they had been drawn up by local health and education staff - and by including their own agency logos. The working group also took sole responsibility for launching and disseminating the guidelines. We therefore feel that our efforts to ensure that staff had ownership of the development work were effective.

In order to ensure that the working group did not become too dependent on the research team, and continued to meet after the project ended, the development phase was planned so that the research team gradually withdrew their involvement and support. In practice, this had to be carried out in a much more gradual manner than planned. When it came to the point where the research team moved from facilitating to monitoring the work, the working group did not have a clear idea of how they wanted to run the group or who would take responsibility for tasks such as setting the agenda, chairing and taking minutes of meetings. As a result, the researcher assisted them in finding a chair for future meetings, and discussed the agenda for the next meeting with the new chair in advance of the event. In addition, it was decided that the researcher would take minutes of meetings and send these to all members of the group. In

hindsight, it might have been useful to have devoted time earlier in the project to clarifying how the group would run their own meetings during the monitoring phase. However, we do know that the working group plan to meet on at least two occasions after the end of the project, to complete their work on implementing the model.

4.6.2 How the staff worked together

Overall, it seemed to us that the health and education staff who had taken part in the project had formed an effective working group. They collaborated successfully to produce a model for improved communication, which met the needs of the two agencies and various professional groups involved. As expected, during the course of the development phase, there had been times of tension and conflict, when bringing people from very different professional backgrounds to work together. As outside observers of the group, it was apparent that much of the tension within the group occurred as a result of inconsistent attendance at working group meetings. In drawing attention to this issue, we acknowledge that most members of the working group made efforts to attend meetings on a regular basis. However, this was not always possible. As the project progressed, key people within groups occasionally missed whole or parts of meetings. This meant they missed input by the research team, including presentations on factors to consider when implementing change. It also meant they were not party to group discussions which lead to the development of plans. As a result, when they did attend meetings they often disagreed with the plans which had been put in place, and in a few instances dismantled or amended them. Despite these periods of difficulty, most members of the group have remained committed to the group and to taking forward the changes suggested by delegates at the first workshop.

It does seem likely that the way in which the group worked together during the project was influenced by the presence of the research team. Though the researcher was meant to be acting as an outside observer during the monitoring phase, in practice she was much more of a participant in the process. It is impossible to speculate on what would have happened if the research team had simply held a series of workshops and not had contact after this point. Perhaps the group would have been quicker to take responsibility for running their own group. Alternatively, it may be that, without the presence of an outside observer monitoring the work, the group would have made slower progress.

4.6.3 Recommendations to others carrying out similar work

Reflecting on our experience suggests a number of recommendations for others seeking to facilitate inter-agency development work (see Box 2).

Box 2: Recommendations for facilitating inter-agency development work

- Draw on knowledge of group process and management of change in designing and carrying out development work.
- Be prepared to be flexible with regard to timing events.
- Prepare groups for working independently: help them to put in place practical arrangements for running meetings.
- Ensure staff have ownership of the work: give them responsibility for designing and implementing the changes.
- Encourage people to attend meetings as regularly as possible, explaining the potential difficulties if they do not.

CHAPTER FIVE

THE DEVELOPMENT PHASE: INVOLVING SERVICE USERS

5.1 INTRODUCTION

As we reported in Chapter One, service users influenced the project from the outset, since its stimulus was findings from our earlier research involving young people and parents. However, we wanted to make sure that service users had ongoing input in the development work. We did this in two ways; first, by ensuring that staff carrying out the development work were familiar with the research findings on why parents and young people felt there was a need for improved communication between health and education staff, and their ideas on how such improvements might be made. This was done through presentations at the first workshop, which formed the basis of professionals' initial discussions about priorities for change. Secondly, we sought to recruit parents and young people to act as advisors to the project. By advisors we mean people whom staff could consult about their plans throughout the development work.

In this chapter, we first describe the involvement of service users as advisors to the project. We then set out the views on this involvement from members of the working group and the advisors. The chapter concludes with the research team's reflections on this aspect of the development work.

5.2 THE PLAN AT THE OUTSET

The research team's intention at the outset of the project was to establish and facilitate two expert advisory groups: one of parents and the other of young people of secondary school age with a range of chronic health conditions and physical disabilities. Initially these service user groups and the staff group would remain separate. The rationale for this was twofold. First, from the staff's perspective, our previous research suggested that there might be inter-professional issues which staff might wish to address in the first workshop. Many of the staff involved had never met before, and it seemed important to give them time to get to know each other and discuss any inter-professional issues before engaging with service users.

Secondly, from a service user's point of view, establishing separate groups of parents and young people was intended to strengthen their voice in subsequent planning for change. Through giving members of each group an opportunity to get to know each other, discuss the issues and form a group, we hoped to avoid risking their involvement being seen as 'tokenistic' and their views being lost among the large group of staff (Tozer and Thornton, 1995).

Once staff members of the working group had been identified, our plan was that all three groups

might be brought together at the second workshop. At this workshop, delegates would then decide themselves how they wanted to work during the rest of the project, in particular whether to continue meeting as three separate groups or to merge.

5.3 WHAT HAPPENED IN PRACTICE: PARENTS

5.3.1 Recruitment

We had five sources of recruitment for parents. We started by contacting families who had been involved in the previous research study. We then turned to other sources, including families involved in other studies at the research unit; families known to health professionals involved with the development project; and local support groups for parents of children with a chronic physical condition. Except for those involved in the previous study, families remained anonymous to us, being contacted through a third party who passed on a project information pack on our behalf. This meant that some families were approached on more than one occasion through our various contacts. One parent who did participate reported that she had received an information pack through three sources: the school; a health professional; and a support group.

A total of 47 information packs were sent out through these various routes. From this group, parents from five families volunteered to take part in the project (see Table 5.1).

Table 5.1: Recruitment of parents

<i>Route</i>	<i>Number of packs sent</i>	<i>Number who volunteered</i>
Previous research participants	12	2
Families known to researcher colleagues	7	0
Schools	12	2
Health professionals	6	1
Parents' support group	10	0
<i>Total</i>	<i>47</i>	<i>5</i>

All those who agreed to take part were mothers. Their children ranged between seven and 15 years of age and had different conditions (one child had two conditions): septo optic nerve disphasia; renal failure; muscular dystrophy; ME, diabetes, and epilepsy. Four of the five parents who volunteered had a child in secondary school.

