

An Exploration of Different Models of Multi-Agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs

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Executive Summary

Introduction

A key worker has been described as a named person whom the family can approach for advice about, and practical help with, any problem related to the disabled child. Provision of 'key workers' or 'care coordinators' for disabled children and their families, working across health, education and social services, has often been recommended in policy guidance, most recently in the Children's National Service Framework. Up to now, research has shown that less than a third of families with severely disabled children have a key worker, but compared to those who do not have a key worker, those who do show benefits in terms of relationships with and access to services and overall quality of life. However, as more key worker services have been developed, different models of service and ways of working have proliferated and there has been no research on the outcomes for families of different types of services. This study aimed to explore the effectiveness of different models of multi-agency key worker services.

Aims of the research

The aims of the project were:

- To compare the implementation and operation of different models of key worker services.
- To assess the outcomes for parents and children of the provision of different models of key worker services.
- To investigate sources of funding and costs of different models of key worker services.
- To identify the features of the services that contribute to improved care for disabled children and their families.
- To inform standards of good practice in services for disabled children and their families.

Methods

Questionnaires were sent to 225 children with disabilities teams across the UK; 70 per cent returned the questionnaire. Thirty provided a key worker service, and replied to the questions regarding the characteristics, funding and costs of the service.

Seven services representing different models of key working were selected for detailed case studies, comprising interviews with staff and families and questionnaires to all families receiving the services. Data were analysed quantitatively and qualitatively.

Eighty-seven interviews were conducted with key workers, members of the steering groups and managers of the services. Interviews were also carried out with staff in 14 schools attended by children in the sample.

Two hundred and five parents and thirty children completed questionnaires on their experience of the services. Service use data were collected. The outcome measures in the parent questionnaire were: parental satisfaction with the service, the extent to which the key worker had influenced parental quality of life, parental unmet need, and child unmet need. Path analysis was used to trace associations between family and service characteristics and outcomes.

Sixty-eight interviews with parents/guardians and nine interviews with children/young people were carried out to explore families' experiences in more detail.

Key findings

The UK wide survey of care coordination schemes identified only 30 services providing key workers for disabled children. These services varied in their structure, organisation, funding arrangements, and costs. Seven services, encompassing different models of working, were selected for more detailed research. The key messages for policy and practice from this research are summarised below.

- The research showed that key workers provided a valuable service for families and had positive impacts on many families' lives. Key workers' collaborative work with other agencies and professionals and with schools facilitated access to appropriate support for disabled children and their families.
- However, outcomes for families varied between and within areas. Factors relating to better outcomes included the management of the service, definition and understanding of the key worker role, and provision of training and supervision for key workers. The findings have a number of implications for the further development of key worker services.

Management of the service

- Results showed that key worker services provide the most benefit to families when they are effectively managed, and when health, education and social services are all committed to the service and provide adequate resources in terms of funding, staff and managerial support.
- A multi-agency steering group, involving senior managers from each agency, who have the power to commit resources, should oversee the service, facilitate information sharing and agree ways in which the service will gain families'

consent for information relating to them to be shared between professionals and agencies. The involvement of parents in the group helps to focus on the needs of families.

- At a minimum, funding is required to cover the time of a dedicated service manager and some administrative support. Such funding should be agreed on an ongoing basis. Short term funding produces uncertainty for staff and families and increases the fragility of the services.
- The service manager's role should include inducting key workers, organising ongoing training and opportunities for key workers to meet together, ensuring key workers are provided with regular supervision specific to their role, organising joint care planning and review meetings, and drawing up information about the service and publicising the service to families, other agencies and professionals.
- If non-designated key workers (i.e. workers who key work with a few families in addition to their normal professional role) are employed, it is important that they have protected time to undertake the key worker role and that this is recognised in their case loads. Part of the role of the manager and of the steering group members is ensuring that line managers in agencies from which key workers are drawn understand the role of the key worker and are committed to the key worker service. The time commitments of the role should be recognised and agreed between the service and the agencies that provide key workers.
- Multi-agency care planning and review meetings should be part of the service. These provide a valuable means by which actions of different agencies and professionals can be agreed in collaboration with parents and, hopefully, young people. Such meetings are also an important part of information sharing. Key workers should support families to prepare for and take part in these meetings. Whenever possible, meetings should be combined with other reviews, such as statementing reviews, so that families are not required to attend multiple meetings.

The key worker role

- In some areas, there was confusion about the role of the key worker among families and key workers themselves. The most effective services had clearly defined the role and ensured that both key workers and families understood what it covered. Outcomes for families were strongly related to the extent to which key workers carried out the different aspects of the role.

- A definition of the role of key worker should be drawn up and incorporated in a job description. The service manager should ensure that every key worker understands the role. Information for families should also make clear what is and is not within the key workers' role and key workers should explain this to families. Families should have written information about the role to refer back to. Other services in the locality, including schools, should receive information about the key workers' role, and key workers and service managers should be proactive in ensuring that relevant professionals know about, and understand the remit of, the service.
- The best outcomes for families are achieved when the role of the key worker includes: providing information to families about services and support available, both locally and nationally, and how to access these; providing information about the child's condition where needed; identifying and addressing the needs of all family members; coordinating care and supporting families with care planning and review; improving access to services; speaking on behalf of the family when dealing with services; providing emotional support; and providing help and support in a crisis. The extent to which the key worker carries out different aspects of the role will depend on the particular needs of each family.
- Key workers should be proactive in contacting families regularly at intervals agreed with the family.
- Key working is a service for the family, not just parents. Key workers need training to support them in working with disabled children and young people, particularly those who have cognitive and/or communication impairments. In addition, time is needed for key workers to ensure this work can take place. Children and young people's participation in decisions about developing the service should also be promoted, again this will need time, resources and support for children.
- Key workers have an important role in improving children's education and school experience in a number of ways, including mediating between schools and families to tackle problems and to resolve sensitive or contentious issues. It is important that key workers introduce the service to schools when they are allocated to a child or when children start school. This facilitates relationships with schools and enables key workers to be proactive rather than reactive.
- Key workers have a 'hybrid' role that requires a broad range of skills and knowledge. The research showed that it is performed best when it is not an add-on role without time and training allocated to it.

Key worker training and supervision

- Key workers who received regular training, supervision and support were likely to carry out more aspects of key working and had more positive impacts for families.
- Key workers require induction and ongoing training specific to their role. This should include information about: the work of all agencies relevant to disabled children and their families, common disabling conditions, relevant legislation, and sources of financial support for families and eligibility criteria. Training should also cover disability awareness and the personal skills needed by key workers – communication, listening and negotiating skills, communicating with disabled children, and time management.
- Key working is a demanding role and supervision and guidance specific to the role helps workers to meet these demands. In addition, regular opportunities for key workers to meet each other are important aspects of learning and support.

Type of key worker

- Designated key workers were found to have some advantages over non-designated key workers, in terms of contributions to outcomes for families, ease of management and development of team spirit. However, findings suggested that the potential disadvantages of non-designated key workers could be overcome by provision of training, supervision and peer support. Nevertheless, the appointment of designated key workers should not be ruled out solely on cost grounds. Analysis of costs indicated that estimated average costs per family per year for services with designated key workers were £1,380 to £2,300 and those for services with non-designated key workers were £1,565 to £2,935.

Quality and costs of the service

- The higher costs of more intensive contact with families were associated with greater satisfaction with the service and a greater impact on parental quality of life. However, when controlled for other aspects of the service, costs were not directly related to better outcomes for families suggesting that the way key workers provide support may be more important than overall levels of contact.

Chapter 1: Background

1.1 Introduction

Research on the needs of families with disabled children has produced consistent findings, indicating that substantial numbers of families report a 'constant battle' to negotiate access to services through the different agencies. Families report difficulties understanding the roles and responsibilities of different agencies and professionals, they do not know which service or professional to go to for different needs, they report conflicting information from different people, being passed from one agency to another, and having little information about what services are available and how to access them. As a result, high levels of unmet need are reported (Quine and Pahl, 1989; Sloper and Turner, 1992; Beresford, 1995; Chamba *et al.*, 1999; Watson *et al.*, 2002a), linked to high levels of parental distress (Harris and McHale, 1989; Sloper and Turner, 1992), which in turn affects children's cognitive, social and behavioural development (Wallander and Varni, 1998), social exclusion and quality of life (Morris, 1998a; Oldman and Beresford, 1998; Watson *et al.*, 2002b).

These problems are related to the multiplicity of agencies involved with disabled children, and the lack of coordination between agencies. The need for service coordination for disabled children and their families, and partnership working between the agencies involved in provision of such services, has been a central concern in policy for many years (Department of Health, 1976; Department of Education, 1978; Department of Health, 1989; Audit Commission, 1994). Provision of 'key workers' or 'care coordinators', working across health, education and social services, has often been recommended in policy guidance, and a consistent finding from studies of parents' views is that the majority of families are calling for such a service. However, research continues to show that less than a third of families have a key worker (Sloper and Turner, 1992; Beresford, 1995; Chamba *et al.*, 1999; Noyes, 1999). Even when families do have someone they see as a key worker, this tends to be on an *ad hoc* basis, at the initiative of an individual professional, as a result if this professional leaves the service, the role does not continue. Points of transition between services (pre-school to school, primary to secondary school, and transition to adult services) have been identified as crucial times where cooperation between agencies is vital, yet even at this time the provision of key workers appears to be rare (Petrie *et al.*, 2003). Similarly, evidence from a survey of Child Development Teams (McConachie *et al.*, 1999) showed that less than half provided key workers or care coordinators. The implementation of key worker services as a systematic part of inter-agency working, supported by multi-agency organisational systems, has been rare.

1.2 Recent policy initiatives

In both England and Wales, recent policy initiatives have placed increased emphasis on partnership working between agencies, both in general and specifically in relation to services for disabled children. In England, Section 31 of the Health Act 1999 was designed to allow greater flexibility in sharing of financial resources through enabling local authority and NHS agencies to set up pooled budgets, lead commissioning and integrated services. However, an analysis of the first 32 partnerships (Hudson *et al.*, 2002) found that these provisions were rarely used in children's services. The *Quality Protects* programme (Department of Health, 1998) also sought to increase inter-agency collaboration in children's services and one of the targets for QP for 2002-3 was increasing the availability of key workers for disabled children and other measures to improve coordination.

Poor information sharing and coordination in services for children was highlighted in the Laming Report into the death of Victoria Climbié (Laming, 2003). In England, the ensuing Green Paper, *Every Child Matters* (Department for Education and Skills, 2003), included a number of recommendations to improve multi-agency working, including Children's Trusts and Directors of Children's Services, integrated teams of health, education and social services professionals based in schools and Children's Centres, a common assessment framework and information sharing, a lead professional for children in contact with more than one specialist service, and joint inspection teams judging services on how well they work together. The Children Bill (2004) creates a statutory framework in England and Wales for cooperation between local authorities, key partner agencies and other relevant bodies to improve the well-being of children. It places a duty on local authorities to make arrangements to promote cooperation and a duty on key partners to cooperate. It also gives the power for all partners to provide resources and establish a pooled fund. In England, the National Service Framework for Children, Young People and Maternity Services (NSF) (Department of Health/Department for Education and Skills, 2004a) also places considerable emphasis on coordinated services for all children: Standard 3 states that 'Children, young people and families receive high quality services which are coordinated around their individual and family needs and take account of their views.' In Wales, the recently published National Service Framework for Children, Young People and Maternity Services in Wales consultation document (Welsh Assembly Government, 2004) also strongly emphasises the need for coordinated services for children and young people, stating that 'the achievement of true partnership working will achieve more in terms of improvement of services and outcomes for the benefit of children and families than anything else contained within these standards' (p.7). Local Children and Young People's Framework Partnerships (Welsh Assembly Government, 2002) involving local authorities, health services, other statutory bodies, such as police, and relevant voluntary organisations, are already in place and will be empowered to pool budgets. A key action under the first

NSF standard - Child and Family Centred Services, applying to all children, is that children and young people who require more than two ongoing specialist services will have services coordinated by a key worker.

Specific policies for disabled children also promote multi-agency working and provide more detail on how this should be undertaken. The Early Support Programme in England for services for disabled children from birth to three was developed from guidance in *Together from the Start* (Department of Health/Department for Education and Skills 2003). It is a multi-agency programme which aims to improve service provision so that services are family-focused and well coordinated. One of the recommended ways in which this can be achieved is through the development of key worker systems. Standard 8 of the NSF also highlights the need to coordinate services for disabled children: 'Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives' and guidance states that agencies should ensure that 'families caring for a disabled child with high levels of need have a key worker/care manager to oversee and manage the delivery of services from all agencies involved in the care and support of the family...' and 'the key worker service is....supported by cross-agency senior management commitment' (p.28) (Department of Health/Department for Education and Skills, 2004b). Similarly, in the chapter on disabled children and young people of the NSF for Wales, a key action is 'Service providers jointly agree and provide a key worker service for families with disabled children with complex needs.' (p.85). These policies are based on the results of extensive consultation and the existing research evidence on the need for and the effects of multi-agency key worker services.

1.3 Evidence on the effectiveness of key working

There is fairly small body of evidence from research in the UK and USA on the effects of having a key worker (for example, Glendinning, 1986; Marcenko and Smith, 1992; Sloper and Turner, 1992; Beresford, 1995; Koren *et al.*, 1997; Prestler, 1998; Mukherjee *et al.*, 1999; Tait and Dejnega, 2000). Some studies have simply compared families who say they have a key worker with those who don't, so attributing differences to key workers in any individual study is problematic. Others have been small-scale qualitative evaluations of a local service. However, consistency of findings between studies adds weight to the evidence. One study (Glendinning, 1986) compared families receiving a key worker service with a control group. Liabo *et al.* (2001) in a review of the evidence, concluded that findings indicate that:

- If they receive a key worker service, the overall quality of life for families is improved.
- Specific outcomes are better relationships with services, better and quicker access to services and benefits, and reduced levels of stress.
- Good personal relationships between key workers and parents are reported by parents as important factors and of value in themselves.
- Key workers report satisfaction with the role and believe that it makes a positive difference to the lives of children and families.
- While a key worker in the role of independent advocate can be effective, a key worker who works for a service appears more able to access resources necessary to meet families' needs.

1.4 The role of the key worker

Drawing on the evaluations of key worker projects in three local areas (Mukherjee *et al.*, 1999; Tait and Dejnega, 2000), a number of points can be made about the role of key workers. Both key workers and families reported that the role of the key worker encompasses:

- Providing information and advice to the family.
- Identifying and addressing needs.
- Accessing and coordinating services for the family and ensuring their timely delivery.
- Providing emotional support.
- Acting as an advocate for the family.

The balance between these activities will differ for different families and at different times in a family's life. This underlines the importance of the service being flexible and responsive to families' views and needs.

Families reported that the following elements were important in a quality key worker service (Mukherjee *et al.*, 1999):

- Proactive, regular contact initiated by the key worker. This should be at intervals agreed between key worker and family and often may be just a phone call. Families did not want it to be left up to them to contact the key worker. The service should not be just a crisis intervention service.
- Listening to families and developing a supportive open relationship, promoting a sense of trust which allowed family members to be honest and open with their key worker. This takes time to develop and highlights the importance of the personal qualities of the key worker and of continuity of worker. It was facilitated by key workers visiting families at home, so that families were on home ground and felt more in control, and so that key workers got a more holistic view of the child and family and an understanding of the everyday experience of caring for the child.

- A family centred approach, acknowledging and exploring the needs of all family members, not just the disabled child.
- Working across agencies, those agencies that were formally included in the key worker scheme, but also others, such as housing and the Benefits Agency. Key workers needed to know what different agencies can offer and how to go about accessing different agencies. Having named contacts in agencies helped in this. It was also important that this was seen by managers as an integral part of the key worker role.
- A flexible approach, identifying families' strengths and preferred ways of coping, and negotiating with them as to the support and input needed from the key worker and other services. The negotiating model for working with families (Dale, 1996) seems to be central to a good key worker service.
- Working for the family rather than working solely within a certain professional or agency role. If necessary, some families wanted key workers to be able to act as advocates for them.

1.5 Factors affecting the provision of key worker services

In order to provide a co-ordinated service to families, key worker systems must involve active partnerships between different agencies. Social Services Departments, Local Education Authorities and schools, NHS Trusts and Primary Care Trusts are central to this partnership, but families' needs also encompass the roles of voluntary agencies, housing departments, leisure services and the Benefits Agency (Dobson and Middleton, 1998; Beresford and Oldman, 2000; Beresford, 2002). The role of the key worker involves liaising with and coordinating support relating to these different agencies.