5.3.2 How parents advised staff

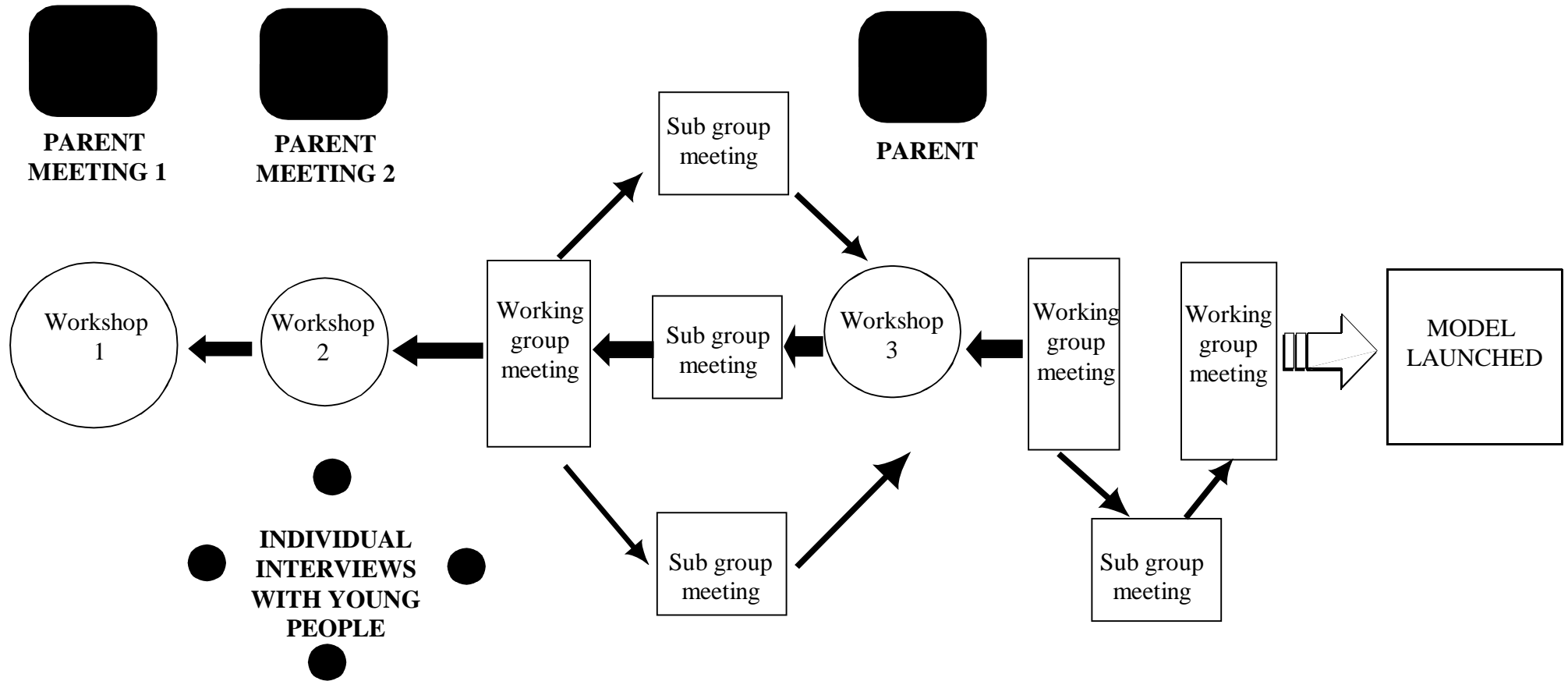
Parents met as a group on three occasions: prior to the first workshop; between the first and second workshop; and after the second workshop (see Figure 5.1). Each meeting was held in the evening at the University and lasted an hour and a half. On each occasion, the research team acted as an intermediary between the parents and staff, who did not meet up during the course of the project as we had envisaged.

When staff were asked by the researchers about meeting with parents and young people at the second workshop, they felt that they still had a number of inter-professional issues to resolve, and so would prefer not to meet. When we asked parents about meeting with staff, initially their feelings were mixed. On the one hand it was thought useful to be 'round the table' with staff; but on the other hand, meeting separately and using the researchers as a 'go-between' meant that parents felt freer to discuss what they wanted and to give the staff more honest feedback. After their third meeting, parents felt that their advice-giving work was done, since deciding how to implement plans for improved communications between staff was a task for the staff themselves.

The aims of the first parents' meeting were for people to meet each other; find out about the previous research findings and share their own experiences; and learn about the current project and their role within it. At the second meeting, the researchers outlined the four key elements of the staff group's plans for improving communications: the named teacher, the named health professional, the health care plan, and the Smart card. Parents were given time to discuss these ideas and then asked to rank them so that staff would know what they felt was particularly important or urgent. At the third meeting, parents were updated on the staff group's progress in firming up their plans. They were also asked to comment on the additional idea of establishing school registers of pupils with special health needs. Appendix Six describes these meetings in more detail.

Researchers made records of parents' meetings, detailing: the context of the meeting; input provided by the research team; the process of group working; the content of the discussion (advice to professionals, and reasoning behind it); and parents' views on how they wanted to contribute to the project in the future. To assist with writing these records, all meetings were audio taped and flip chart summaries of the discussions were retained. Parents were sent a copy of the notes of their discussions.

Figure 5.1: Involvement of service users



May 1999.....March 2000

5.3.3 Content of parents' advice

When asked at their second meeting to rank the staff's four ideas, parents felt that, ideally, they should all be taken forward since they complemented one another. If forced to choose, they said that the named teacher would be the key change, since it could be a platform for other improvements. Parents were keen to promote the idea of the Smart card, since they felt that this would be a good way of encouraging children to take responsibility for their condition and securing any necessary support.

At the third meeting, parents were delighted that staff were planning to take forward all of the four developments originally proposed. However, they expressed caution as to whether sufficient resources would be available, and urged staff to consider what they could still put in place - for example, the Smart card - without too much additional work. In ensuring that implementation did take place, parents suggested that staff might consider setting targets for action. Parents also recommended that the LEA take responsibility for ensuring that schools do have a named teacher. While parents had no objection to the idea of a health register, they were unsure as to its purpose and were again concerned about resources in terms of the work required by teachers to set up and maintain a register.

5.4 WHAT HAPPENED IN PRACTICE: YOUNG PEOPLE

5.4.1 Recruitment

In recruiting young people to the project we wanted to ensure that those approached were of secondary school age since we felt they would need to be this age to feel comfortable attending meetings with professionals. We sent out information packs to young people through two routes where we were sure of the young person's age: previous research participants and schools. In total, 24 young people were invited to take part in this way and four responded positively (see Table 5.2). Three of the four young people who volunteered also had parents involved in the project. One young person who had been involved in the previous research study also volunteered to take part, though their parents were not interested in doing so.

Table 5.2: Recruitment of young people

Previous research participants	12	3
Schools	12	1
<i>Total</i>	<i>24</i>	<i>4</i>

The young people who took part were aged between 12 and 16 years. Two were male and two

were female. They had a range of health conditions (one young person had more than one condition): renal failure; septo optic nerve dysplasia; muscular dystrophy; cystic fibrosis; and epilepsy. All the young people were pupils at secondary schools in York (two were pupils at the same school).

5.4.2 How young people advised staff

Although we were pleased that young people of different age ranges and with different conditions - and therefore different service support needs - had volunteered to take part in the project, the small number of advisors presented us with a potential difficulty in how we wished to work with them. We had hoped that the young advisors would work as a group, but from our previous experience in running groups with teenagers it seemed unlikely that a small group of just four young people, comprising males and females of such varying ages and with different medical backgrounds, would feel comfortable working together in this way. In the event, only one young person was keen to be part of a group; the others preferred to meet a researcher on their own. As a result one researcher met with all the young people individually in their own homes. These discussions were audio taped, with the young person's consent. The researcher offered to send each young person the audio tape of the meeting once they had written up notes. One young person subsequently asked for and was sent a tape.

Young people were visited prior to the second project workshop (see Figure 5.1). They were given details about the project, including what it meant to be a young advisor, before being asked for some background information on what difference their health condition made to their life in school, what teachers knew about their health, and where teachers got their information. The researcher then went on to explain that the working group had some ideas on how to improve teachers' understanding of pupils' special health needs and would like young people's views on these. The researcher told young people about the Smart card and the health care plan. Since pupils would not necessarily have had much contact with a school doctor, the interviewer introduced the idea of the named teacher and named health professional together, as two people who would collaborate. Young people were asked what they thought were any good and bad points about each idea, before choosing their favourite.

At the end of the discussion, all four young people said they would be happy to continue providing advice to the working group and were keen to be kept informed of progress. Two people now said they would like to do this in a group with other pupils involved with the project, but the other two did not want to work in this way. It was therefore clear at this stage that if the working group were to continue to consult with young people this would have to be done on a one to one basis.

The young advisors' views were summarised by the researcher and fed back verbally to the working group at the second workshop. A full written report on the meetings with young advisors was also given to working group members for reference and brought to their attention at a later stage of the project when they were making design decisions about the Smart card.

The working group were told of the young people's willingness to continue being involved with the project. However, at this point in the project the working group were concerned with getting on with developing their plans and felt they had as much advice as they needed from the young people. Following the third workshop, the key health and education representatives from the working group were contacted by the research team to ask if there was any aspect of the project in which they would like to involve young people, for example design of materials, or launch events. The working group did not feel this was necessary, so the research team wrote to the young people to let them know and to thank them for their involvement.

5.4.3 Content of young people's advice

Young people made a number of comments about the pros and cons of each of the proposed changes. They also made suggestions about the content of a Smart card and the role of a named teacher. Their views are detailed in Appendix Seven. When asked to prioritise the ideas, the young people made their decision based on what would help pupils most. Two selected the Smart card as their first choice, explaining that the card was better than the health care plan as staff would probably not look at the plan. Another selected jointly the card and the health care plan so that there is a back-up in school if pupils forget their card. Reasons for favouring the Smart card were: allowing pupils to obtain help from staff quickly; having some control over the information passed on; and not having to explain things to teachers. The fourth advisor selected the named teacher as their first choice, suggesting that if this worked properly there might be little need for the card. Young advisors had most difficulty seeing how the health care plan on its own would help pupils, but could be integrated with a Smart card, if the latter was a shorter version of the plan. One young advisor felt very strongly that young people themselves - not just staff - should be involved in writing the plan, since they might have needs that are not already known to staff.

The role of young advisors underlined the fact that the emphasis on improving communication in order to benefit *pupils* should be central to the project, as illustrated by one young person's advice to the working group:

The ideas should be for the pupils mainly, but for the teachers to make sure they are doing the right thing. The focus should always be for the pupils, not for the

side people.
(Young advisor)

5.5 STAFF VIEWS ON INVOLVING PARENTS AND YOUNG PEOPLE

During the early stages of the project, staff's response to the prospect of involving parents and young people was very positive. At initial meetings with key staff in the LEA and NHS Trust, the opportunity to consult with service users was one of the reasons given for wanting to be involved in the project. At the outset, the research team had intended to take a flexible approach to the model for involvement of service users.

Given the initial enthusiasm from staff, we assumed they would probably wish to meet with service users. However, when it was suggested that could happen at the second workshop, the working group did not feel ready, as they had issues to discuss among themselves. Instead, at the second workshop, the research team fed back comments from parents and young people about the changes planned. Users' views convinced the working group that they should take forward the idea which was favourite among young advisors - the Smart card - but which had been considered a fairly low priority by staff.

However, some members of the working group had reservations about the role of parent and young advisors. They queried whether the individuals involved were typical of service users more generally. Furthermore, although the feedback from parents was supportive of the proposed changes and of the staff involved with the work, it seemed to be perceived by some members of the working group as criticism. This happened most often in relation to comments from parents urging staff to be realistic about what was attainable and not to take on too much. Consulting with service users, particularly young people, seemed to be something with which health staff seemed more comfortable than education staff. Health staff spoke at some length about the importance of working in partnership with families and how they did this in their everyday practice. Some education staff were sceptical about children's understanding of their own condition, questioning both their ability and wish to be involved in drawing up health care plans. They were also concerned about what would happen if a teacher and young person disagreed about what should be in a plan.