Research on inter-agency working in services for children and young people points to difficulties encountered in terms of different professional cultures; funding structures; potential overlap of roles; lack of understanding about the roles and responsibilities of different agencies; ensuring commitment of staff within the different agencies; communication both within and between agencies; and differing concepts regarding confidentiality of information (Dyson *et al.*, 1998; Sloper *et al.*, 1999; Coles *et al.*, 2000; Atkinson *et al.*, 2001; Webb and Vulliamy, 2001). There are indications that the different responsibilities and structures of agencies involved in services for disabled children can also present barriers to cooperation. For instance, ensuring that LEAs and schools are partners in a coordinated inter-agency approach can pose particular problems in relation to the autonomous status of schools (Webb and Vulliamy, 2001).

There are a number of factors that appear to work against the implementation of key worker services (Sloper *et al.*, 1999; Beattie, 2000):

- If key worker services are to be part of the service system, implementation must take place on an inter-agency basis. It is therefore dependent on a basis of good multi-agency working at both strategic and practice levels. However, this has been under-developed in many areas.
- Key working is underpinned by collaboration between different disciplines. Lack of trust between disciplines undermines this.
- The role of the key worker is different from the usual professional roles. In some professions, a priority is to provide focussed, time limited, task oriented solutions, directly aimed at specific problems and goals. In contrast, a key worker has a longer-term and proactive role, covering a variety of issues and problems that cut across disciplines and agencies. This can challenge existing professional cultures.
- The role of a key worker currently carries no status.
- Current referral systems and lack of funding are also barriers.
- Implementing a key worker service is about changes which challenge current patterns of work.

More general research on multi-agency working also provides consistent findings on factors that can facilitate or act as barriers to coordination of services (for example, Watson *et al.*, 2002b; Cameron and Lart, 2003; Sloper, 2004). At the organisational level, key factors facilitating joint working have been found in the planning, implementation and ongoing management of multi-agency services. In planning the service, studies suggest that successful multi-agency working is promoted by:

- Clear and realistic aims and objectives which are understood and accepted by all agencies, leading to a clearly defined model of how the multi-agency service will operate.
- Agreement about how resources will be pooled or shared.
- Clearly defined roles and responsibilities, so everyone knows what is expected of them and of others, and clear lines of responsibility and accountability.
- Commitment of both senior and frontline staff, which is aided by involvement of frontline staff in development of policies.
- Strong leadership and a multi-agency steering or management group.
- An agreed timetable for implementation of changes and an incremental approach to change.
- Linking projects into other planning and decision-making processes.
- Ensuring good systems of communication at all levels, with information sharing and adequate IT systems.
- Involving service users in development and evaluation of the service.

Research suggests that the implementation and ongoing management of the service requires:

- Shared and adequate resources, including administrative support and protected time for staff to undertake joint working activities.

- Recruitment of staff with the right experience knowledge and approach. Interestingly, Atkinson *et al.* (2002) found that many of those involved in the multi-agency initiatives had worked in multiple agencies during their career, suggesting that a new type of 'hybrid' professional may facilitate joint working.
- Joint training and team building, and 'time out' to take part in these activities.
- Appropriate support and supervision for staff.
- Monitoring and evaluation of the service, with policies and procedures being reviewed regularly in the light of changing circumstances and new knowledge.

Studies also highlighted that professional and agency cultures can facilitate joint working: understanding, respecting and valuing the roles of other professionals is important and can be promoted by joint training.

In addition, the context in which a multi-agency service is developed can aid its success. A past history of joint working between the agencies involved allows agencies to build on previous arrangements and co-location, in shared offices or the same building, increases opportunities for communication between staff, promoting understanding and information sharing. Interprofessional education and joint training appear to facilitate multi-agency working when carried out post-qualification and in the workplace (Koppel *et al.*, 2001).

Factors that hinder joint working include: constant reorganisation; frequent staff turnover; lack of qualified staff; financial uncertainty, difficulties sustaining initiatives when funding ceased and difficulties in ensuring equity from partner agencies; and different professional ideologies and agency cultures.

However, although there is a considerable body of research on the process of multi-agency working, there is a dearth of evidence on the outcomes for service users of such models of working (Cameron *et al.*, 2000; Watson *et al.*, 2002b; Sloper, 2004).

As noted above, Liabo *et al.*'s. (2001) review of research on key worker services for disabled children indicates positive outcomes for families, and in the UK there have been a number of small scale evaluations of local key worker services (Appleton *et al.*, 1997; Mukherjee *et al.*, 1999; Sloper *et al.*, 1999; Tait and Dejnega, 2001; Mukherjee *et al.*, 2000). However, there is little research on key worker systems investigating the type of partnerships that are established between the relevant agencies; which agencies are involved; how, or if, key worker services link with other initiatives, such as Sure Start, Early Years Services, Connexions or Health Action Zones; whether partnership arrangements under the Health Act 1999 have been utilised; how the type and level of partnership between agencies and the organisation and management of the service impacts on the services families receive and the outcomes for families of different models of service.

One study investigating in more detail multi-agency working in services for disabled children is that of Townsley *et al.* (2004), which explored the impact of multi-agency working on disabled children with complex health needs and their families. The study looked in detail at six services, four of which provided key workers to families. This study found positive effects on relationships and communication between different professionals and agencies, professionals' knowledge about each other's work and their relationships with families. However, some barriers were identified to multi-agency working: in the absence of clear guidance staff interpreted the key worker role in different ways; there continued to be duplication of meetings and assessments and information was not always shared across agencies; a lack of adequate ring-fenced time for multi-agency working was a problem for a few professionals; and the issue of advocacy for families was problematic and could conflict with professionals' own agency role. The services mainly seemed to be aimed at parents and there was little evidence of relationships being built between professionals and children and young people. Lack of time and barriers associated with communication impairments were identified by professionals as factors that militated against building relationships with children. In addition, difficulties were encountered in getting all key agencies on board. In every service except one, education was mentioned as the agency with whom it was most difficult to work. It was felt that the statutory framework for education was a barrier to multi-agency working for this group of children and also that education staff who best knew the children, teachers and assistants, were rarely available to take part in meetings. Three areas had also encountered difficulties in getting active cooperation from health agencies.

Despite these difficulties, two thirds of the families interviewed reported that the services had made a positive difference to their lives and there was some indication that having a key worker had an impact on families' access to services and their quality of life. The services were providing effective support in helping families to manage their child's health care needs at home and children of school age were all supported to attend school. However, impact of the multi-agency services on other aspects of children's and families' lives was more varied, with families still experiencing practical, social and emotional difficulties and children experiencing many barriers in areas of their lives such as communication, leisure activities and friendships. Many of these difficulties stemmed from lack of existing resources for disabled children and their families in the areas concerned and it is clear that whilst multi-agency working may improve access to services, it does not on its own provide more services in areas where there are deficits in provision. Commitment is needed to joint action to identify shortfalls and duplication in provision and work together to remedy these, but lack of resources also impacts on such provision. However, in addition to this, problems in the multi-agency services themselves impacted on families, and it was clear that, in many areas, important elements of a key worker service were not being provided. For instance, lack of clarity about the role of the key worker in the service itself meant that families were also unclear about what to

expect and only a minority felt that their key worker did coordinate services; there were large differences in the frequency of contact with key workers and whether key workers were proactive in contacting families; and few families felt that the whole family was helped by the service.

1.6 Evaluating key worker services

The study reported here aimed to explore the effectiveness of different models of multi-agency key worker services. The aims of the project were:

- To compare the implementation and operation of different models of key worker services.
- To assess the outcomes for parents and children of the provision of different models of key worker services.
- To investigate sources of funding and costs of different models of key worker services.
- To identify the features of the services that contribute to improved care for disabled children and their families.
- To inform standards of good practice in services for disabled children and their families.

In meeting these aims, the research set out to investigate the outcomes for families of the key worker services and the specific processes within such services that were related to better or poorer outcomes. As the aim was to investigate multi-agency services which provided key workers for disabled children and their families, part of the process was defined in advance – the study was not concerned with services that were not multi-agency and did not have key workers. However, even within these constraints there was likely to be considerable diversity in models of service and service processes.

Evaluating the outcomes of multi-agency partnerships is notoriously difficult and the lack of evidence on outcomes in this field is testament to such difficulties (El Ansari *et al.*, 2001). The many and diverse factors that may contribute to the effectiveness of the process of multi-agency working are not easy to measure, but some assessment of these factors is vital if research is to be able to answer questions about not just whether an intervention works, but how it works. Evaluation needs to explore the mechanisms by which a service produces positive outcomes (or not) and the context (circumstances of the service and of recipients) in which these mechanisms operate to produce these outcomes, or 'what works for whom and in what circumstances' (Pawson and Tilley, 1997). The concept of an outcome must also be clarified (Nocon and Qureshi, 1996), distinguishing between 'intermediate outcomes', such as the delivery of a particular service or effects on the knowledge and practice of professionals, 'process outcomes' that is the effects of the way in which the service is delivered on users, and the impact on users of the service, such

as changes in well-being – sometimes termed 'distal outcomes' (El Ansari *et al.*, 2001). Although intermediate outcomes are important and can help to explain the mechanisms by which the service impacts on users, they are not sufficient measures of effectiveness. In order to assess outcomes, it is important that evaluation obtains the views of the different stakeholders in the services on the extent to which the services meet their desired objectives and the appropriateness of the service to the needs of users (Glendinning, 2002). As well, as exploring outcomes, Glendinning notes that evaluation of multi-agency services should also look at efficiency, that is the relationship between costs and benefits.

Previous research on the needs of families with disabled children and existing studies of local key worker services provide important information to help define outcomes to be measured when comparing models of key worker services. For example, questions about intermediate outcomes are: Does the service lead to better coordinated care for disabled children and their families, better access to services, better relationships with services, and better information provision to families? Do key workers provide support to families in the areas identified by research as important elements of the service? Questions about impact on families are: Does the service result in fewer unmet needs for parents or children? Does the service impact on family burden and quality of life? Does the service impact on levels of social inclusion for children and parents? In order to understand the context in which these outcomes are produced detailed information about the services and the processes which affect them is needed.

It is clear from the above that the evaluation of models of key worker services requires a mixed methods approach, gathering evidence from a variety of sources. Quantitative measures can provide information on some outcomes, but qualitative methods are required to explore some of the processes that may be important in producing such outcomes. A number of authors now advocate such a mixed methods approach to bring new insights in the study of joint working (for example, Popay and Williams 1998; El Ansari *et al.*, 2001).

The current project adopted a mixed method five-part approach to the evaluation of models of key worker services. These parts represent collection of different types of data and data from different categories of respondents, and were not necessarily sequential.

- Part One was a quantitative UK wide survey to identify care coordination and key worker services in operation and their key features. From this survey, seven areas operating differing models of service were selected for case studies.
- Part Two comprised qualitative interviews with staff in the case study areas (key workers, service managers and members of multi-agency steering groups, and in three areas school staff).

- Part Three was a quantitative survey of families (parents and children) receiving the key worker service in each of the seven areas. This survey included measures of the families' perceptions of the effects of the service.
- Part Four comprised qualitative interviews with a sub-sample of parents and children in each area, exploring in more depth perceptions of the process and outcomes of the services.
- Part Five analysed the costs of providing the services.

Chapter 2: Research Design and Methods

This chapter describes the methods used during the different stages of the project. The methods used in the different stages were diverse and each will be described separately. Methods used for analysis of costs are described in Chapter 6, along with the results of this analysis.

Ethical approval for the research was obtained from a Multi-centre Research Ethics Committee.

2.1 Stage One: survey of care coordination schemes

This first stage was a survey to all Children with Disabilities Teams in the UK, to gather information about the structure of existing care coordination schemes.

2.1.1 Procedure

The survey questionnaire was piloted with three managers of care co-ordination schemes. Questionnaires were then sent by Care Coordination Network UK (CCNUK) to 225 local authorities across the UK. If an area had a care co-ordination service that was known to CCNUK the questionnaire was sent direct to the manager of that service. In areas where there was no known service, the CCNUK development worker telephoned each local authority area to obtain the name of the most appropriate manager to whom to send the questionnaire. In most cases this was the manager of the local children with disabilities team. In Scotland, questionnaires were sent to the Children's Services Plan Co-ordinator in each local authority. In Northern Ireland the questionnaire was sent to the Director of Social Services for each of the four Health and Social Services Board. Attempts were made to ensure a high response rate by means of reminders. The questionnaires were returned over a three month period (October, November, and December 2002).

2.1.2 Topics covered by the survey

Respondents were given the following definition of the terms 'care coordination' and 'key worker':

For the purpose of this questionnaire we will define care coordination as a service or scheme involving two or more agencies that provides disabled children and their families with a system whereby services from different agencies are coordinated. Care coordination encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels, and a named care coordinator or key worker for the child and family. This is someone whom

the family can approach for advice about any problem related to the disabled child. The named person has responsibility for working with professionals from their own and other services.

The first question then asked whether there was a care coordination service in their area. If there was, they were asked to complete the remaining sections of the questionnaire (see Appendix 1 for survey questionnaire).

Section A covered: agencies involved in setting up, overseeing and funding the service; the involvement of parents, children and young people in setting up and overseeing the service; whether there was a lead agency; whether the service was accessible to families from minority ethnic groups; whether there had been an evaluation of the service; whether the Health Act 1999 Partnership Arrangements/Flexibility Funding provisions or the Quality Protects/Children First/Changing Children's Services funds been used. Services were also asked to provide information about expenditure in the last financial year.

Section B concerned the children and families who were users of the service. Respondents were asked: the age group of the children covered by the service, the eligibility criteria for children and families, how many families were currently supported by the service and who referred families to the service.

Section C concerned the coordination system or process. It covered: whether initial planning meetings and review meetings were held between the family and professionals involved in their care; if the service had a manager to oversee its running; who employed the manager; how much time he/she spent on the role; where the service was based; and whether the service provided key workers. When the service did provide key workers, respondents were asked for information on the professional backgrounds of the key workers; how many key workers worked in the service; whether they were designated key workers, i.e. those employed specifically as full-time key workers, or non-designated key workers, i.e. those who key work with a few families as part of a larger case load; the number of families per key worker; whether there was a waiting list of families requiring key workers; training of the key workers; the key worker's role; how key workers and families were matched; whether families could choose their key worker; and whether key workers visited the family at home.

Section D asked, in the case where no care coordination service was present, whether there was the intention to set one up over the coming year.

2.1.3 Sample

One hundred and fifty-nine services returned a questionnaire (70 per cent response rate). Thirty-five areas reported having a care coordination service: 26 in England,

five in Scotland and four in Wales. Thirty of these reported that they provided key workers for families.

2.1.4 Data analysis

Results were analysed using SPSS and frequencies were calculated for the responses to each of the survey questions.

2.2 Stage Two: Selection of seven services and staff interviews

In this stage, seven services representing different models of key working were selected and their members of staff were interviewed. Staff in schools were also interviewed in three of these areas.

Services were selected according to the following criteria in order to ensure a spread of services in the case studies: whether they had designated or non-designated key workers, dedicated funding or not, resided in an urban or rural area, or were longstanding or more recently set up. Managers of the services were then contacted to discuss participation in the research. Six services agreed to take part, but one service was in the process of reorganisation and the manager felt that it would not be appropriate to take part at this time. An alternative service was selected and agreed to participate. Information about the study was sent to all services and researchers then visited all services to meet staff and steering groups and explain the research. Dates were then agreed for researchers to carry out interviews with staff and steering group members in each area.

2.2.1 Interviews with key worker services staff

Procedure

Packages, each containing a cover letter, an information sheet, a response form and a postage paid return envelope, were sent to the managers of the seven services (see Appendix 2). The managers distributed the packages among their key workers. When the schemes included a large number of key workers, managers were instructed to distribute the packages amongst a sample of 20 key workers from a variety of professional backgrounds. Packages were also sent to all the members of the services' steering groups, including the parent representatives. Recipients were asked to return response forms to say if they were interested in taking part in the research and if so, to provide contact details.