At the final meeting held with the working group to close the project, the research team took the opportunity to ask for feedback on how the group felt about the model through which they had accessed the views of parent and young advisors. The research team reminded the group that the way of working with advisors had been left to the group to decide. Various options would have been possible, including occasional meetings, or a merged working group, but the group

opted not to meet and instead used a 'go-between' model in which the research team checked out the group's ideas with advisors and reported back. In discussion on their choice of model, a member of the group reported that they were reluctant to meet with parents face to face as they believed it might be difficult for parents to be honest with staff under these circumstances, particularly if they were receiving services from this professional. This feeling was consistent with what parents themselves had told us. Other members of the group talked about not wanting parents to hear about the difficulties they experienced in attempting to meet families' needs. The importance of young people having the opportunity to express their views was acknowledged, although again concerns about representativeness were expressed. The research team reminded staff that these young people were acting in an advisory capacity, and not as research subjects. The project itself had stemmed from research into needs for service support gathered from a larger number of young people.

5.6 FEEDBACK FROM PARENTS AND YOUNG PEOPLE

We received feedback from advisors both during and at the end of the project. During the project we heard about parents' and young people's preferences for ways of working. For parents, this concerned the pros and cons of meeting as a separate group or with staff (see section 5.3.2). For this group of parents at least, there were benefits on balance from meeting as a separate group with a researcher as 'go-between' communicating between parents and staff. From young people, we learned that their preferences varied as to whether they would like to give their advice to a researcher on a one-to one-basis, or would like to do so via a group discussion with other young people (see section 5.4.2). This confirms the value of being prepared to be flexible so as to respect individual preferences.

At the end of the project we sent a short questionnaire to parents (n=5) and young people (n=4) to ask for feedback on what it had been like to be an advisor to the project. The questionnaire asked both what the person had liked and disliked about being an advisor. We also asked whether the person had any comments on the local guidelines, a copy of which had been sent to all advisors.

Prior to sending out these questionnaires, we telephoned parents to let them know that the questionnaires were coming and to explain why we were asking for feedback. One of the parents was not contactable at this time. We also telephoned the young person directly whose parents were not involved in the project. We received only two questionnaires, one from a parent and the other from a young person. While disappointed at the low response, we do not conclude that this means participants found their experience of little worth, since the telephone conversations

suggested that users had valued taking part in the project.

The parent who responded made only positive comments. She said that she had liked being an advisor because, having on-going responsibility for their child, parents need to be involved in all aspects of their child's welfare. For this reason, she mentioned being willing to take part in future projects. She also valued being involved from the outset of the project.

The young advisor who responded said that it had been good to talk to someone about problems at school, and hoped that their views would help in providing more support for pupils with health problems. Being an advisor had sometimes been difficult, because to help others meant saying things that you might otherwise have kept to yourself. This young person said that s/he thought the guidelines for use in York were good because they included all the necessary details.

5.7 THE RESEARCH TEAM'S REFLECTIONS

The research team feel it was worthwhile to have had young people and parents as advisors to the project since their views did influence the ideas that were taken forward. In particular, it seems unlikely that the working group would have included the Smart card in their guidelines for good practice if both groups of advisors had not favoured it so strongly. For the researchers, there were two main areas for reflection about involving service users in the project: low recruitment; and ambivalence from users and staff about meeting together.

With hindsight, it is not surprising that recruitment of service users to act as advisors to the project was difficult. It is, after all, asking a great deal of parents and young people to commit themselves to providing regular advice. Several families whom we approached because they had participated in our previous research explained that, while they had been happy to take part in the research, they did not want to continue spending time focussing on the illness but would prefer to 'get on with life'.

The small number of young advisors recruited was disappointing for us in that it limited the prospect for forming a group, which could in turn have enabled them to develop a strong voice in presenting their views and discussing issues directly with staff. However, young people themselves were not keen to form a group and we were able to work with them individually to obtain their advice.

There were clearly differences between our perceptions of the role of the young advisors and the perceptions of some of the staff. For us, their role was as individual expert advisors, not as part of a representative research sample. However, staff's queries about the validity of comments

from the small number of young advisors suggested that they saw them as having the latter role. In responding to staff's reservations, we drew attention to this difference between advisor and research subject roles, but sensed that there was still some scepticism. Since staff were very much in favour of user involvement at the start of the project, in hindsight it seems to us crucial to be clear about the role of an advisor, if scepticism is to be avoided. One way we might have done this was to present to staff early in the project the 'stakeholder' rationale in the literature for involving users; that is, the special contribution they can make through having expert knowledge which other 'stakeholders' do not have (see Chapter Two). In particular, the 'stakeholder' argument may have helped make clearer for staff a model in which a small number of service users can legitimately advise a project, indeed much in the same way that individual staff members contributed to the working group.

Turning to the ambivalence of staff about meeting service users, it has occurred to us that one reason for their reluctance may have been that they perceived the project as primarily about inter-professional relationships and systems. This was certainly true in respect of the detailed planning; indeed, parents gave this reason for not needing to meet with staff once they had commented on the outline plans. However, the researchers might have been able to play a greater part in encouraging staff to take a holistic approach and keep in mind the central aim of supporting families.

Feedback from the working group also suggests other reasons for staff's reluctance to meet with users, for instance nervousness about how parents might respond to them. Yet parent advisors were very positive about the work being undertaken by the working group. Staff were also anxious about admitting to difficulties they have in supporting pupils, yet parents' comments reveal sensitivity to the burdens placed on staff in doing so. It may be that such myths would have been dispelled if these two groups had met face to face, with the discussion facilitated by a neutral person, such as a member of the research team. However, there is a need to respect the wishes of both parties in such situations and it was clear that both staff and parents had reservations about meeting together.