Respondents were contacted by telephone to answer any questions and provide further information and, if they agreed to take part in the research, a date and time for the interview was established. Respondents were then sent confirmation letters

and a bullet-point list of the main questions that would be asked of them. The interviews were generally held at the headquarters of the service, although in one case the interviews were held in a rented venue in the city centre. Interviews lasted approximately one hour and, with participants' permission, were tape-recorded. Signed consent to take part was obtained before the interview commenced.

Interview schedules

The interview schedule for interviews with key workers included questions about: the key worker's professional background; the key worker role; their typical day; caseload allocation and number of families they key worked with; contact with the families; assessment and review of the families' needs; documentation for assessment and review; the key worker's personal documentation; assisting the family during transition; problems encountered in their practice; training and supervision received; the structure and funding of the service; liaising with education and schools; advantages and disadvantages of the scheme.

The interview schedule for interviews with members of the steering group included questions about: their role on the steering group; involvement with the key workers; the steering group meetings; multi-agency involvement in the steering group; barriers to establishing partnerships between agencies; arrangements for reviewing and monitoring the service; shared access to family records; involvement of parents and children in setting up and overseeing the service; the role of the key worker; funding and advantages and disadvantages of the service.

The interview schedule for service managers included questions about: their professional background and how long they had been in their current role; the history of the service; multi-agency involvement in the service; parent and child involvement in setting up and overseeing the service; funding of the service; how the service could improve; advantages and disadvantages of the service. Service managers were also asked to describe the story of a hypothetical family from referral onwards.

Sample

A total of 87 interviews were conducted. Details of the professionals interviewed across the seven services are given in Table 2.1.

Table 2.1 Interviews conducted with staff

<i>Service</i>	<i>No. of interviews with key workers</i>	<i>No. of interviews with steering group members</i>	<i>No. of interviews with service managers^a</i>	<i>Total</i>
Service A	9	5	1	15
Service B	6	1	1	8
Service C	4	9	1	14
Service D	9	5 ^b	1	13
Service E	10	4	1	15
Service F	11	4	1	16
Service G	1	4	1 ^c	6

^a In all sites except E, there was just one service manager for the service.

^b Two steering group members were also key workers

^c Joint interview with service manager and secretary who carried out much of the day to day running of the service.

Data analysis

The interviews were transcribed and three researchers each read a set of transcripts to identify *a priori* and emergent themes. A coding framework, consisting of main themes and sub-themes within these, was agreed and transcripts were then coded using the qualitative analysis programme Max QDA, with any new emergent themes being added to the framework. Transcripts for each site were coded by a single researcher and this researcher then produced a report on the interviews from that service. Reports were checked by a second researcher and were also sent to the service manager in the appropriate site for further checking. These reports were then drawn together, with checks and reference to the original coding where necessary, to produce the cross-service report in Chapter 4. In this and other chapters reporting qualitative data, examples cited in interviews and quotations from interviews are used to illustrate the identified themes (Mason, 1996).

2.2.2 Visits to schools and teacher interviews

The aim of this part of the research was to explore teachers' perceptions of key worker services, the nature of the contact key workers had with schools and the ways in which they affected families' relationships with school and educational provision for disabled children. We were also interested to discover teachers' views on the advantages and limitations of key working not only for children and families, but also for schools and teachers. Three services were selected to for this part of the study. Selection criteria were that services with designated, non-designated and both types of key workers; services in inner-city, urban and rural areas; and services in England and Wales should be included.

Procedure

The service managers of schemes in three services were contacted and asked to suggest up to five schools that they knew had pupils to whom key workers were allocated and which they thought would be willing to participate in the research. Fourteen schools were suggested across the sites and headteachers and/or SENCOs given as the teachers with whom to make both the initial contact and request an interview. They were telephoned and the project was explained (followed up by a project information sheet), as was why contact was being made with them. All those contacted agreed to be interviewed. One semi-structured taped interview took place during each school visit. The visits usually also involved being shown around the school and opportunities for informal conversations with other teachers and teaching assistants who were involved in working with disabled children and liaising with key workers.

Interview schedules

The interview schedules for teachers comprised the following topics: background information on the school and provision for disabled pupils; knowledge about the key worker service; frequency and nature of contact with key workers; ways in which key workers affected school relationships with families and educational provision for their children; any wider contributions by key workers to the school's provision for disabled children; perceptions of the advantages and disadvantages of teachers acting as key workers; benefits and limitations of key working for children and their families and schools; and suggestions for service developments.

Analysis

The process of analysis was similar to that adopted for the other interviews. Emergent themes were then related to those generated by the interviews with service managers and key workers and the parent interviews to give an in-depth picture of key worker services and education.

Sample

The following schools of various types were visited to provide access to a range of issues in relation to key working: four primary schools, one junior school, one infant school, three secondary schools, two units for children with autism (a primary and a secondary) and three special schools. Staff interviewed were two heads of units for children with autism, three heads of special schools, three SENCOs in secondary schools and seven SENCOs in primary schools (a joint interview with two SENCOs was carried out in one school).

2.3 Stage Three: family survey

In this stage, questionnaires were sent to parents and disabled children who were the users of the seven key worker services.

2.3.1 Procedure

Questionnaires were sent to each service. Each service received double the number of questionnaires to the number of families registered in the scheme, in order that reminder questionnaires could be sent. The services were asked to post a questionnaire package to all the families who were currently receiving the key worker service. Each package contained a questionnaire for parents, a questionnaire for children, an information sheet for the parents, an information sheet for the child, a covering letter from the researcher, a postage paid envelope for return of the questionnaires, and a covering letter from the manager of the key worker service (see Appendices 3 and 4). Parents were asked to give the children's questionnaire and information sheet to their child if this was appropriate.

The design of the questionnaires incorporated aspects known to reduce non-response: questionnaires were made attractive by being printed on coloured paper, using clear fonts and well-spaced text, and children's questionnaires used illustrations. Questionnaires were piloted with four parents and their suggestions and comments were incorporated into the final version.

The questionnaire booklet for parents comprised a number of socio-demographic questions, five open-ended questions, scales concerning: their child's disability, unmet parental needs, unmet child needs, satisfaction with the service, aspects of key working, quality of life, the Measure of Processes of Care (MPOC). At the end of the questionnaire, the respondent was asked whether he/she would be willing to be contacted for the next stage of the study.

Approximately one month after questionnaires were sent out, the services posted to the families a second copy of the questionnaire package, with a reminder note from the manager of the service.

Some of the services sent questionnaires out to both 'active' and 'passive' cases, as there was a lack of records about which families were currently receiving a key worker service. Questionnaires were sent to 644 families, most of these were actively receiving a service. Questionnaires were completed by families between October 2003 and March 2004.

2.3.2 Measures: parent questionnaires

Socio-demographic questions

Participants were asked questions regarding age of respondent and child, ethnicity, child gender, number of children in the family, marital status, employment and effects of having a disabled child on employment, socio-economic status, child's schooling, statementing, diagnosis, child's age at diagnosis, receipt of disability living allowance, and contacts with other professionals in the last three months.

Questions on contacts with the key worker

Respondents were asked about the frequency and duration of their contacts with the key worker: 1) In the last three months how often have you seen your key worker? 2) Typically, how long do these visits last? 3) Would you like to see your key worker a) More often, b) About the same c) Less often? 4) In the last three months, how often have you spoken to your key worker over the phone? 5) Typically, how long do these contacts last? 6) Would you like to talk to your key worker a) More often, b) About the same, c) Less often? They were also asked whether their key worker was proactive in making contact, i.e. whether the key worker usually made contact with them regularly or left it up to the parent to make contact.

Measurement scales

The following scales were used:

Disability scale - An eight-item scale was used, measuring the type and level of difficulty experienced by the child. These items were: communication, behaviour, learning, mobility, health, vision, hearing, and continence. Respondents were asked to rate whether their child had difficulties in each of those areas, either 'Not at all', 'Moderately so', or 'Very much so'.

Parental needs - A 23-item scale of parental needs was used. The scale has been used in previous research (Quine and Pahl, 1989; Sloper and Turner, 1992; Beresford 1995) and comprises items covering needs common to parents with disabled children, such as 'getting a break from caring for my child', 'spending more time with my partner', 'having more time with my other children', 'help with managing my child's behaviour' and 'help getting my child to sleep better'. Items are rated on a three-point scale, of 'Getting enough help', 'Need help' or 'Help not needed'. Alpha reliability was 0.85 (N=129).

Child needs - An 11-item scale of child needs was used. The scale has been used in previous research (Beresford, 1995) and comprises items such as 'to learn skills which will help him/her be more independent', 'finding someone to talk to about being disabled', 'moving about independently', 'help with communication', and 'help with

developing his/her physical abilities'. The items are rated on a three-point scale, 'Getting enough help', 'Need help' or 'Help not needed'. Alpha reliability was 0.77 (N=139).

Satisfaction with the key worker service - One item measured how satisfied the respondent was with the key worker service. The question was 'Overall, how satisfied are you with the key worker service you receive?' The question was rated on a four-point scale from 'Very satisfied' to 'Not at all satisfied'.

Aspects of key working - A ten-item scale was used measuring how much the family's key worker performed various aspects of the key worker role. Items in the scale are based on earlier research on the role of the key worker (Mukherjee *et al.*, 1999). Examples of items are: emotional support, information about your child's condition, information about services, advice, identifying the needs of all family members and addressing the needs of all family members. Respondents rated the items as 'Not at all', 'Some' or 'Very much', according to how much support they received from their key workers on each of these. Alpha reliability was 0.95 (N=163).

Impact of key worker on quality of life - A seven-item scale was used to measure the effects of having a key worker on parental Quality of Life (QOL). This scale had been used in previous research (Mukherjee *et al.*, 1999) and incorporated items such as 'My physical health or well-being (for example, sleep, rest, exercise)', 'My emotional/mental health (for example, stress, anxiety, depression)', 'Time to myself (for example, work, studies, interests)', 'My relationships', and 'My financial or material circumstances (for example, income, housing)'. Participants rated these items either as 'Positive impact', 'Negative impact' or 'No impact', according to whether the key worker had an impact on these areas of their lives over the past six months. Alpha reliability was 0.85 (N=173).

Measure of Processes of Care - The anglicised version (McConachie and Logan, 2003) of the Measure for Processes of Care (MPOC, King, Rosenbaum, and King, 1995) was used. The MPOC is defined as a means to assess family-centred behaviours of professionals in services for disabled children and is a self-report measure of parents' perceptions of the extent to which specific behaviours of care professionals occur. The 55-item anglicised version was revised minimally for British idiom, has been adapted for use with community services by taking out explicit references to a 'centre', and has demonstrated validity as an outcome measure of child disability services in Britain. Respondents are asked to rate each item on a four-point scale from one Never to four Always, or as 'not applicable'. Alpha reliability (in our sample) was 0.99 (N=31). For the purposes of this study, an additional question on whether the key worker had helped with this was added to each item.

Open-ended questions

Additional open-ended questions were asked: 1) Please describe the greatest need you have at the moment and how you would like this to be met; 2) Which is the aspect of your key worker service you value most? 3) Which is the aspect of your key worker service you value least? 4) Do you have any specific comments on the key worker's role in relation to the different services your family receives from Education, Social Services, and Health? 5) Any other comments. Content analysis of responses was used to inform topics to be explored in more detail in interviews with parents.

2.3.3 Children's questionnaire

Children were asked to respond either 'yes' or 'no' to ten statements, which were: My key worker makes my life easier; My key worker helps me to become more independent and do things for myself; My key worker understands about my illness or disability; My key worker knows how to help and look after me; My key worker asks me for my ideas and listens to what I have to say; My key worker knows what I need; When I need something I know my key worker will do everything to meet that need; My key worker respects my religion or my family's custom; My key worker gives me advice and information; I ask my key worker questions and he/she explains things to me. The questionnaire was developed with disabled young people as a means to measure key aspects of service quality which were found to be important to young people (Mitchell and Sloper, 2001, 2003). For the purposes of this study the words 'the staff' in the original version were replaced with 'my key worker'.

2.3.4 Data preparation

Scoring of the scales

Items for the Disability scale, Parental Needs, Child Needs, Aspects of Key working, and Quality of Life were computed to comprise total scores for each of these scales. Scales were scored as follows:

- 1) Disability was scored by summing the responses from the items, which went from one (not at all) to three (very much so) so that the higher the total score, the more severe the child's disability.
- 2) Parent need was scored by summing the number of unmet parent needs, so that the higher the score, the higher the number of unmet needs per family.
- 3) Child need was scored by summing the number of unmet child needs, so that the higher the score, the higher the number of unmet needs per family.

- 4) Aspects of key working was scored by summing the responses, which went from one (not at all) to three (very much). The higher the total score, the more the key workers provided families with the various aspects of the key working role.
- 5) Quality of Life was scored by summing the scores from one (negative impact) to three (positive impact), so that the higher the scores, the more positive was the impact of the key worker on the parent's quality of life.

Scoring the MPOC

Before scoring the MPOC, a factor analysis was run on its items to explore the scale's factor structure. Although McConachie and Logan (2003) reported a five-factor structure, the results of the factor analysis showed a single-factor structure, which was confirmed by the Scree plot. An attempt was then made to compute the five factors of the MPOC according the scoring of McConachie and Logan (2003) in order to investigate the correlations among sub-scales, which ranged between 0.622 and 0.976 ($p < 0.0001$). These high correlations suggested that it may not be accurate to score the MPOC factors separately. Rather, a single factor appeared to be more appropriate. The MPOC was thus scored as a single factor.

As each item of the MPOC has the possibility of being rated as not applicable, and items rated in this way are not scored, the mean of the items scored was used, rather than the total score. The additional question on whether the key worker helped with this issue had a lot of missing data, ranging from 25 per cent to 34 per cent for each item. Therefore, these data were not used in the analysis.

Assessment of normality of distributions

Interval level variables and ordinal variables with at least a four-point scale were explored to see if they were normally distributed, through examining the data graphically and through summary statistics. Whilst there was evidence of skew in many of the variables, this was not at a level to cause concern given the sample size. Therefore parametric statistics could be used with these variables.

Coding of service context variables

In order to explore the effects of different aspects of the key worker service models on outcomes for families, characteristics of services that had emerged as important from interviews with staff and managers were coded for each service. These covered eight criteria:

- 1) Having ongoing, regular training for all key workers.
- 2) Having ongoing, regular supervision specific to key working for all key workers.
- 3) Having peer support with other key workers.

- 4) Having some dedicated funding for the scheme.
- 5) Having a dedicated service manager who is in charge of running the scheme, and whom the key workers can approach for advice and support.
- 6) Having parental involvement in the steering group.
- 7) Having a clear, written, job description that is given to all the key workers.
- 8) Having designated or non-designated key workers.

Coding for the majority of these criteria was binary (met or did not meet the criteria). With regards to job description, one service had a job description that consisted of a few bullet-points that covered part of the key worker role, four services had more detailed job descriptions and two services did not have a job description. On this criterion, services were coded as yes, partially and no. Families with a designated key worker were coded as one and families with a non-designated key worker were coded as two. Therefore Service A (the service with both designated and non-designated key workers) had some families coded as one and others as two.

When variables were coded, there was 100 per cent overlap between having training, supervision and peer support. These were therefore combined as one variable.

As noted earlier, one of the criteria on which the study services were selected was whether the service was longstanding or recently set up. Services were also coded on length of time they had been in operation in order to investigate whether this had any impact on outcomes. Two services had been in operation for over ten years, one for five years, one for three years, and three for two years.

2.3.5 Statistical analyses

Descriptive analysis

Frequencies and mean values were calculated for demographic variables and variables about the characteristics of the service, and the main outcome (dependent) variables for the study: parent unmet need, child unmet need, impact of quality of life, and satisfaction with the key worker service. Pearson Product-moment correlations were run among the continuous dependent variables, and Spearman's correlation coefficients were run among the dichotomous independent variables. One-way analysis of variance (ANOVA) was used to test whether there were any significant differences between services on dependent variables and key independent variables.