CHAPTER SIX

THE OUTCOME OF THE DEVELOPMENT WORK

6.1 INTRODUCTION

In this chapter we describe the outcome of the development work. We begin by describing the model for improving communication between health and education staff that was developed by the working group and the rationale behind it. We then go on to outline the approach taken to implementation, which involved the dissemination of local guidelines on good practice for health and education staff. The chapter ends with the research team's reflections on both the outcome of the work and the approach to implementation, focussing particularly on how the local guidelines, and the way in which they were implemented, compares with the guidelines published jointly by the Department for Education and Employment (DfEE) and the Department of Health (DoH) on 'Supporting pupils with medical needs' in 1996.

6.2 THE MODEL FOR IMPROVING COMMUNICATION

By the end of the second workshop the working group had decided that if they were to improve communication between health and education staff about pupils with a chronic illness or physical disability, they would need to introduce a system which:

- clarified *who* was responsible within education and health services for liaising with staff in their own and other agencies;
- clarified *what* information they were expected to routinely pass on to colleagues in other agencies;
- and introduced *standard documents* for collecting health information which would be used systematically throughout York.

For this reason, they decided to introduce:

- *A Named Teacher for health in every mainstream school in York*

This person would have overall responsibility within the school for liaising with medical staff and the LEA as appropriate. Together with a Named Health Professional, the Named Teacher would be responsible for setting up a Health Register, Health Care Plans and Smart cards. Each school should decide for themselves who would take on the role; it need not necessarily be the SENCO.

- *A Named Health Professional for every mainstream school in York*

It was decided that each School Medical Officer (SMO) should take on the role of Named Health Professional for a specified group of primary and secondary schools. The SMO, together with the school nurse, would be responsible for liaison between health staff, education staff, and

parents on health matters. Together with the Named Teacher, s/he would be responsible for setting up a Health Register for the school and for preparing Health Care Plans.

- *Individual Health Care Plans in respect of pupils with an illness or disability*

The working group drew up a uniform set of documentation to be used in producing Health Care Plans, which they specified should be completed systematically for all pupils in mainstream schools who have:

‘a significant medical need which requires extra care/supervision/support to be given to the child to ensure his/her safety and the safety of others’.

The Health Care Plan includes information on the child’s medical background, action to be taken in an emergency, location of medication, contact telephone numbers for family members and the child’s General Practitioner, details of medication to be administered and who has been trained to do so. To make it easier for teachers to retain information about the pupil, it also includes a photograph.

The SMO, in conjunction with the parents and the Named Teacher, would be responsible for drawing up the plan, and all parties would sign it and receive a copy.

- *A Health Register*

This register would include the pupil’s name, medical condition, and information about health support needs which *all* staff need to know. Most schools would already have such a register, in some form.

- *Smart cards for pupils with an illness or disability*

This card would be held by the pupil and include their name, and any information the pupil might want to disclose quickly, or discreetly, to teachers about their condition.

The Smart card is different from the other elements of the model in that its purpose is primarily to increase direct communication between pupils and teachers. In one sense the Smart card could act as a safety net, making it easier for pupils to pass on information when the other mechanisms failed and a teacher was unaware of their special health needs. This was thought to be particularly important for pupils in secondary school where it could be difficult to ensure that every teacher is aware of the special health needs of all pupils. The Smart card would also enable pupils to take responsibility for asking for help when they needed it. Smart cards were reported to already be in use in York for pupils with emotional and behavioural problems, who show the teacher a card when they need to leave the classroom to calm down.

In drawing up the model, working group members focussed on the fact that teachers are *in loco parentis*, so sharing information is important for the safety and well-being of pupils and to improve life in mainstream schools for children with special health needs. The model needs to ensure that teachers have information on any acute problems, continuing care needs, and any changes in the pupil's circumstances. At present, health care plans are sometimes - but not always - written for pupils who may have a medical emergency at school.

Full details of the remit of each element of the model are given in Appendix Eight as part of local guidelines developed by the working group.

6.3 THE APPROACH TO IMPLEMENTATION

The working group decided they would implement the changes throughout York, rather than pilot the new model in a few schools. There were two reasons for this approach. First, it was consistent with the aim of having a systematic approach to communication across York. Secondly, it was felt that if a few schools volunteered as pilot sites, they would be likely to be 'keen' schools and feedback from this might not be very helpful. Instead, the working group opted to evaluate the model after it had been running across York for a pilot *period*.

It was decided that the most appropriate way to introduce the model was by disseminating joint guidelines on good practice for both health and education staff, to ensure that staff in different agencies receive a consistent message, and to make each group of staff aware of each other's responsibilities. Underpinning the production of guidelines was an awareness of the need for staff to understand the role of the Named Teacher and the Named Health Professional. Therefore, the guidelines explained in some detail what could be expected of the people taking on these roles. A copy of the guidelines is in Appendix Eight.

The decision to issue guidelines - as opposed to pursuing a formal LEA policy - was taken on the grounds that the model would not require additional resources and so taking proposals to committee meetings would be unnecessary and simply result in delaying implementation. It was agreed that the working group would take responsibility for organising an audit to check whether the guidelines had been implemented. The findings from this audit would then be used to review and update the guidelines. It was also thought carrying out an audit might in itself serve to motivate people to apply the guidelines.

Altogether 250 copies of the guidelines were published for the purposes of local dissemination. All members of the working group were involved in the dissemination process. The main focus of the dissemination strategy was ensuring that those who would have an active role in the model

were made aware of the guidelines, that is teachers and SMOs. In March 2000, the guidelines were 'launched' at a Head Teachers' Conference. Each delegate received a copy of the guidelines in their conference pack and the lead representatives on the working group from health and education services gave a joint presentation on the guidelines. The education advisor spoke at the conference about the overall aim and rationale behind the guidelines. She explained that they did not just apply to pupils with SEN. She emphasised that the guidelines complemented existing advice from the DfEE, that they were based on research, and were resource-neutral. The aim of the guidelines was to support schools by improving communication, and not to place an additional burden on staff. She said that the guidelines should be implemented in schools in the Autumn Term and that the LEA and York Health would carry out a joint audit in Spring 2001. The consultant community paediatrician then went on to talk about the components of the Health Care Plan and to explain the respective responsibilities of the staff involved.

Since their 'slot' at the conference was a concession to the LEA by the Head Teachers in a full agenda, there was no time for questions at the end of the session. However, the education advisor felt that education staff had liked the fact that health staff had been pro-active, and that the community paediatrician's physical presence at the conference had been very valuable in this respect. To ensure that all mainstream schools in York received a copy of the guidelines, copies were also sent to all Head Teachers in York, accompanied by a covering letter from the Director of Educational Services (See Appendix Nine).

SMOs attended a training event run by the consultant community paediatrician to go through the guidelines and discuss the implications for their every day work. Each SMO was given a copy of the guidelines. SMOs were also told that they were expected to implement the guidelines in Autumn 2000.

LEA officers and health staff on the working group were each given a number of copies of the guidelines so that they could inform colleagues. Some chose to do this in an informal, *ad hoc* manner, while others gave short presentations at meetings.

The working group took responsibility for all of these dissemination activities. In addition, the research team sent a copy of the guidelines to the wider group of health and education staff who had attended the first workshop and to the expert advisors to the project (parents and young people).

6.4 REFLECTIONS ON THE OUTCOME OF THE DEVELOPMENT WORK

After 11 months of planning, the working group have produced a set of guidelines which on the

surface appear to be fairly similar to those produced by DfEE/DoH some four years previously. Both sets of guidelines are concerned with a similar group of pupils and suggest that schools produce Health Care Plans. Has the project simply 'reinvented the wheel'? In presenting the local guidelines at the Head Teacher's Conference, members of the working group talked about the guidelines 'building on' those disseminated by the DfEE/DoH. Comparing the two documents does reveal some important differences. The local guidelines:

- *Set out to do different things*

The title of the DfEE/DoH guidelines 'supporting pupils with medical needs' reflects its purpose, which is to:

'help schools draw up policies on managing medication in schools, and to put in place effective management systems to support individual pupils with medical needs'.

By comparison the York guidelines take a wider focus on health-education communication, stating that:

'Health and education have been looking at ways of improving life in mainstream school for pupils with chronic health needs. The sharing of medical and health related information is an important aspect of this.'

- *Clearly spell out staff responsibilities*

This was an important issue for the working group since the research findings indicated that one of the main barriers to communication was health and education staff's lack of understanding of each other's roles. The working group spent a lot of time ensuring that roles and responsibilities were explicit in the guidelines they produced. This is different from the DfEE/DoH guidelines which have been criticised failing to make explicit where responsibility lies for providing care and support for children with health needs in school (House of Commons Health Committee, 1997: para 88).

- *Strive to achieve a consistent approach across schools within the LEA*

In order to achieve this the York guidelines provide a template of a health care plan which *all* schools are asked to use. This is different from the DfEE/DoH guidelines which do provide an example of a health care plan, but suggest that schools modify them to fit their needs. The working group wanted to ensure that the same format was used throughout schools in York so that health care plans could be transferred with a child when s/he changes school.

- *Explain local arrangements with regard to legal indemnity, thus reassuring school staff anxious about involvement with medical care*

The national guidelines draw attention to the need for LEAs to provide legal indemnity, warning that ‘staff who provide support for pupils with medical needs, or who volunteer to administer medication, need support from the head and parents, access to information and training, and reassurance about their legal liability’. The local guidelines build on this, explicitly stating that teachers in York who are involved with providing medication are legally indemnified, so long as they have received the appropriate training.

- *Suggest the use of Smart cards and a Health Register*

Since the focus of the local guidelines is on improving communication, they suggest mechanisms other than health care plans for ensuring that information is available to teachers in school, including the use of Smart cards and a health register.

- *Provide a named contact within health and education services, who is available to offer advice and support in relation to implementing the guidelines*

In addition to the content of the guidelines differing, the process of implementation is also quite different to the approach taken with the DfEE/DoH guidelines. The DfEE sent a circular to all LEAs and schools notifying them of the guidelines and it was up to individual schools to be proactive in seeking them out. In our earlier research, we found that many teachers were unaware of the national guidelines (Lightfoot *et al.*, 1998). Implementation of the local guidelines took much more visible forms:

- The local guidelines were launched at a local Head teachers’ conference, where senior staff within the LEA and the Health Trust were seen to be backing the document.
- A copy was sent to all schools with a supporting letter from the Director of Educational Services.
- A meeting was held with SMOs to discuss the guidelines and the implications for local practice.
- Further meetings were held for other staff who are involved with pupils with an chronic illness or physical disability, but whose everyday work is unlikely to be affected by the guidelines.
- The guidelines were sent to the wider group of health and education staff who taken part in the first workshop, which identified priorities for change in York.
- Use of the guidelines will be monitored through an audit.

In addition, perhaps one of the most significant benefits of producing *local* guidelines is that they are seen as arising from the efforts by local health and education staff to improve how they work together. This in itself may serve to strengthen relationships between staff in different agencies.

Initial indications are that there is local interest in the guidelines, with members of the working group reporting requests from schools for additional copies and that the school staff they have spoken with have been positive about the document. It remains to be seen whether this is sufficient to ensure that the guidelines are followed. Results of the audit scheduled for Spring 2000 will provide an insight into whether the implementation has been effective.

CHAPTER SEVEN

CONCLUSIONS

7.1 INTRODUCTION

In this final chapter we draw out conclusions from the project. In doing so, we highlight both its strengths - including where it adds new knowledge - and its limitations. Our aim in doing so is to provide information which can help to guide others wishing to make similar inter-agency service developments.

At the outset of the project we had four objectives: first, to investigate local health staff's views about communication with education staff about pupils with a chronic illness or physical disability. Secondly, we would then share the research evidence from health and education staff, parents and pupils among all parties. Thirdly, the project would lead to the development and implementation of an improved system for health-education communication, with involvement from staff and families. Fourthly, we would draw up and disseminate recommendations to guide other areas in developing more effective inter-agency communication.

The involvement of the research team terminated at the time of the initial implementation of the system to improve communication. In designing the project we were aware, from previous experience of researched development work (Mukherjee *et al.*, 1999; Sloper *et al.*, 1999), that the process of full implementation of change is lengthy, and that evaluation of such change is not feasible until it has been in place long enough for initial problems to have been solved and effects to be apparent. It was clear that we would not be able to continue our involvement and undertake an evaluation within the funding limits of this NHS Regional Research and Development initiative. We can, however, draw conclusions from the research and development aspects of the project.