Path analysis

The relationships between independent and outcome variables were explored using path analysis. Path analysis requires a series of multiple regressions based on

assumptions of potential causal order reflected in the grouping of variables into blocks (Davis, 1985). Table 2.2 shows variables included in each block. In the path diagrams in Chapter 5, Block 1 variables appear on the left and are exogenous, having no predicting variables in this model. They represent the aspects of the *family and service context* in which the key worker services operate and include key demographic variables (child age, social class, level of disability) and service context variables (how long the service had been in place; whether it had any dedicated funding; having regular training, supervision and peer support for key workers; having a dedicated service manager and a clear job description for key workers; type of key worker; and parent representation on steering groups). Block 2 variables represent the *mechanisms* by which the key worker service may impact on families: the measure of the extent to which key workers carry out key aspects of the role; the frequency and duration of contact with key workers and whether this is rated by parents as appropriate to their needs; and whether contacts are proactive or reactive. The Block 3 variable – MPOC scores – is a measure of *process outcome*, that is whether parents perceive services as providing information, coordinated, respectful and supportive care, and working in partnership with them. The outcome variables are measures of 'distal outcome', which we have labelled *family outcomes* – the impact of the service on quality of life, unmet needs of parent and child, and satisfaction. Separate path analyses were carried out for each of these outcomes.

Table 2.2 Blocks of variables entered in path analyses and outcome variables

<i>Block 1:</i> <i>Family and service context</i>	<i>Block 2:</i> <i>Service mechanisms</i>	<i>Block 3:</i> <i>Process outcome</i>	<i>Family outcomes</i>
Family and child context: -age of child -level of disability -social class	Aspects of key worker role	MPOC scores	Impact on quality of life
Service context: -dedicated funding -length of time in operation -regular training, supervision and peer support -dedicated service manager -clear key worker job description -type of key worker -parent representation on steering group	Key worker contacts with family: -frequency -duration -appropriate -proactive		Unmet parent needs Unmet child needs Satisfaction with key worker service

The pattern of analysis was the same for each outcome variable. The first stage of each analysis was to identify all independent variables having a significant bivariate relationship with the outcome variable, using ANOVA and correlations, and enter these into a multiple regression. The multiple regression identified variables with a direct relationship to the outcome variable that was independent of the effects of other variables in the regression. Block 3 only has one variable (MPOC scores). If MPOC scores were significantly related to the outcome variable in the first stage of the analysis, the next stage was to treat MPOC as a dependent variable in its own right. Independent variables for this analysis were selected on the grounds of their significant correlation with MPOC and were entered into a multiple regression on MPOC scores. Variables identified in this stage were generally, but not necessarily, also significantly related to the outcome measure. The stages of analysis then continued with any Block 2 variables identified as predicting the outcome measure or MPOC being treated as dependent variables and independent variables being entered into a multiple regression on these Block 2 variables.

The path analysis diagrams in this report (Chapter 5) indicate when predictor variables were not related to the outcome by the use of a dotted line. Interpretation of such results stresses the conditional nature of these relationships. For example, the path analysis of satisfaction with key worker showed longer telephone contacts to be a predictor of satisfaction. Longer contacts were predicted by higher child disability scores, which were not significantly related to satisfaction. Level of child disability, therefore, was relevant to satisfaction with the key worker service only when it was associated with the amount of contact with the key worker.

To summarise this procedure, final path analyses linked the outcome measures directly to predictor variables which were selected if they (a) were significantly associated with the outcome measure and (b) remained significant in a multiple regression analysis. Indirect predictors were identified by treating the direct predictors as dependent variables in further regression analyses. Thus each path analysis identified the significant variables directly and indirectly associated with the outcome variable, arranged in an assumed causal order.

The path analysis diagrams are annotated with the Beta coefficient values of each path, an indication of the strength of the bivariate relationship when controlled for other significant variables. The product of these values may be used to evaluate the strength of a relationship which passes through one or more intervening variables.

2.3.6 Sample

Questionnaires were sent to 644 families, most of these were actively receiving a service, but some were not, so some questionnaires were returned stating that the family did not have a key worker. Two hundred and five (31.83 per cent) completed questionnaires were returned.

Response rates by service

Response rates varied by service, some services had a response rate of over 50 per cent, while others had a response rate of below 50 per cent. Response rates by service are shown in Table 2.3.

Table 2.3 Response rates by service

<i>Area</i>	<i>Response rate</i>	<i>High or low response rate</i>
Service G	65.38%	High
Service A	64%	High
Service C	55.2%	High
Service D	37.5%	Low
Service B	23.57%	Low
Service E	22.59%	Low
Service F	19.40%	Low

The response rates for the seven services varied from 19.40 per cent to 65.38 per cent. Services E and F showed the lowest response rates, probably due to the artificially inflated number of participants included in the original subject pool. In these particular services both active and passive cases had been included in the mail-out, due to a lack of records held by the service managers of the schemes, thus lowering the response rate. We were not able to obtain figures for active cases from these services.

In order to test whether data from the services with lower response rates were comparable to data from the other services, response rates were divided into high (over 50 per cent) and low (under 50 per cent). Services G, A, and C were scored as one (high) and services D, B, E, and F were scored as two (low). Statistical tests were carried out on nine demographic variables to check whether services with low response rates differed from services with high response rates. These variables were: socio-economic status, marital status, ethnicity, sex of child, age of child, age of respondent, age of partner, number of children in family, complexity of disability. There were no significant differences and therefore responses from low response sites appear to be comparable to those from high response services.

2.4 Stage Four: Interviews with parents and children

The aim of this stage of the research was to gain a more in-depth understanding of families' experience of the key worker services, the positive aspects of the service and the areas for improvement. We also wanted to find out the extent to which key

workers worked with children as well and parents, and the relationship between children and their key worker.

2.4.1 Procedure

Questionnaires from families (stage 3) contained a final section on whether families were willing to be contacted for further research. Respondents who had indicated that they were willing to be contacted further were telephoned and asked if they were willing to consider participating in interviews. Families were also asked whether their child was able/willing to participate in an interview. If the family was willing to be interviewed, a provisional date and time were set for the visit. Families were sent an information sheet about the study, a bullet-point list of the topics the interview would focus on and a letter confirming the provisional date and time of the interview (see Appendix 5). Families were assured that they did not have to participate and they could withdraw at any time without having to give a reason. Interview arrangements were then confirmed and written consent was obtained before the interview took place. All interviews except four took place at the family's home. One interview took place at the child's school, and three parent interview were carried out by telephone as parents were not available when researchers were visiting the sites. Parent interviews lasted approximately one hour and children's interviews lasted up to 30 minutes. With respondents' permission, interviews were tape-recorded.

2.4.2 Interview schedules

The interview schedule for parents comprised the following topics: the parent's understanding of the key worker role; the parent's views on their key worker service; how the key worker had been chosen; parent's views on the key worker's training and knowledge of different service areas; whether the key worker and the services in the area were able to meet the needs of the family; experiences of multi-agency planning meetings and reviews; the coordination of services; the quality and availability of services in the area; the key worker's relationship with the child and family; advantages and disadvantages of the service; information about the key worker's relationship with the child's school or nursery; and possible improvements to the service.

Topics covered in the interview schedule for children were concrete and adapted to the child's abilities and experience. As noted above, the main aim was to explore the child's relationship with the key worker. Parent interviews were carried out before child interviews and thus the interviewer was able to find out about the child's cognitive and communication abilities and adapt the interview as necessary. Photographs of key workers were used as prompts to help the child. Topics included were: whether the child knew the key worker well or a little; amount and nature of contact; likes and dislikes about key workers and what they did; whether the child felt

able to talk to the key worker and felt the key worker listened; things the child would like the key worker to do.

2.4.3 Analysis

The process of analysis was similar to that in stage two. The interviews were transcribed and a subset of interviews examined to identify *a priori* and emergent themes. A coding framework was developed and transcripts were coded using Max QDA, with any new emergent themes being added to the coding framework.

2.4.4 Sample

The aim was to interview ten families from each service. This was largely achieved. Where more than ten survey respondents had indicated that they were willing to take part in interviews, the sample to be contacted was selected to represent a range of different views on satisfaction with the service. Apart from the two services in which all but one of the family survey respondents were very satisfied or satisfied with the service, interviewees therefore covered a variety of experiences of key working. Sixty-eight interviews with parents and nine interviews with children and young people were carried out (see Table 2.4). Fifty-nine interviews were with mothers, two of whom were adoptive mothers, six interviews were with fathers, and three interviews were with both parents, one of these being adoptive parents. The characteristics of parents interviewed and their children mirrored those of the larger survey sample. Four parents (six per cent) were from minority ethnic groups, 50 (73.5 per cent) were married or living as married, 18 (26.5 per cent) were single parents.

Table 2.4 Interviews with parents and children

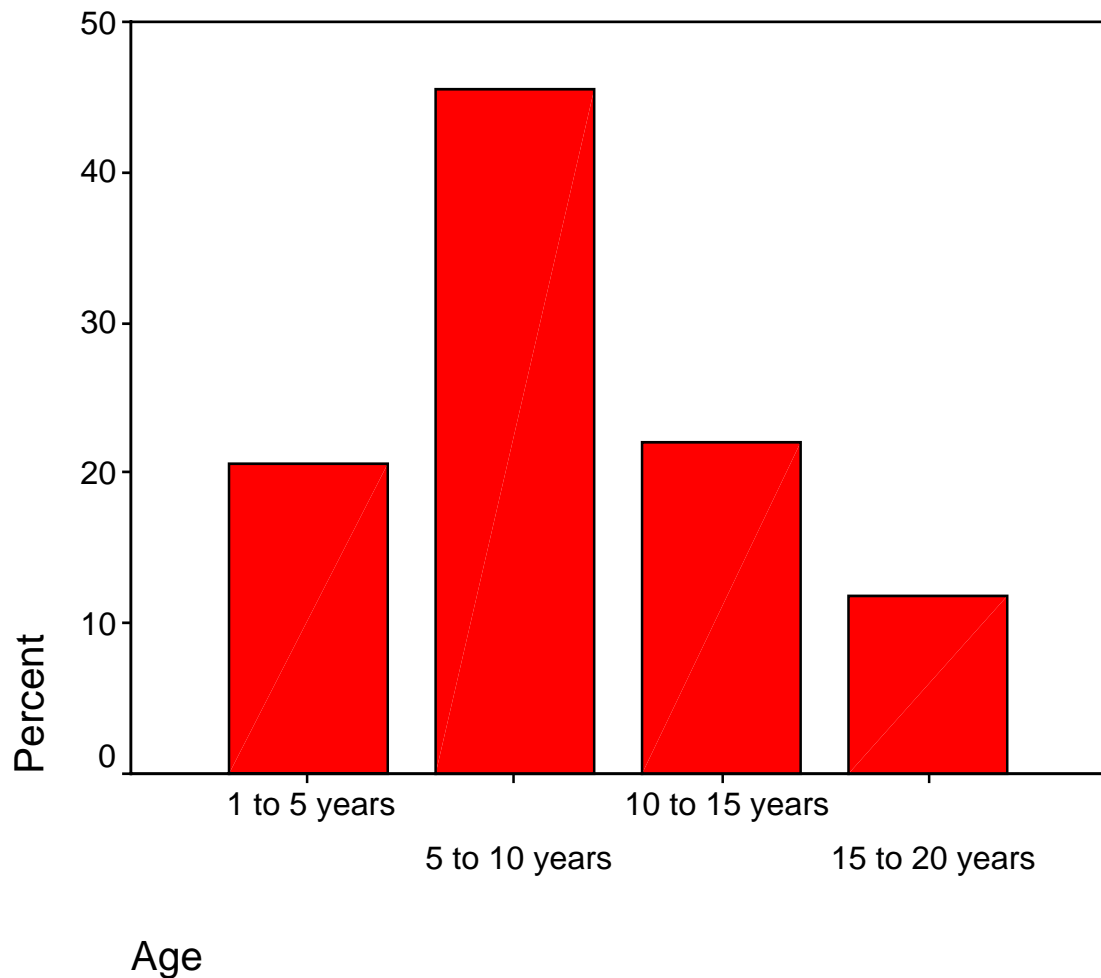
<i>Site</i>	<i>Number of parents interviewed</i>	<i>Number of children interviewed</i>
Service A	10	3
Service B	11	2
Service C	10	0 ^a
Service D	11	0
Service E	10	2
Service F	7	0
Service G	9	2

^a Families in this service all had children under five.

The mean age of the children of parents who were interviewed was 8.12 years (SD 4.36, range 14 months to 18 years; see Figure 2.1); 43 (63.2 per cent) were male and 25 (36.8 per cent) female. The children's conditions/impairments varied widely: 31 (45.6 per cent) had two or more conditions. The most common conditions were

cerebral palsy (n=14), epilepsy (n=14), autistic spectrum disorder (n=10), developmental delay (n=9).

Figure 2.1 Ages of children whose parents were interviewed



Of the nine children interviewed, one was aged seven, one was 11, three were 12, two were 15 and two were 16 years. Eight were male and one was female. The children had a range of disabilities, including muscular dystrophy, learning disabilities, autistic spectrum disorders, attention deficit hyperactivity disorder, Down's syndrome and spina bifida and hydrocephalus.

Chapter 3: Results of a UK-Wide Survey of Care Coordination Schemes¹

This chapter presents the results of a survey of care-coordination schemes in the UK. The survey was carried out at the end of 2002.

3.1 Prevalence of care coordination schemes

One hundred and fifty nine questionnaires were returned (70 per cent). Thirty-five areas (22 per cent) reported having a care coordination scheme: 26 in England, five in Scotland and four in Wales. No schemes were reported in Northern Ireland. Fifty areas were planning to develop a care-coordination scheme within the next year.

3.2 Setting up, overseeing and funding the schemes

Health, social services and education were involved in setting up and overseeing the majority of schemes, but the contribution of all three agencies to funding the schemes was more rare. Table 3.1 shows the number of agencies setting up, overseeing and funding schemes.

Table 3.1 Number of agencies involved in setting up, overseeing, and funding the schemes

	<i>Setting up the scheme</i>	<i>Overseeing the scheme</i>	<i>Funding the scheme*</i>
3 agencies	28	25	8
2 agencies	2	2	10
1 agency	5	7	9
Missing data	0	1	1

* 7 received no separate funding

Twenty-nine schemes reported that parents were involved in planning the scheme, while 18 reported parents overseeing the scheme. Five schemes reported children and young people involved in planning the scheme, and two reported children and young people involved in overseeing the scheme. Five schemes reported no parent or child involvement.

¹ Results of the survey have been published in Greco and Sloper (2004). Results are reproduced here with kind permission of Blackwell Publishing.

Twenty-two schemes had a lead agency. Lead agencies were: education (n=3); social services (n=9); health (n=6); voluntary (n=3: NCH and Barnardo's); other (n=1: Learning Disability Trust).

Ten schemes were pilot projects and 25 were mainstream. Among the pilot projects, two were funded for three years, five were funded for two years, one for 18 months, one for nine months, and one did not specify length of funding. Among the mainstream projects, nine had ongoing funding, one had partly permanent, partly temporary funding, two were funded for three years, one was funded for two and a half years, two were funded for two years, one was funded for a year, eight had no dedicated funding, and one was unspecified.

In answer to questions about the use of Health Act 1999 Partnership Arrangements or Flexibility Funding provisions, one scheme reported use of both pooled funds and lead commissioning. One scheme used lead commissioning by the Learning Disability Trust. Two schemes used integrated provision. Sixteen used Quality Protects (England)/Children First (Wales)/Changing Children's Service(Scotland) funds to support the scheme.

3.3 Types of schemes

Twelve schemes were a separate team with their own manager and budget. Twenty-three schemes were non-separate schemes.

Thirty-one schemes identified someone who had management responsibility for overseeing the day-to-day running of the scheme. In nine schemes, this was a full-time responsibility. These managers were employed by social services (n=11), health (n=8), education (n=1), joint social services and education (n=1), joint health and local authority (n=3), and voluntary agencies (n=3), (missing data=4).

3.4 Accessibility of the scheme to ethnic minority groups

Twelve schemes had acted to make the scheme accessible to families from ethnic minority groups. The most common provision was to translate information into other languages.

3.5 Referral to and eligibility for the scheme

Twenty-seven schemes operated open referral. Two took referrals from health, education, social services and voluntary agencies; three from health, education and social services and one was a pilot scheme where families were selected at random. In one scheme, social services and the care management process referred families to the scheme. One scheme was considering open referral.

Most schemes reported that the eligibility criteria for children and families comprised having a child with complex needs, requiring the significant involvement of more than one or two agencies. Five schemes covered only the age group from 0 to five years. Four schemes covered the age group from 0 to 11 years. Three schemes covered the age group from 0 to 15 years. Twenty-three schemes covered the age group from 0 to 16+ years.