There are two pieces of work outstanding. First, in September 2000 we will be holding a workshop for health and education staff in other areas, to disseminate the project's findings, both in terms of its *outcome* - details of the communication system developed in York - and the *process* through which we worked with staff, parents and pupils. Secondly, following the audit in Spring 2001, staff have agreed that the research team may have access to the results and write an Addendum to this report, so that information on the progress of implementation will be available.

7.2 RESEARCH PHASE

At the outset of the project we set out to fill a gap in research knowledge concerning the

perspectives of health staff on communication with their colleagues in education. We gathered data from staff working in a wide range of health professions involved with pupils who have special health needs (see Chapter Three). These data served to complete the picture on communications from all ‘stakeholders’, adding to existing research evidence from school staff, parents and pupils.

In collating these data, it is clear that support for pupils is *ad hoc*, dependent on the chosen practice of individual health and school staff. Given the wide variation in practice, it follows that some pupils are well-supported, but others are not. In turn, this evidence points to the need for a more systematic approach in health-education communication. In seeking to make improvements, research points to a need to address communication issues both *within* and *between* agencies. There appear to be two over-arching barriers to effective communication requiring attention: first, lack of clarity about roles and responsibilities for communication about this group of pupils among health and education staff; and, secondly, blocks in the flow of information within and between agencies.

While our research data from teachers, parents and pupils were drawn from three research sites, data from health staff were drawn from one Trust only for the purpose of informing the local development work in York. While caution is needed in interpreting these data more widely, it was clear that the data from health staff were consistent with the wider picture obtained from pupils, parents and teachers in the larger study.

7.3 DEVELOPMENT WORK

In this section, we split our conclusions between the *outcome* of the development work - that is, the content and implementation of the model for improved communication in York - and the *process* through which the model was developed. Our conclusions draw on the reflections of all those involved.

7.3.1 Outcome

As we noted earlier, conclusions about the outcome of implementing the model are inevitably limited, since the model is not expected to be taken up across York until September 2000. We can, however, draw some conclusions based on the work completed to date. These conclusions can be separated between those concerning the model itself (as set out in the guidelines) and those concerned with the working group’s approach to implementation; that is, a launch followed by York-wide implementation.

The York model

There are a number of perceived strengths of the York model for improved health-education communication. Members of the working group valued production of a model itself as tangible evidence of successful inter-agency working in York. Since the working group had no power to impose the model on health and school staff, but rather encouraged its adoption through issuing guidelines for good practice, a particular strength of the model for staff was that it was resource-neutral, since this was felt likely to facilitate take-up. A strength of the model from the researchers' perspective was that - through seeking to clarify roles and responsibilities and the flow of information - it tackled the key barriers to inter-agency communication identified from research. In doing so, this local model built on and strengthened existing national policy guidance for supporting pupils with medical needs, which has been criticised for failing to make explicit where responsibility lies for supporting these pupils (see Chapter Six). In addition, including the Smart card among the improvements demonstrated a willingness to pursue an idea which had found favour among the parent and young advisors. Parents themselves reported satisfaction with the elements of the proposed system.

There are two limitations to the model which we, as researchers, would wish to mention. The first of these is that the model was developed locally and so took as its starting point existing inter-agency relationships and resources in York. It follows that, while there is value in disseminating the model as an example of one approach for improving health-education communication, the details of the model itself are not necessarily generalisable elsewhere. Instead, staff in other areas would need to reflect on the York model in the light of their own local circumstances, drawing from it what is helpful. This reflective approach is what we have planned for the September 2000 workshop.

The second limitation of the York model that we observe as researchers is that, while the guidelines tackle the inter-agency action needed to improve communication, attention is not drawn directly to communication issues *within* each agency which the research evidence suggests also need to be addressed. It is, of course, possible that attention to these areas will follow once the current guidelines are in place and staff are actively pursuing their effective implementation.

Approach to implementation

Turning to the working group's approach to implementation - a joint launch at a local Head Teachers' conference followed by a York-wide implementation - again, it is difficult as yet to draw firm conclusions about the appropriateness of this approach in securing take-up of the model. However, discussion among members of the working group reveals that they see three strengths of their approach.

First, considerable emphasis was placed on joint ownership of the model: for example, the guidelines include the logos of both the City of York Council and York Health; and the consultant community paediatrician and the education advisor (special needs) gave a joint presentation to the Head Teachers' conference. Secondly, the working group thought it important for all staff to receive a consistent message and be clear about the roles and responsibilities of others, not just themselves. To achieve this, a single set of guidelines was produced for all staff. The third strength perceived by staff of their approach to implementation was a decision not to pilot the model in a small number of schools but to pursue York-wide implementation with an audit after one term. The rationale for this approach was that the approach to implementation should be consistent with the aim of the project: that is, a systematic approach to communication for all pupils with special health needs.

7.3.2 Process

In this section, we turn to what has been learned from the approach adopted in the project to developing research-based change in professional practice. Conclusions can be drawn about four aspects of this work: the appropriateness of a staged model; the resources required; working with more than one agency; and involving service users. Recommendations for others seeking to undertake similar work are in Chapter Four.

A staged model

Following the literature on managing change (see Chapter Two), we designed a staged model which moved from setting out the problem and demonstrating the need for change (via presenting the research evidence), through detailed and realistic planning of what needs to change and how, to taking action by implementing these plans. Reflection by members of the working group on the way in which the project was organised and run suggests that the staged model is appropriate for tackling research-based change. In particular, staff valued the focus on realism: a realistic outcome and timescale; and breaking down the work into manageable tasks.

Resources required

Our experience has also drawn attention to the resources of time, group membership and facilitation skills required to carry out this type of work.