3.6 Planning and review meetings

Twenty-four schemes held initial planning meetings and 29 held regular review meetings involving the family and all professionals involved in their care. The most commonly found frequency of review meetings was every six months.

3.7 The use of key workers

Thirty schemes provided key workers to families. Of the five that did not, one scheme consisted only of a database containing information on families, which helped co-ordinate care; two schemes incorporated care co-ordination only in relation to initial planning meetings or reviews; two schemes had just started and they did not have key workers, but this was planned.

The main difference found in models of key working was between schemes with 'designated' key workers – those employed specifically as full-time key workers, and 'non-designated' key workers – those who key work with a few families as part of a larger case load.

Table 3.2 shows number of schemes divided by separate or non-separate teams and designated or non-designated key workers or both. It is notable that all the designated key workers operated within separate teams, apart from one area in which there were both designated and non-designated key workers in a non-separate team.

Table 3.2 Types of care coordination schemes

	<i>Separate team with own manager and budget</i>	<i>Other</i>
Designated key worker	5	None
Non-designated key worker	4	17
Both	2	1

NB. One scheme left missing information and five had no key workers.

3.8 Training, supervision and background of key workers

Seventeen schemes provided special training for key workers on appointment. Twenty-one provided ongoing training for key workers. Five reported no training of either type and five left missing information. In 12 schemes, key workers were supervised by the scheme manager; in 12, supervision was provided by line managers in the key workers' own agencies; and in two no supervision was in place as yet. Four left missing data.

Fourteen schemes did not specify which professional backgrounds key workers came from. Professional backgrounds of key workers of the remaining schemes (n=16) are shown in Table 3.3. The professionals most frequently taking the role of key worker were social workers and health visitors.

Table 3.3 Professionals who act as key workers

<i>Staff category</i>	<i>Number of schemes employing staff</i>	<i>Average number of professionals per category</i>
Social workers	11	6
Health visitors	9	4
Community nurses	8	2
Paediatricians	4	2
Physiotherapists	1	1
Speech therapists	4	1
Occupational therapists	4	3
Teachers	9	2
Nursery nurses	1	2
GPs	0	0
Psychologists	1	1
Workers with voluntary agencies	2	1.5
Other: e.g. School nurse, youth worker, dietician, parent	5	4

3.9 Caseloads and matching key workers and families

The median number of families per designated key worker was 30 (range 12-40). The median number of families per non-designated key worker was three (range one-35).

Key workers and families were matched by asking families their personal preference (n=7), according to geographic location (n=1), depending on caseload (n=4), by matching skills of key workers to needs of families (n=4), by allocation by a local

panel or a team manager (n=7), or a combination of two or more of these (n=3). Four schemes left missing information.

Twenty-seven schemes reported that key workers regularly visited families at home.

3.10 Summary

Thirty-five local authority areas reported having a care coordination service (22 per cent, December 2002). Fifty schemes were about to be developed over the coming year. The majority of the schemes had all three statutory agencies (Health, Education and Social Services) involved in setting up and overseeing the schemes. However, only eight schemes had all three agencies contributing joint funding. The majority of the schemes had parents involved in setting up and overseeing the schemes. However, the involvement of children and young people was less common. Only nine schemes had permanent funding. Eight had no dedicated funding. The majority had temporary funding, ranging from nine months to three years in duration.

Thirty schemes provided key workers to families. Five had 'designated' (that is, full-time) key workers. Twenty-one had 'non-designated' key workers, who co-ordinated care as a small part of their professional role. Three had both designated and non-designated key workers. Approximately half of the schemes had induction training for key workers in place and approximately two thirds had ongoing training for key workers.

Chapter 4: The Seven Key Worker Services

This chapter describes the key worker services in the seven case study areas: how the service was set up, structured and funded; eligibility criteria and arrangements for referral to the service; assessment and review; the type of key workers employed and their professional backgrounds; the arrangements for training and supervision of key workers; the role of key workers; the management of the service; and multi-agency collaboration. It draws on findings from interviews with key workers, managers and members of steering groups, and following description of the nature of the services, examines professionals' perspectives on the successes and challenges of the service and the advantages and disadvantages for families and professionals.

4.1 Overview of the seven services

As noted in Chapter 1, the seven services were all developed and overseen by a multi-agency steering group, involving all three statutory agencies and all provided key workers for families with disabled children. However, within this general model, there was considerable diversity, both in service models and in characteristics of the areas in which the services were sited. In the descriptions below, names of the areas have been changed to A, B, C, D, E, F and G.

Service A covers a predominantly rural county in Wales with a population of about 113,000, and density of about 70 people per square kilometre. Levels of unemployment are above and average earnings are below the national average. The population is predominantly white, with 0.9 per cent from an ethnic minority.

The service was set up in 2001, after a series of consultations with parents and professionals on how to improve multi-agency working in the area. These consultations were carried out by a project manager employed by a voluntary agency, but funded 50 per cent by health and 50 per cent by the local authority. Parents' views were that, given the geography of the county, a single building based multi-agency children's centre was not practical, and that what they most needed was accurate information and coordination of services by means of a key worker system. The project manager then gathered information on key worker services from research and from other areas who had implemented such services, and presented this information to parents and professionals in a further consultation. Interestingly, this led to a proposal for a service based on three full-time designated key workers employed by the voluntary agency with multi-agency funding. This was based on parents' views that key workers who were independent of the statutory agencies would be free to advocate for families. However, funding was not available for this model and the model agreed was based on agencies contributing non-

designated key workers who would spend a proportion of their time on key working. Shortly before the service became operational, funding was found through Children First money for one full-time key worker.

The service is managed by a service manager (who was formerly the project manager carrying out the development work). This manager also manages the multi-agency Children's Centre in which the manager, full-time key worker and administrative assistant are based. Thirty per cent of the manager's time is spent on managing the key worker scheme. Funding for the manager and part-time administrative support is contributed by health (50 per cent), education (25 per cent) and social services (25 per cent). The service manager is employed by a voluntary agency. The service is overseen by a management group, comprised of the service manager, two parents, and management level representatives from health, education, social services and the voluntary agency. At the time we visited, the service had one full-time designated key worker and eight non-designated key workers, and 50 families were receiving the service.

Service B covers another predominantly rural county in Wales with a population of about 75,500, and density of about 40 people per square kilometre. The county has two main conurbations. Levels of unemployment are above and average earnings are below the national average. The ethnic minority population is 1.4 per cent.

The service was set up in 1991, after a research evaluation of services in the area for children with learning disability. The research recommended that full-time key workers should work within a multi-agency team, with a manager who also managed the Child Development Team, to ensure coordination between the two teams. This model was adopted and it was decided that the team would work with all disabilities. Funding was initially provided by the Welsh Office, under the All Wales Strategy. Since 1995, mainstream funding has been provided by health, education and social services. The original operational policy for the team was drawn up by the team members, this was then developed further after consultation with parents who received the service. A number of services as well as key working are now provided within the team. Currently, these include physiotherapy, occupational therapy and a respite care service. Two youth workers have also been appointed to the team, with a role to ensure that young people have a voice within the service.

The service is overseen by a steering group consisting of the service manager and management level representatives from health, education and social services. At the time we visited, the service comprised a team of six designated key workers, the service manager, one senior social worker who took on half a caseload of families as well as supervising some of the key workers, and an administrative assistant. Team members are all based in the same building. One hundred and forty families were receiving the service.

Service C covers a northern city with a population of approximately 715,500 and density of about 1,300 inhabitants per square kilometre. 8.2 per cent of the population is from an ethnic minority background. Average earnings and levels of unemployment are below the national average.

The service was set up in 2000 as a two-year pilot project. The scheme had its beginnings in a Parent Participation Group that was run by the Development Officer who had responsibility for disabled children. Parents expressed a great deal of dissatisfaction at the provision that was available to them. They wanted a service that would provide them with support, and co-ordinate the input from all the professionals who were involved in their children's lives, and felt that this should be a full-time service with designated key workers. Using the views of these parents, and supported by evidence from research, a bid was made for Health Action Zone (HAZ) funds, which was successful in securing finance for two years. As further support, the Social Services Department provided line management and the Education Department seconded a nursery officer as a full-time key worker. In November 2002, at the end of the initial term, HAZ released further funds to extend the scheme until the end of the financial year and, at the same time, Social Services were able to offer support which carried the scheme through until June 2003. HAZ also agreed to fund the project for another year. At this point, money from a Children's Services grant was utilised to expand the service and make it permanent and Children's Fund money was used to appoint a further key worker.

The service is managed by a project manager, who worked half-time as a key worker and half-time as manager, but with the extension of the service will work full-time as manager of the service. The setting up of the service was overseen by a steering group, and once the project was underway, the group became an Advisory Group. Members include representatives from the two teaching hospitals, the Children's Community Health Team, and the NHS Trusts for Acute Children's Services. Education and Social Services are also represented, and the project manager is a member. Previously a member from a voluntary agency was present, but no one from voluntary bodies was represented at the time of the interviews in this area. From the start of the scheme parents had also been well represented on the advisory group, and at the time of the interviews four or five parents attended on a regular basis.

The team is based at a hospital on the outskirts of the city. The key workers and the project manager share office space. At the time of our visit, the team consisted of the project manager, four full-time and one part-time designated key workers and a part-time administrative assistant. Two of the full-time key workers and the part-time key worker had only recently been appointed. Fifty-eight families were receiving the service. Initially the service was aimed at children aged 0-5, however with the appointment of further key workers, one of whom has experience with working with older children, the service was about to be extended to include young people up to

the age of thirteen. Unlike other services, the remit of this service is to provide time-limited support. As a general principle the aim is to set a time limit of six months work with each family and, at the first review meeting, to hand over to another appropriate professional who may already be providing frequent support. This time-limited input is designed to overcome initial problems and support the family to become familiar with the routines and care their child is receiving, empowering families to become independent and in many cases to be their own care coordinator. However, if the family care situation changes or they feel they needed further input, the key workers can be contacted at any point.

Service D covers three different geographical areas in the Midlands: a city with considerable cultural diversity and a large ethnic minority population of 36 per cent, total population of 285,000 and density of about 3,890 people per square kilometre. Unemployment is slightly above and average earnings are considerably below the national average. The second area is a county with a larger population of 615,000 and density of about 300 people per square kilometre. Five per cent of the population are from an ethnic minority. This county encompasses both urban areas and rural areas supporting flourishing market towns and one main conurbation. Unemployment is below and average earnings are slightly below the national average. The third area covered is a small rural county with a population of 35,000 and density of about 90 people per square kilometre. Only 1.9 per cent of the population are from an ethnic minority. Unemployment is below and average earnings are above the national average.

The service was set up in 1999 as a pilot project. During 1995/6, co-ordination of services for children with complex needs was identified as a priority in all three areas covered by the service. In 1997, a multi-agency steering group was set up, which comprised middle and senior managers from Health, Education, Social Services and voluntary agencies, and this was given the remit to design and implement a two-year pilot project. The pilot was funded by a successful joint finance bid, involving the County Council, which at the time covered both counties involved in the service, and the Health Authority. The steering group met regularly throughout 1998 and after a year of debate, 'considering a multitude of options' and extensive consultation it was decided that the care coordination project should go ahead and group members signed up their agencies for participation in the project. After two years, the service was evaluated by independent researchers, recommendations informed the further development of the service and the service became mainstream. Fifty per cent of funding, plus accommodation and office costs, comes from the Primary Care Trust. Social Services and Education also agree in principle to contribute funds and, at the time of our visit, were invoiced retrospectively according to what had been spent rather than contributing pre-specified amounts. This posed a problem in terms of forward planning, but issues had not yet been resolved. As the service uses only non-designated key workers, the various agencies absorb the time and travel costs of the key workers.

The service is managed by a full-time project manager supported by a clerical assistant, both are based in the administrative headquarters of the Specialist Community Child Health Services. The project manager is employed by health, but accountable to all agencies participating in the scheme. The service is overseen by a steering group consisting of representatives of all the statutory agencies involved, voluntary organisations and four parents. At the time we visited, the service comprised 40 non-designated key workers, and 64 families were receiving the service.

Service E covers a large, mainly rural southern county with a population of 711,000 and density of about 110 people per square kilometre. Only 1.1 per cent of the population are from an ethnic minority. Unemployment and average earnings are both below the national average.

The service was set up in three areas of the county in 2001 and in a fourth in 2002, but it has not yet been implemented in one area of the county. The service resulted from a review of services, carried out by Social Services, and consultation work with parents. Parents wanted one person who would take care of the coordination of services. A strategic plan to set up Joint Agency Teams (JAT) was drawn up and all three statutory agencies signed up to it. Each of the four areas now has a JAT, each one covering a Primary Care Trust locality, but there are some differences between areas in staffing volume and composition of the teams and at the time of our visit, changes in the make-up of the teams were still taking place.

Each team has a full-time manager, funded 50/50 by the PCT and the local authority. A Directorate Manager oversees the whole scheme and it also employs a full-time administrator and a full-time referral coordinator. The service is overseen by a steering group, the Joint Agency Team Strategic Implementation Group (JATSIG), comprising the Directorate Manager, the managers of the four teams, a joint agency manager from the area that does not currently have the service, a manager from the Local Education Authority, the strategic health authority NSF professional and a manager from Early Years. Although key working is a rolling topic on the agenda for this group, the group has a wider remit and thus it is only one of the topics they discuss. Parents are not involved in the JATSIG. Rather, a parent-led, parent-run locality forum invites members of the steering group to their forums. At the time we visited, the scheme comprised approximately 80 non-designated key workers distributed among the four joint agency teams and it was estimated that over 200 families were receiving the service. Within the service there was a distinction between the core team and the non-core team. The core team over the whole service consisted of between thirty-five and forty professionals: the referral officer, the managers in the service, and the key workers. Key workers in the core team were seconded by the agencies and had agreed to take on key working as part of their role. The non-core team was made up of professionals who would help with the assessments and would occasionally be asked to coordinate care although they

were not officially part of the existing team. The scheme also made a distinction between initial key workers, professionals who only oversee the initial assessment process, and long-term or ongoing key workers. The system of having an initial key worker and then passing the role on to another professional was put in place so that the initial assessment would be carried out as quickly as possible and then passed on to the most appropriate person, according to the child's needs. Key workers were based all over the localities depending on the agency that employed them and each JAT did not have any joint base.

Service F covers an area served by three PCTs and four local authorities in a large, mainly rural northern county with a population of 314,000 and density of about 70 people per square kilometre. Two main conurbations fall within this area. Only 0.65 per cent of the population are from an ethnic minority. Unemployment is above and average earnings are below the national average.

The service has two parts, Team Around the Family, set up in 2001, and Special Needs Panel, set up in 2002. Consultation with parents and professionals identified problems in coordination of services and multi-agency working, some positive practice was taking place but it was very patchy. Pre-School Panels already existed in some areas to bring together the family and the professionals involved with them to discuss issues for the child and family and identify actions to be taken. However, parents felt these did not meet their needs, they often felt intimidated and did not get the opportunity to voice their own views, and panels were poorly organised as there was no administrative support. Families wanted a clear plan to emerge from the meetings, along with identification of who their key worker would be. In 2000, funding was obtained from the Health Action Zone for administrative support to set up panels. In a multi-agency workshop, professionals agreed that they would work together within existing financial resources and would coordinate care and key work for families. The Special Needs Panel model would be used to bring together the family and all the professionals who work with the child, but with the key worker discussing with parents beforehand who to have at the meeting and liaising with the family prior to the meeting. A second workshop considered that the Team Around the Child model (Limbrick, 2001) could be of benefit to families, although the term Team Around the Family was preferred. This model involves a smaller number of professionals, those who work closest with the family, meeting in the family's home. Although Team Around the Child workshop focused on designated key working, Service F did not have any extra time or resources to allocate to this, and the conclusion was reached that they had to work out of existing monetary budgets and existing time schedules, with people taking on the key worker role within their other responsibilities. It was felt that professionals were already key working informally and the new scheme would formalise this. It was decided that the Team Around the Family (TAF) would be implemented with pre-school children and the Special Needs Panel (SNP) with school-age children with complex needs.

The full-time Coordinator for Services for Disabled Children oversees the running of the service, and chairs and coordinates the SNP and TAF meetings. However, this is only one aspect of her role and takes up about a third of her time. She is supported by an administrative assistant. The scheme does not have a designated steering group, although the service coordinator has an advisory group for her post, which advises her on all the projects she works on. This advisory group is composed of 17 people, from the three statutory agencies and voluntary agencies, and includes parent representatives. Some of the professionals on the advisory group are also key workers. At the time we visited, the service had approximately 60 non-designated key workers and it was estimated that over 60 families were receiving the service.

Service G covers a Welsh county borough council area with a population of 128,500 and density of about 260 people per square kilometre. Only 1.1 per cent of the population are from an ethnic minority. Levels of unemployment are below and average earnings are above the national average.

The service was set up in 1993 as a research project with funding from the Welsh Office. Health and social services were instrumental in developing the service. The service is based on a Special Needs Panel, a multi-disciplinary group which meets monthly to decide whether cases referred are suitable for care coordination. If referrals are accepted the panel try to find an appropriate professional who will take on the care coordination/key worker role. After the completion of the research project, the service became established and at the time of our visit, 20 professionals were acting as non-designated key workers as part of their existing work and it was estimated that about 25 families were receiving the service. There was no dedicated budget for the scheme.

The service currently does not have anybody who has sole responsibility for management of the scheme. The Manager for the Social Service's Child Health and Disability Team oversees its running and the administration of the scheme is undertaken by a secretary in the Social Services Department. In 2002 the service commissioned some research into their care coordination as it existed at the time and, as a result of the recommendations, set up a new steering group to evaluate, advise and support the service. At the time we visited, the group was made up of the Social Services Disability Team Manager, the Care Coordination Administrator, a Social Services Audit Officer, the Pupil Support Officer for Primary Education, the Planning and Development Officer for Children's Services from the local council and a parent. Until recently, there had always been representation from health (a Community Paediatrician) but this person had just retired and had not yet been replaced on the group.

The view of all those interviewed was that after working successfully for a number of years, this service had declined over recent years and needed to be regenerated.

As noted above, a new steering group had been set up, and plans were being made to relaunch the service. A number of factors were thought to have contributed to this decline. It was generally agreed that the real loss of impetus began when the Child Health and Disability Development Officer, who had been instrumental in setting up the scheme, left. Since that time no one person with a relevant background had been responsible for overseeing the scheme on a full-time basis. Most interviewees believed that it was vitally important to appoint someone who could devote the necessary time to the task of supervising the service. In addition, a number of other factors were cited: inability of the steering group to make and act on decisions because these needed approval at a higher managerial level than the group members possessed; lack of clarity about the key worker role and lack of supervision for key workers; lack of dedicated funding and 'ownership' of the service by any of the agencies; staff shortages in different agencies and lack of time limits or exit criteria for the key worker service.

4.2 Aims of the services

The basic aims of the services were very similar across all seven services. These were:

- Identifying the needs of the child.
- Drawing up and reviewing a multi-agency care plan.
- Working with other professionals.
- Providing information to families.
- Providing key workers as a main point of contact for the child and family.
- Providing support for families and helping them to access services.

Some services stated additional aims:

- Participation of children and families in decisions on their own care and in planning services (three services).
- Reduction of duplication and gaps in services (two services).
- Ensuring clarity in professionals' roles for parents and professionals (one service).
- Reducing costs (one service).
- Providing a proactive service (one service).
- Flexibility and taking account of families' needs and coping strategies (one service).
- Providing a finite service which helps families develop the infrastructure they will need in the future (one service).

4.3 Service model

4.3.1 Eligibility criteria and referral

For all services, eligibility criteria included needing specialist services from more than one agency and being resident in the area covered by the service. All but one service covered children of all ages up to transfer to adult services. All agencies and parents themselves could refer families to all the services.

4.3.2 Assessment and review

In four services, initial assessments were carried out after referral by a key worker visiting the family. Three of these services then completed a fuller assessment using the Framework for the Assessment of Children in Need, or a local adaptation of this. One used the initial assessment to define what actions should be taken and who should be contacted and then six months after referral a multi-agency meeting would be held to draw up a care plan. In one service, there was no assessment process specific to the service, parents joining the service signed a form agreeing to professionals sharing relevant information, then an initial multi-agency planning meeting was held with parents and drew on existing assessments. In two services, a professional (not necessarily a key worker) would be identified to make an initial assessment and gather information from other agencies.

All services drew up multi-agency care plans in collaboration with other professionals and parents. These plans detailed actions to be taken and time scales, and parents were given copies. The most notable area of difference between the services was whether the key worker was involved from the beginning and was there to support families at the first care planning meeting or whether a key worker was allocated at this meeting.

All services reviewed the care plan at regular intervals, ranging between six and 18 months. It was common for the service manager to chair planning and review meetings so that key workers could concentrate on supporting families and providing input. Three services noted that they specifically tried to tie in planning meetings and reviews with education statementing reviews where appropriate and if this met the family's wishes, another commented that more work needed to be done on this.

Some services were flexible about the organisation of reviews and planning meetings, recognising that these could be stressful for parents and they may be more comfortable if the meeting is in their own home and/or the number of professionals attending is restricted. Flexibility could extend to key workers undertaking a review without a meeting if this was parents' wish. In this case, key workers would agree with parents all the people involved with the child and family,

and then contact these people individually to check on progress and find out what they were planning to do during the next six months, record decisions, draw up a plan detailing actions to be taken and a timescale, and circulate this to everyone involved. Two services noted the importance of key workers providing support to involve children and young people in care planning and review meetings.

The importance of the multi-agency care plan was highlighted in many services. It was felt that this gave key workers legitimacy with other services when they needed to check on actions taken or chase up an action that had been agreed and focused the work they did.

I feel that particularly useful are the regular meetings. I think the way they're written up is very parent friendly and very accurate. The action plan is very clear and sort of you know you are carrying on, and it brings you back far more to what the focuses are and identifies the particular areas that we as a team need to address really, and what the specific issues are, and so I think that the meetings are particularly useful.

4.3.3 Exit from the service

The service with a time-limited input was the only one with a clear exit strategy. Others provided the service until transfer to adult services. One stated that they had 'active' and 'passive' cases, but families who were characterised as 'passive' stayed on the service's books and could become active at any point. Two services recognised the problems that could build up if there were no criteria for exit from the service. One noted that cases were kept open even if families were no longer using services from the partner agencies, and there was lack of clarity in this about what having a key worker meant if there was no contact with the family. In the other service, it was felt by key workers and the service manager that one or two families no longer needed the service and key workers were asked to discuss this with families, but the service would not be withdrawn unless families agreed.

4.3.4 Waiting lists

At the time of our visits, only two services had a waiting list but in one this was substantial, amounting to 80 families.

4.4 The key workers

As can be seen from the descriptions of the services, the seven areas employed different models of key working, the main distinction being between designated and non-designated key workers: two services used only designated key workers, four used only non-designated key workers and one used both.

4.4.1 Recruitment of key workers and matching key workers to families

Designated key workers were usually recruited in the usual way, through advertisement, application and interview.

Recruitment of non-designated key workers was most commonly through matching of key workers to families according to the child and family's needs, with consideration also being given to which professional was most involved with the family. Matching often took place at a panel or allocation meeting and staff were then approached to take on the role. Key workers could change as the child and family's needs changed.

In four services, families had a choice as to who was their key worker, although for one service this was limited. In the other three, the two which had designated key worker teams and the one which had both types of key worker, there was no choice, but it was acknowledged that if there were problems for either party a change of key worker could be made.

4.4.2 Professional background and cross-fertilisation of knowledge

Across all services, key workers came from a range of professional backgrounds. Social workers, health visitors and community nurses were the most common professions, but therapists, teachers, workers with voluntary agencies, Portage workers, nursery nurses, youth workers, paediatricians and a dietician were also represented. In one service, some parents took on the role of coordinating care for themselves, supported by the service manager. Another service did not have social workers acting as key workers. Initially, one social worker (a children with disabilities social worker working within a general children's team) acted as a key worker but this did not work well and there was too much of a clash between the statutory role and the key worker role, with the statutory work always taking first place. Families asked for a change of key worker, and after discussion between the service manager and the social work team, they decided that social workers would not be key workers.

Key workers brought a range of knowledge and skills from their professional backgrounds to the key worker role. It was noted that having a diversity of professional backgrounds was an asset in providing a range of knowledge and expertise to the team.

I think it's a situation of synergy where the sum of the individual members is greater than the whole. Nobody knows everything and everybody has their weaknesses, and that is the advantage of a true team where people are aware of the weaknesses of others but they have their own strengths which compensate. So I think that's the

advantage of having people from different disciplines and they can make a contribution in their own way.

This synergy was only possible where key workers were able to meet each other and exchange views and information. The two designated key worker teams who shared accommodation were obviously at an advantage here, but one service with non-designated key workers arranged regular training and group support meetings, and key workers found this very valuable. Key workers particularly valued the opportunity to meet other key workers. Another service had just set up some training workshops for key workers, after an evaluation pointed to the need for more training. However, key workers in the other three services had few opportunities to meet and learn from each other.

Key workers also identified much that they had learnt from being a key worker, and non-designated key workers felt that this learning transferred to their main professional role. In every service, key workers said they had learnt about the different agencies and services in their local area and how they work. They had also learnt more about the needs of disabled children and their families and what it is like having a child with a disability. They were able to generalise from the issues they dealt with in their key worker role to see that these issues would apply to other families with whom they worked.

I've made an awful lot more contacts, particularly looking at the children's issues from a far wider point of view. Usually I would have been involved specifically in what their OT needs are. I think with being a [key worker] I've been involved in far more issues and have been aware of far more issues that are obviously concerning them.

They gained a greater appreciation of the problems families face in dealing with all the different agencies.

I didn't realise and obviously families must know this very well, I mean you can see why key workers are needed because, because the amount of work it takes to, to help families deal with all their complex system of support and care, it's unbelievable, as well as take care of the child.....Boy, I don't think I realised that when you have a child with complex needs what you've got is a family with complex systems of all sorts and I didn't realise how complicated the whole thing was and how time consuming.

They had also learnt about liaising with other professionals and developed their communication skills.

I suppose I've also learnt sort of professionally how to work with other professionals, mutual respect, and I think I've also learnt ... a bit about diplomacy, that it definitely does work, because there's no point getting angry with people because it doesn't work.

4.4.3 Role

There were differences between services in how the key worker role was defined and the extent to which there was an agreed definition of the role between all key workers interviewed in a service. In four services, interviews with service managers, steering group members and key workers showed clear agreement about what the role of key worker encompassed. These services defined the role as being the main source of information, advice and support for families, enabling and empowering families, overseeing and coordinating the implementation of the care plan and information sharing between professionals. These services all had a clear written job description for key workers. However, in other services we found that different key workers interpreted their role in different ways. Many of the key workers felt that the role was not clear to them or did not perceive that there was any difference between the key worker role and what they had always done.

I'm still a little bit unclear as to what the key worker should do.

In some ways it just feels like a name change, there's not a lot of difference for my work ... because of the complexities of the cases you're already liaising with Health, Education, etc ... and I'm still doing that.

Some key workers expressed uncertainty about how families and other professionals understood the role.

I personally don't think that the families have an idea that that role is anything other than your professional role really. I don't think, I don't think they see it as being different really to, to what you would do anyway.

...and the key worker role I think is, is a little bit fuzzy, well I think in everybody's mind, certainly in mine.

In services where there were problems in understanding the role, we found considerable discrepancies in individual key workers' accounts of their work with families. Some were clearly undertaking the role defined in research and in the other services where there was a clear definition, but others saw their role as more limited. Some professionals did not feel comfortable to contact a family in their key worker role. They would normally be in contact for issues regarding their ordinary professional role but would not normally call them to ask if everything was proceeding smoothly and whether help was needed. They also did not feel that contact with other professionals regarding the family was part of their role. The following contrasting accounts from workers in the same service illustrate this diversity in understanding of the role:

I suppose my main idea of it is that it's my responsibility to communicate with all other professionals involved and make sure everyone's up-to-dateand you'd like to feel that you're the first person the family would turn to if they've got worries. And I'd also feel a responsibility in getting the

problem sorted, even if it wasn't in my area I would feel that was my job to be acting as an advocate really for the family.

I wouldn't contact them, I wouldn't contact them purely in a key working role....it wouldn't be on a, is everything OK, you know, how are you going, have you sorted this ... I wouldn't be proactive I think is what I'm saying.. in looking for things that there might be difficulties with...

It's not part of my role.... to visit their homes.

I'm not checking up on other professionals and their involvement in families, that's not my role, I do not see that as my role.

Where the role was unclear, some key workers would have welcomed written guidelines.

Another aspect of defining the key worker role is whether it is seen as providing support for both the family and the disabled child or whether one takes precedence over the other. In all areas, respondents saw parents and children as interdependent, and considerable emphasis was placed on providing an holistic approach encompassing the whole family. It was recognised that reducing stress for parents is beneficial for children. This requires key workers to work across disciplines and agencies and emphasises the need for a range of skills and knowledge:

Where there are huge social problems going on the impact for the children is immense. I mean I've got one with horrific housing issues and another one where there are parent health issues and I have to deal with the parent health issues because that has a consequence and effect on the care of the child.

However, it was also recognised that children's and parents' needs may not be synonymous and at times their views may conflict, especially as children get older. In this case, some key workers felt it was important to keep in mind that they were working for the needs of the child. One key worker described part of her role as ensuring that she heard the child's views as well as the parents'. Seeking the views of children, particularly those who have complex disabilities, was an issue mentioned by some key workers as one where more work was needed.

We've had lots of children attend meetings but we have not really actually made it the child's meeting and I think that's something we should work towards doing if that is appropriate to the child's cognitive ability and age.

4.4.4 Skills and knowledge needed by key workers

There was considerable agreement between everyone we interviewed about the skills, knowledge and personal qualities that are needed by key workers. These were:

- Good communication and listening skills.
- Ability to empathise with families, build rapport and develop relationships of trust with families and other professionals.
- Ability to 'stand back and step outside' one particular discipline. As one interviewee commented key workers should not be 'precious' about their own particular profession.
- Negotiating skills and diplomacy.
- Ability to see the whole family.
- Team working.
- Knowledge of the roles of other agencies, how other agencies work and what is available locally and nationally.
- Ability to find information and to admit that they don't know all the answers.
- Time management skills, ability to plan effectively and be a good organiser.

In addition to these general skills and a broad base of knowledge, some interviewees noted the importance of having more specialised skills within the key worker group as a whole, including medical knowledge applicable to children who have specific health needs. Others mentioned having a good understanding of disability issues.

Greater emphasis was placed on 'people skills' than specific knowledge, as it was felt that knowledge could be learnt but these softer skills were harder to acquire. In areas, where regular training was provided this was an important way in which key workers acquired knowledge, and learning from each other also contributed to this. Interestingly, managers in two areas which did not have key worker training noted that training was needed for key workers to acquire the knowledge necessary for the job.

4.4.5 Training

Three services had induction training and regular ongoing training for key workers. Two currently had no initial or ongoing training, although one of these had such training in the earlier years of the service, and it was seen as very important, in providing key workers with both information and opportunities to meet and share ideas and experiences. Plans were being made to set up training sessions again. In another service, some induction training was provided, consisting of one workshop when the service was first starting. In the other service, each new key worker met with the service manager who explained the aims and nature of the service and what was expected of key workers. The service manager also ran occasional sessions to look at key working in more detail. This service was also in the process of setting up more ongoing training workshops.

In those services that had regular training, this covered a wide range of topics, including: childcare law, child protection, the Children Act, direct work, life story work,

charging policy, presentation skills, housing grants and benefits, Disability Living Allowance, Motability, direct payments, statementing, disability rights legislation, the roles and working of different agencies, what services are available and where to get information, and team building. In addition to topics identified by service managers, key workers commonly identified issues on which they required training. Key workers generally spoke very positively about the training they received: 'The training we've been given has been wonderful, it really has, we've learnt a lot from it'.

In services where key workers did not receive regular training, views were mixed. Some felt that the training they received in their every day professional role was sufficient and covered many issues relevant to key working. Others expressed a need for training and/or group meetings for key workers to share with and learn from each other.

4.4.6 Supervision and peer support

The three services which had regular training also had regular supervision and opportunities for peer support between key workers. In these services, supervision specific to the key worker role was provided by the service managers at intervals ranging from fortnightly to six-weekly. Both supervision and peer support was highly valued by the key workers in these services.