Time: Managing change means that those who are involved go through a process in which they acknowledge the need for change and then alter their behaviour, all of which takes time. Indeed, although we worked on the project in York over a period of eighteen months, at the point at which we withdrew, the improvements planned were still to be fully implemented. The amount of time needed for this type of work is inevitably difficult to predict and, ideally, there needs to be some flexibility in funding and in the use of development workers' time. In our case, we and our funders were able to be flexible to a certain extent, allowing work to cease on the project when the working group had a lull over the Summer of 1999. Nevertheless, neither funding timescales nor development workers' commitments to single projects are likely to be open-ended. What we have learned from the project is the value for making real progress by working at the participants' slower pace rather than forcing our own.

Group membership: Members of the working group made several recommendations in respect of securing appropriate membership of a staff group responsible for planning and implementing change. Key recommendations were: to include people with power to take decisions; to ensure representation from all the constituencies involved, while at the same time avoiding over-representation of any one group; and to maintain commitment by attending meetings. On the last point, while accepting that it is unrealistic to expect all members to attend all meetings, having observed the group being diverted from an agreed path from time to time by members who missed meetings, we would argue that regular attendance also helps to maintain a consensus about the focus and direction of the work.

Facilitation skills: Members of the working group drew attention to the importance of good facilitation in securing the success of the project. They were particularly appreciative of the research team's approach in encouraging them to take ownership of the work, and of chairing skills, such as taking a neutral stance and sensing when the discussion needed to be moved on, or brought back to focus on the task in hand.

For our own part, we were aware of the need for a careful balance between meticulous planning of events which we were organising and taking a flexible approach on the day to accommodate the needs of participants in how to spend their limited time together. In practice, this meant taking many decisions 'on the spot' about extending or eliminating individual sessions. While this might seem to suggest that time spent in detailed planning is inefficient, our experience

taught us that, in practice, having paid close attention to planning meant that we carried a clear sense of what could and could not be sacrificed on the day, and so was preparation time well spent.

Having valued the researchers' facilitation role, members of the working group and the research team felt that the researchers' gradual withdrawal had posed difficulties for the group in taking full responsibility for managing their meetings. Although we signalled our withdrawal verbally on several occasions, we do concur with feedback from the working group that time for a group to plan explicitly and practically for such withdrawal is likely to be of value in this type of work.

As researchers who are also experienced in development work designed to facilitate research-based practice, we are aware that development work requires different skills from those of the researcher. It follows that, while there may be advantages in researchers carrying out development work - for instance, familiarity with the research evidence - it does not necessarily follow that only researchers can fulfil this role. Furthermore, if researchers are to do so, attention is needed to the additional skills required.

Working with more than one agency

It is clear that managing change among staff of more than one agency magnifies some of the issues around group process and management of change which require attention. Members of the working group found valuable the time spent in enabling people from the different agencies to get to know and trust each other. Some of the key benefits of the project identified by staff were better knowledge of other services and of individual staff. The neutrality of whoever chaired meetings and a balance of agency representation on the group were also important issues. Our own observation of how the discussion in meetings changed in focus between health and education according to who was present adds weight to the likely importance of these factors.

Involving service users

As part of our approach to managing change, we set out to involve service users - parents and pupils - in the development work along with staff. Although we wanted all parties to have the freedom to decide how they wished to work together, we ourselves hoped that the three sets of 'stakeholders' might have formed a merged working group at some stage. In drawing conclusions from this aspect of our approach, we have noted a number of barriers to involving service users, including aspects of our approach. Despite these factors, parents and young people did have an opportunity to comment on staff's plans for change and, in turn, staff did incorporate their views.

The staff and parents' groups both identified barriers to working face to face. For both groups,

the issue was that of being honest with one another: parents said that having a researcher as ‘go-between’ meant that they could be more honest than if speaking to staff directly; and staff were reluctant to disclose any difficulties they experienced in meeting pupils’ health needs at school. Parents also felt that meeting with someone other than staff meant that they were freer to raise issues of concern to them, which suggests that they perhaps feared that the staff’s agenda might have dominated joint meetings.

We have reflected on the part the researchers may have played in limiting the likelihood of professionals and service users working together. First, from the outset we established three separate groups: staff, parents, and pupils. The rationale for this approach was two-fold: to allow members of each ‘stakeholder’ group an opportunity to discuss among themselves issues they thought important; and to strengthen the voice of the user groups (in particular, young people) when working directly with staff. In our view, convening a joint group from the start would have been unlikely to have met these needs. However starting as three separate groups may have contributed to participants’ subsequent reluctance to meet as a whole group.

Secondly, we may have limited the prospects for people wishing to work together through making clear to all parties that *staff* would have responsibility for decisions about the plans to take forward, and that parents and young people were in advisory roles. Our rationale for this demarcation was that detailed planning would require knowledge of the day to day working life of relevant professionals, the systems they operate and the practical scope for improving these. We considered that asking service users to participate in this detailed level of decision making may have risked ‘tokenism’. In hindsight our view was confirmed when parents decided to withdraw from the project at the point of detailed planning when they felt that their capacity to offer advice had become exhausted. This view of parents reminds us that users should be involved appropriately; that is, in matters about which they feel they have knowledge and expertise.

As reported in Chapter Five, the low level of recruitment of young advisors caused the working group to question the validity of their contribution to the development work. We feel that more explanation of the role of young advisors could have been beneficial to the working group’s understanding of the nature and value of their contribution.

7.4 CLOSING REMARKS

Despite the many reservations that are inevitably set out when drawing conclusions, this project has had two key benefits: a model for improving health-education communications has been developed in response to research evidence; and a group of health and education staff have demonstrated that they can successfully complete such a task together, including responding to the views of parent and young advisors. In doing so, the staff involved have increased their awareness and knowledge of each other's roles and of other services, and have developed relationships of trust and co-operation. This may have spin-off effects in the future for other aspects of local inter-agency working.

The way in which the researchers worked with those involved has been largely successful from everyone's perspective. It is clear from the feedback we have from participants that those taking part have derived satisfaction from the project. For ourselves, it has also been enormously satisfying to see research findings acted upon in such a positive way. In describing the project, and noting its limitations, we hope to encourage other areas in tackling similar work

We know that the NHS is clearly committed to both research-based practice *and* inter-agency working. The model we have used in this project appears to have helped, in one local area and for one particular task, in achieving both these aims. Wider challenges for those responsible for securing these goals nationally and locally will be to consider who will carry out this type of work and who will fund it?

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