I've never been in a situation of being formally supervised. In my last role I had supervision but now I know what supervision is I didn't. It's, it's excellent, you know. So there are, there are issues we go through, issues about key working generally and, you know, the team, the key working team and stuff, and then we go through the families if I need to, you know, I can go through every one of them and it's really useful to say look I'm at loggerheads here, which she'll say well have you tried doing that, you know.

We very much support each other within the team a lot, and it's quite unique. Whereas it's often, it's only the other members of the team who know sometimes the tricky balancing acts that you do in different situations that you might be in, or just to ask advice about this family – but 'so and so, have you got any ideas?'

In the other services, most key workers found that the supervision they received from their line managers in their day-to-day professional role and support from other professional colleagues was sufficient. However, some wanted more support and guidance in their key worker role than they received.

4.4.7 Caseloads and patterns of contacts with families

There was considerable variation in caseloads. Designated key workers commonly worked with between 20 and 40 families. In four of the services, non-designated key

workers usually worked with between one and five families in addition to their usual role and other caseload. In the other service, workers spent a greater proportion of their time on the key worker part of their role and non-designated key worker caseloads ranged between two and 25 families. Some key workers in this area felt that they spent more time on key working than on their other professional role and they would have preferred the balance to be the other way round. One commented that because of the number of families on her key worker caseload she could only work with them on a very basic level.

Key workers also emphasised that the amount of time they spent on the key worker role varied according to families' levels of need at any particular time. Sometimes considerable demands were made of them and both designated and non-designated key workers could struggle to cope if more than one family had a crisis at the same time.

It's not just, it's not down to just numbers is it, it depends really on, cos a few of them are quite heavy and they can just be all consuming really, you know, they can take so much of your time, whereas some of the others you might only contact on the telephone once every six months, so huge again variety and the others, as I say, they can be on the phone every day.

Similarly, patterns and frequency of contact varied according to need. Because of this, most non-designated key workers found it difficult to estimate what proportion of their time they spent on key working.

Generally both parents and key workers initiated contact. In some services, key workers would routinely contact families to check how they were, but this was less clear in other services. All key workers agreed that frequency of contact varied depending upon individual families' needs.

I would aim at some weekly ... some monthly, some three monthly and some six monthly and there are just one or two that just annually might need a phone call, because they know that we're here, they know that all they've got to do is pick up the phone so ... yeah, most of them I would have a good handle on every three months, say, some of them it's almost day to day ... and the majority I think from one to three monthly, or visit when I'm in the area.

Key workers in the service that aimed to provide a time-limited input, initially for families with pre-school children, generally saw families frequently at first, about every two weeks. They found that the families needed high input when they were first accepted, but gradually became able to take on more responsibility for organising the care themselves and, accordingly, their need for contact with their key worker diminished.

What we try to do is – because the idea of our work will be that we have short-term input with families – initially when we meet a family there is a lot of work to sort out and a lot, a lot to do for a family but then – I mean

we were worried that we would start to create dependence for families that would become very, very dependent on us – but in actual fact what's happened in practice is that after we've sorted out a lot of the initial problems, and once the family know who's who, we just gradually tail off the lengths of visits and the amount of visits that we do. It just automatically gets less 'cos there's less to sort out and the families sort of overlap and sort of start picking up their own care then.

When we asked key workers to estimate how much of their key working time they spent in direct contact with families, many were unable to do this. However, those who did make an estimate suggested that actual contact with families took up about 25 to 50 per cent of their time with related administration and contacts with other services taking up the rest of the time.

In designated key worker services, standard forms had been devised for case records and these were used by the whole team. However, for non-designated key workers, services differed in their approach. In three services, non-designated key workers kept their case records in ways that fitted with what they did in their own agencies and, in two of these services, supplemented their records with additional notes for key working. However, in the third service the key workers interviewed reported not making any particular notes for their key worker role. In another service, record sheets for key working had been devised but some workers reported that they had to keep two sets of records on the families they key worked with – one for key working and one for their own agency. Key workers in this service were more likely to comment that they found the paperwork too laborious.

4.4.8 Key workers' roles in transitions

Transition times (diagnosis, preschool to school, changing schools, leaving school and transition to adult services) have been identified as particularly stressful times for families. They are times when services change, uncertainty is high, families find it difficult to get support and coordination and continuity is lacking (Forbes *et al.*, 2002). The role of the key worker can assume particular importance at these times. Key workers recognised this and spoke about the need to give increased support to families at this time. At diagnosis, part of the key worker's role was seen as helping the parents accept the child's diagnosis and giving information and support during this time. They would inform parents about existing services and help the parents to decide which services the family needed. In one service, early input at the time of diagnosis was seen as a key part of the role of the service:

When they are first diagnosed.....we try to visit in the hospital within twenty-four hours to give them information, answer questions, you know, at that time they're so shell-shocked by what's happened that, you know... anything they're told they need to be told more than once because it all goes over their heads...

Supporting children and families in transitions to pre-school and school was also seen as an important part of the services. Key workers visited schools with children and parents, supported parents in requests for alternative placements, and provided information for school staff (Chapter 7 deals in more detail with the links between key workers and schools).

Transition to adult services is an area of work where many problems have been highlighted in recent research and coordinated multi-agency working is crucial (Beresford, 2004; Department of Health/Department for Education and Skills, 2004b). A number of the services we visited had not yet experienced this transition. For one of the services that had, this was recognised as a problem area, due to staffing difficulties, restructuring and changes in adult services. However, another service had set up a system that seemed to be working. Key workers would start to prepare the young person and family for transition when the young person was between 14 and 16 years. They would introduce a member of the adult team to the family and would continue to provide support in transition meetings. At 18, the young person's case notes would be transferred to adult services, but the key worker would still be available if help was necessary and the service would not withdraw completely until 19, thus helping to ensure a slow transition.

4.4.9 Constraints and problems of the key workers' role

Key workers were all asked whether they experienced any constraints or problems in their role. A consistent theme among non-designated key workers was having insufficient time to devote to the role. This was linked to a number of factors, some of which varied between areas: not having protected time for the role, uncertainty about how much time they were allowed to spend on the this role and feeling that they needed to justify the time spent on the role to their line managers, and the time demands of the service's paper work. Many of these key workers also talked about the problems of juggling their two different roles, their key worker role and their ordinary professional role. Some non-designated key workers had agreed a certain amount of time per week that they would spend on the role, but for others key working time was integrated into their caseload and no specific amount of time was agreed. In either case, the realities of key working and the uneven patterns of need of different families at different times meant that flexibility was required: a lot of time might be spent on the role in some weeks, but very little in other weeks. For some workers, this caused problems and they could feel that they were in danger of not doing justice to either their main job or the key worker role.

I'm supposed to be key worker for one day a week, that's part of my role, and you can't do it like that. You can't say Thursday I'm going to be a key worker because there's bits of your time throughout the day. You might get a phone call from the family, something that needs to be done there and then so I just can't pin it down really, but I do know that it's eating into

a lot of the time that I'm doing [my usual job], that's juggling too many balls up in the air..... and I just feel I'm not doing anything right at the end.

However, others felt that the key worker role was simply an extension of the care that they were already providing and thus the demands were only slightly more than their usual role. Whether or not key workers were able to juggle roles successfully and without too much stress to themselves depended on the size of their caseloads in, and demands of, their main job. If line managers did not recognise the need to balance demands with the key worker role, it was difficult for key workers to carry out either job successfully.

Another consistent theme across services was the constraints engendered by gaps in the provision of services in their area and lack of resources, which meant that the needs they identified could not be met.

Problems in making contact with other professionals, both to pass on information and to obtain information, were common. The time spent trying to contact other professionals who were not there when they called and did not get back to them when messages were left, was a common cause of frustration, and some key workers felt that it was difficult to get other professionals to understand their role and liaise with them, so that important information was not passed on to them and communication seemed to be one-way.

Other problems were mentioned in just some of the services. In those services where key workers did not have regular supervision in their key worker role, lack of support could be a problem. It was noted that the key worker role was emotionally demanding and not all workers had professional support structures in their main jobs that could allow them to share concerns. Another outcome of lack of training and supervision was that some key workers felt that they did not understand the system, both in the key worker service and in other agencies, and they did not know who to turn to for information or advice. Similarly, lack of relevant information and knowledge, for example information relevant to children's health needs for key workers who did not have a background in health, was a problem noted by some key workers where training and supervision were lacking.

4.5 Role of the service manager

All services but one had a service manager whose role included responsibility for the key worker service. The professional backgrounds of these managers were in either health or social services. In three services, the role of the manager was to lead and develop the service, supervise, support and organise training for key workers. In some cases, managers also chaired planning and review meetings for children and families. Two of these services had teams of designated key workers and one had both designated and non-designated key workers. In all cases, these managers also

undertook other related roles: managing an associated Children's Centre or Child Development Team or acting as a key worker. However, it did not appear that these other roles detracted from their management of the key worker service. As noted in section 4.4.6, supervision from these managers was highly valued. They also saw developing a strong team spirit and motivating key workers as part of their role and it was apparent from interviews with key workers that they valued this. The comments below from the manager and a key worker from the same service illustrate this concordance between managers' understandings of their role and the key workers' views.

Well I think it's about.....valuing children, valuing families, but, and then valuing each other, you know, team members, giving people space I think, encouraging people when they have got ideas, giving them space, not being on top of them but trying to be available for them as well.... Yeah, and about shared, having ownership, that the objectives that we have got as a team are shared objectives, and that they come from the bottom up, but also from the families.

(Service manager)

I think the manager has a real aptitude for bringing out the best in people...

(Key worker)

It should be noted that the number of key workers to be managed in these services was relatively small, ranging between five and nine. Thus it was feasible for the service manager to provide regular supervision. One of the managers whose number of key workers was expanding had concerns about her ability to supervise and train a larger number of key workers within the amount of her time that was allocated to the key worker service.

Another service provided some information on this. This service had over 40 non-designated key workers and was managed by a full-time manager. The manager's role included organising care planning and review meetings for children and families, chairing meetings, taking minutes and preparing and distributing reports. She also provided support for key workers and was regarded by them as very accessible and helpful. However, the manager felt that due to pressure of work her contact with key workers was 'erratic' and 'unsatisfactory'. It was not possible for her to provide regular supervision for this number of key workers in the way that managers with fewer key workers did. In addition, key workers in this service did not see themselves as a team. In spite of these difficulties, the manager was regarded with great respect by the key workers and professionals in other services for the way in which she ran the service.

Service managers in the two remaining services had somewhat different roles. Both had a role in overseeing the service and neither supervised, trained or had regular contact with key workers. Both services had large numbers of non-designated key

workers (60-80). In one case, the manager chaired and coordinated planning and review meetings for children, and some key workers felt that if a problem arose they could telephone or email the service manager. In the other case, the manager was responsible for the implementation of Joint Agency Teams (JAT), with key workers, in four areas of the county. Each team then had a manager, but responsibility for supervision of key workers rested with line managers in their own agencies. Some key workers in this service felt that the JAT managers were too busy to be contacted.

It was clear from interviews with key workers that accessibility of the service manager was an important aspect of the service, but with non-designated key worker services which had large numbers of key workers it was difficult to ensure that the service manager could provide support or supervision for key workers and organise training. In one case at least, this dissonance between what the manager would like to do and was able to do was a source of frustration for her, despite the generally positive views we received from key workers in this service.

4.6 The steering groups

The composition of the steering or advisory groups for the seven services is described in section 4.1. All but one currently included representatives from all three statutory agencies, and the majority of these were people at managerial level. Three groups also included representatives of voluntary agencies, five groups included parents and one had links with a parent-run forum.

4.6.1 Roles of the groups

Five groups had a role in finding funding for the service, both initially when the service was set up and currently for new developments or expansion of the service. In the initial stages of developing the services, steering groups had been instrumental in defining criteria for the service and most continued to have a role in monitoring the service, reviewing and developing policies and practices. All saw their role as supporting the service manager, and reports from service managers were a means of monitoring the services and checking that aims and objectives were being met. A newly formed steering group in one area was currently working on regenerating the service, seeking funding for a service manager, producing new policies and documents, identifying performance indicators, and setting up training for key workers. A number of members of steering groups highlighted the role of the group in ensuring a multi-agency focus, raising awareness of the service in other agencies and addressing barriers to multi-agency working.

In two areas, the groups had a much wider remit than the key worker service and there could be a problem that the service was only a small part of the agenda.

All groups met regularly, varying between quarterly and once every two weeks. However, in two areas there were concerns about poor attendance. Various factors affected this. Replacing agency representatives who had left their agencies was identified as problematic in both areas. In one area, a fall off in attendance was also attributed to the fact that the service was now well established and successful so people did not feel that they needed to prioritise group meetings. In the other, there were concerns about lack of representation from some agencies meaning that decisions could not be made, and it was felt that there was a need to get people involved from higher levels of management so that decisions could be acted upon.

4.6.2 Parent involvement

Six groups currently had, or had in the past had, parent members and one had links with a parent forum. The value of having parental perspectives was voiced by managers in all groups. Parents were seen as an important force in keeping the group 'grounded', focusing on things that affect families most and providing a user perspective on the service. Parents themselves endorsed these views and thought that their independence of agency boundaries was an asset. However, there were mixed views about whether there was an equal partnership between parents and professionals on the groups. Generally, parents felt that their views were listened to and respected, but a few suggested that in reality they had little power and those who 'hold the purse strings' are the real decision makers. However, the manager of a service that did not currently have parent representation presented an opposing view. She commented on the importance of parents' voices on the group in lobbying against cuts in the service. Some parent members found it difficult to find time to attend meetings and noted that they needed to feel that they were able to make a genuine contribution, and one parent noted that although expenses for travel and childcare and a small 'consultation fee' were paid, there could be a considerable opportunity cost when work time was lost.

4.6.3 Involvement of children and young people

None of the groups had children or young people involved, although in one young people had been involved in initially planning the service. Four groups mentioned that they were currently looking at ways to involve children.

4.7 Evaluation

Considerable commitment to monitoring and evaluation was apparent. Six services had carried out some sort of evaluation in the past, ranging from external independent evaluation to parents' conferences. There was evidence in some services that when evaluations had been carried out, they had informed new developments in the service. This seemed to be particularly the case when external

evaluations had been commissioned. Three services were currently looking at the issue of evaluation and one quite new service, that had not yet had any evaluation, was intending to use the results of this research.

4.8 Multi-agency working

4.8.1 Facilitating multi-agency collaboration

Despite all seven services having multi-agency involvement in steering the service, there were differences between areas in the extent to which successful multi-agency working had been established. In all areas, the majority of key workers interviewed collaborated with professionals from many different agencies on behalf of families. These agencies included housing, leisure and the Benefits Agency, as well as health, education, social services and other relevant local organisations, such as Sure Start and voluntary agencies. Many examples were provided of key workers liaising with schools and housing departments, helping families to obtain Disability Living Allowance and providing information about and links with leisure services. For example, in one area key workers undertook joint visits to families with Portage workers, in another links had been established between key workers and housing officers. Similarly, links with other agencies and initiatives were made in the funding and management of services. In one area, Health Action Zone and Children's Fund money contributed to funding the service, in another Sure Start money funded an early intervention worker for the service.

In four areas, multi-agency working was seen by managers and key workers as operating relatively well, although some barriers were still identified. In the remaining three areas, the picture was more patchy; in one area collaboration at management level appeared to have been established but key workers identified considerable problems at practice levels; in the other two areas problems were apparent at all levels with lack of commitment and active involvement of some of the statutory agencies. A number of themes emerged about factors underlying successful multi-agency collaboration.

- Building on an existing base of good multi-agency working when the service was set up.
- Having some dedicated funding and financial contributions from all three statutory agencies was seen as key to their commitment to the service.
- Management in the different agencies recognising the need to pool resources to improve services, being open to new ideas and prepared to support different ways of working.
- Good communication, keeping all professionals in different agencies informed about the service and its role, and being clear about each agency's role.

The role of the service manager was central in facilitating successful multi-agency working at practice and management level. Service managers kept agencies and professionals informed about the service, liaised with them, promoted the service to them, and facilitated key workers' access to other agencies. They were seen as 'champions' of the service and their leadership of the service was important in establishing its credibility with agencies.

She does command a lot of respect because she's very clear, very honest and recognises the limitations of what she can and can't offer. It's run in a professional manner and that respect cuts across the board. I think it's taken a lot of work and time for people to see that there are benefits because agencies will only buy into something that they think they are going to get something out of, if they are going to save money, or create a better more cost effective package of service delivery to a family and they will buy into that, so she's created the right ethos.

In addition, steering groups played a key part in clarifying each agency's role and facilitating communication with members' own agencies. In one area, the fact that a voluntary agency was the lead, employing the service manager and chairing the steering group, was seen as helpful in promoting multi-agency working and diffusing tensions between agencies. The work of key workers on the ground also facilitated contacts between agencies.

Some key workers described how the service fostered multi-agency collaboration because through information sharing on specific case loads they came to appreciate more about the working contexts of other professionals, including the constraints that they worked under, and 'as time goes on you realise that you're actually working towards the same thing'. This was viewed as breaking down stereotypes and challenging preconceptions:

Enabling agencies to see the work of [the key worker service] and having it as a principle that this sort of multi-agency working is a really good way forward. And there's a ripple effect isn't there ...they [key workers] will take the principles back to their different organisations and so again it's an attitudinal change as well.....

Sharing information and records between agencies was important in enabling the services to work successfully. Most services had experienced problems around confidentiality and sharing information, but these had been addressed in some areas by setting up systems whereby parents gave permission to share information.

4.8.2 Barriers to successful collaboration

All areas identified barriers to multi-agency working. A number of common barriers had been experienced across areas, whether they had successfully established collaboration or not. These included:

- Lack of funding and resources were key barriers to a successful multi-agency service. In areas experiencing the most difficulties, there was no dedicated multi-agency funding for the service. This was seen as meaning that there was no ownership of the service:
 ...but the problems have always been because no-one owns it, there's no money....I don't know what it's like in other areas but I think my own view is that unless everyone's on board with it then it's a very lopsided service...

Even where there was some multi-agency funding for the service, problems could still arise at practice level over which agency should fund resources or equipment needed by families. This was frustrating for key workers when trying to put together appropriate support for families and it was felt that these problems still needed to be sorted out at strategic levels. Inadequate staffing levels and heavy caseloads in services in many of the areas meant that agencies were unable to commit sufficient staff resources to the key worker service.

- Similarly, where funding was committed from the three statutory agencies, inequities in funding and the funding streams being kept separate rather than as pooled budgets were still seen as barriers to good collaboration.
- Although information sharing was established in some areas, 'confidentiality' was still a problem in others.
- Different knowledge, values, language and working practices between different agencies and professionals often impacted on the services. In the more successful examples of multi-agency working, these problems had been overcome over time as the expertise of the key workers was recognised and key workers were careful that other professionals did not feel marginalised or undermined. It was acknowledged that this was an ongoing issue that key workers needed to address, that 'people can be precious about what they do' and sometimes sought to safeguard their own role against perceived encroachment of a key worker. It was important that other professionals were made aware of what the key worker role was, and where this was not the case and communication was poor, there could be duplication of work between the key workers and other professionals:
 Sometimes it feels like you're chasing your tail a bit because often families will have told you there's a problem and you start to try and resolve it and contact people and before you know it the family's also told their physio the same problem and you can find out that you've done a lot of chasing around and actually it's been sorted out ...
- Lack of joint working at organisational levels and gaps in communication between practice and management levels also impacted on key workers ability

to carry out their role. One key worker described this as the different agencies and professionals working towards the same aims but still travelling on different tracks:

...it's like, it's not just one track of railway line, it's about ten railway lines going along and the weird thing is you're all going in the right, in the same direction but you're never quite meeting, you know, the points are never like brought across.

- Where the service itself was experiencing problems in setting up systems or finding sufficient resources, this impacted on relationships with other agencies. Key workers in one area which had a waiting list for the service felt that other professionals did not have faith in the service because of its long response times.
- Different priorities for the different agencies were mentioned as problems in all areas. In particular, it was felt that education was the agency least committed to the key worker services because as a universal service, they placed less priority on disabled children. This issue is explored further in Chapter 7.

4.8.3 Effects of the key worker services on other professionals and agencies

Where multi-agency working was established, in general interviewees perceived the services as having positive effects on the work of other professionals and agencies. They noted that key workers were able to access appropriate support for families and refer to appropriate services, they arranged meetings and took responsibility for contacting people, they facilitated contacts and understanding between professionals, they undertook work on issues that were not within the specific expertise or remit of other professionals, and by being proactive they could anticipate future needs of families and provide information for management so that forward planning was facilitated. In carrying out these tasks, it was felt key workers reduced the workload of other professionals. However, it was also acknowledged that key worker services could produce more work for other agencies by increasing referrals and making families more aware of services and of their entitlements.

However, it was clear from interviews with key workers that not all undertook the roles described above. In some areas where the key worker's role was less clearly defined and where multi-agency working was not yet well established, some key workers did not see collaboration with other agencies as an important part of their role. Thus tasks such as liaison with housing departments and helping families to obtain benefits were seen by a few key workers as outwith their role.

4.9 Perceptions of advantages and disadvantages of the services

All interviewees were asked about the advantages and disadvantages of their service for parents and children, key workers and other professionals. A number of themes emerged across the services which identified the advantages and disadvantages of key worker services in general. There was a great deal of consistency in these themes and in many ways they echo and summarise many of the themes that have been detailed throughout this chapter. In addition, information about the advantages and disadvantages of particular service models, and the improvements thought to be needed in the different areas, provided further insights into the pros and cons of designated and non-designated key workers and needs for training, support and clarity about roles. In this section, general points will be described first.

4.9.1 Advantages of the key worker services

The role of key worker was seen as having a number of advantages for key workers themselves. Key working was seen as an opportunity to get to know children and families well, build good relationships with them and understand their situation. Key workers felt that they were really able to 'make a difference' for families and so the job was rewarding and job satisfaction was high. As a result of their increased knowledge about children and families, key workers felt that they were better able to communicate with other professionals about the family, and the key worker services themselves provided effective frameworks for information exchange, particularly through care planning meetings and reviews.

...you can communicate with other professionals competently and confidently because you're informed about that family, so that's an advantage.

Key workers also appreciated learning new skills and learning about other disciplines. Where it occurred, working as part of a key worker team, and having opportunities for support and learning from other team members, was also highly valued.

Only one area had parent key workers, but they saw the advantages of their role as being confident that they were doing everything possible for their child and gaining confidence in interactions with professionals.

I suppose its given me peace of mind knowing, I mean my husband he knows the kind of person I am and he feels confident that if I'm sort of looking after her care that it will be done and I suppose because everything's been kept, you know, pretty tight and rolled along that's made more time for [my other child].

Perceived advantages for parents and children of having a key worker were centred around having one person to contact about any concerns, someone who was in charge of coordinating services and making sure needs were met, and not having to keep telling your story to different professionals. This meant that families were not 'battling' for services, there was greater consistency and continuity of care and thus stress was alleviated. In comparison with usual services, key worker services were said to provide better information to families, quicker referral to other services and access to appropriate services and placements, and to reduce misunderstandings and duplication.

The importance of the key worker building a relationship of trust with families and working in partnership with families was emphasised and it was felt that this decreased parents' feelings of isolation. Key workers also built relationships with children and young people. This was seen as valuable in providing a supportive adult outside the family for some disabled children and young people, and in some cases, the key worker could provide a mediating role between parents and children. The key worker's role in 'seeing the whole picture' of the family was also seen as important, enabling key workers to assist in meeting needs of all family members.

The care planning processes that were part of the services aimed to involve families as equal partners, and provided a means for families to 'see a way forward' and have agreed aims that everyone would work towards. In one service, which provided a time limited input, key workers were said to model strategies and practices for accessing resources which families were then able to adopt themselves, and they were then empowered to take on their own care coordination.

Advantages of the service for other professionals were also identified. Again these centred around having one point of contact regarding a family, being a source of information and knowing what all agencies were doing with regard to a family. Key workers were seen as 'lightening the load' and reducing pressure on other professionals, as illustrated by the comments of this professional who was a member of a steering group:

I suppose the advantage for me is that I might have taken on the role as key worker and tried within my busy working day to help individual families. Whereas for me that I feel to be able to pass on that responsibility and know that those needs are being recognised and addressed, and it just makes me able to do my job more efficiently and hopefully help other families. So, you know, I've found it a real benefit.

Key workers' roles in earlier identification of need and facilitating access to appropriate services could avoid waste of resources and prevent need for more intensive intervention. In addition, key workers could highlight unmet need so that agencies could see where services were lacking.

4.9.2 Disadvantages of the key worker services

Most of the disadvantages mentioned for key workers themselves were specific to certain models of service and these will be dealt with in the next section. A more general disadvantage for the service was raised in one area, but could equally have applied to other areas. This was the reliance of the whole service on the service manager. There was concern that if the manager left or the post ceased to be funded, the service would cease to exist. It was also acknowledged that key working is a demanding role, key workers were at risk of becoming too emotionally involved and having appropriate support in the role was important.

Whilst interviewees talked about advantages for families in concrete terms, they found it harder to identify disadvantages. Those they did mention tended to be expressed as possible disadvantages, rather than ones that they themselves had seen. These potential disadvantages included: expectations could be raised that could not be met by the available resources in the area; the service could foster dependency among families; and there may be problems for families if the key worker was not knowledgeable in all areas of a family's needs. In one area there were concerns about the process of choosing a key worker. In this area, parents were asked to choose their key worker from among different professionals at a panel meeting. It was felt that this could put parents 'on the spot' and be daunting for them. In this service, it was also felt that the role of the key worker was unclear to parents, thus increasing problems around choosing a key worker.

The disadvantages for other professionals were also few, mainly centering round the view that other professionals may feel threatened or undermined by the role of the key worker, and if key workers were identifying unmet need they may be seen as 'hassling' other professionals.

4.9.3 Advantages and disadvantages of different models of services

There was considerable discussion of the advantages and disadvantages of designated and non-designated key workers. Table 4.1 summarises views on this.

Table 4.1 Advantages and disadvantages of different types of key worker

<i>Designated key workers</i>	<i>Non-designated key workers</i>
Advantages: <ul style="list-style-type: none">Easier to supervise and manageMore time for key workingGreater availability for familiesGreater knowledge and awareness of servicesClearer job specificationGreater team spiritHigher motivationIndependence of statutory agencies, able to advocate for families	Advantages: <ul style="list-style-type: none">Variety in roles for the individual workerVariety of knowledge and perspectives brought to the scheme by workers from different agencies, so that all could learn from each otherKey worker knowledge and skills informing everyday work
Disadvantages: <ul style="list-style-type: none">Hybrid professionPossibility of losing skills	Disadvantages: <ul style="list-style-type: none">Not having protected time for the key worker roleConflict of priorities between different roles, and key worker role taking second placeNot being 'an expert in everything'Not using key worker skills all the timeUncertainty about the roleLittle contact with other key workersJuggling two rolesFailure to know difference between two roles

As can be seen from the table, more advantages were identified for designated key workers and more disadvantages for non-designated key workers. However, both models were seen to have strengths and some of the disadvantages identified for non-designated key workers may be overcome by better management of the services. For example, uncertainty about the role can be addressed by having a clear job description, training and supervision in the role. Similarly, having protected time for the role is an issue for line management, but it was also acknowledged that key working is not a role that can easily be accommodated in having a set day or hours per week as families do not have crises to fit in with the key worker's timetable. Time difficulties were particularly problematic for key workers who had heavy caseloads in their everyday jobs and who felt that there was little recognition of the key worker role from their line managers. In this situation, they could easily become demoralised and this was a factor that was thought to have contributed to the decline in the service in Area G.

Interestingly, the disadvantages identified for designated key workers were hypothetical, they were seen as a risk of the role but had not been experienced by the designated workers we interviewed.

4.10 Suggested improvements to services

The suggested improvements to services tended to be specific to each service. Improvements said to be needed in some services were already valued features of other services and thus we can begin to identify what were viewed as the important elements of a good key worker service. These features include:

- A clear description of the role of key worker for key workers, families and other professionals.
- Provision of administrative support for the service and for key workers.
- Regular training, supervision and support for key workers.
- A register of information about services for key workers and families.
- Communication between key workers and opportunities to meet and exchange information and experiences.
- Dedicated multi-agency funding.
- A manager who can devote time to supervising the service.
- Frameworks and timescales for assessment and review and explicit guidelines.

In one service, the paperwork devised for the scheme was seen as time-consuming and unwieldy, yet in another service, where key workers had been involved in drawing up forms for paperwork, this was seen as a valuable part of the scheme. In two services, a lack of some of the characteristics described above was identified by some of the key workers we interviewed as impacting on recruitment and retention of non-designated key workers and on the ability and willingness of existing key workers to carry out all aspects of the role. In particular, lack of support for key workers, including training, supervision and administrative support, was thought to be a significant problem.

There were a few improvements that, as yet, none of the services had fully managed to achieve. Non-designated key workers wanted protected time for key working and, in some cases, more negotiation with their line managers about how much time and effort they could spend on their key worker role and reductions in case loads in their main jobs to allow this to happen. Some services recognised the need to involve children and young people in planning the service, but none had done this as yet, and key workers would have appreciated guidance on consulting with disabled children and young people.

4.11 The future of the services

At the time we visited the seven services, all had plans for development. Four were expanding their services, taking on more key workers, increasing the age range of children eligible for the service, and in one case appointing a training coordinator and development workers to assist the service manager. One service manager was hoping to be able to provide group supervision for key workers, another was looking

at a system whereby parents could access the service IT system at home and hoped to encourage parents to take on the key worker role, and a third was looking at regenerating the whole service, appointing a manager who could devote the necessary time to supervising the service and considering the need for designated key workers.

The services are continuing to grow and change and this account is only a snapshot in time of the ways of working and the issues facing the services. In Chapter 5 we will look at how particular characteristics of the services identified as important in interviews with staff relate to outcomes for families. Questionnaires to parents were distributed soon after interviews with staff were completed, so responses reflect the situation at that time. However, it is clear from the plans outlined above that our seven services are not standing still and some of the issues identified in this chapter are already being addressed.

4.12 Summary

Interviews with key workers, service managers and members of steering groups in the seven case study services showed that the services were similar in some respects, such as the basic aims of the service, referral arrangements, having multi-agency representation in setting up and overseeing the service, and drawing up multi-agency care plans. However, but there were also considerable differences both within and between services in other respects. Differences identified as important to how the service operated included: clarity of the role of the key worker; provision of ongoing training and supervision for key workers and opportunities for key workers to support and learn from each other; designated or non-designated key workers; having dedicated funding; the role of the service manager; whether or not parents were represented on steering groups; and the progress of multi-agency collaboration.

Key worker services were seen as providing considerable advantages for families and for staff. However, disadvantages specific to certain models of service were also identified. Clarity of the role of key worker was a crucial issue. Where key workers were unclear about their role, there was variability within services about how the role was interpreted by different key workers and consequently in the provision families received. Provision of a clear job description, training and supervision all contributed to ensuring that key workers understood and were able to carry out the role. The role of the service manager was also seen as crucial. In some services, these managers organised training and supervised key workers, and acted as leaders of key worker teams. In others, roles differed and the managers had less direct contact with key workers. Some managers also facilitated multi-agency working at practice and management levels, and were seen as champions for the service. Lack of any dedicated multi-agency funding for some services was also

identified as problematic, both in indicating a lack of multi-agency commitment to the service and in limiting the resources available for the service.

In the next chapter, we report the results of the analyses of how these differences in service models related to outcomes of the services for families.

Chapter 5: Results of Family Survey

This chapter presents the results of the quantitative analysis of the family survey, covering the questionnaires completed by parents/carers and those completed by children and young people. Results of the parent questionnaire survey are presented in Sections 5.1 to 5.3. Section 5.1 presents descriptive statistics on characteristics of parents and children, characteristics of the key worker service received, and the outcome variables. Results of analysis of differences between the seven key worker services on these variables are also presented. Section 5.2 examines the relationship between service variables and effects on parental employment. Section 5.3 presents the results of the bivariate and path analyses of relationships between parent and child characteristics, service context and service process variables and outcome variables. Section 5.4 presents descriptive statistics on responses to the questionnaire for children and young people.

5.1 Descriptive statistics

5.1.1 Characteristics of sample

Respondents were predominantly birth mothers (87.8 per cent, $n=166$), 17 respondents (9 per cent) were fathers, three were foster mothers (1.6 per cent), two were grandmothers (1.1 per cent), and one was a male guardian (0.5 per cent). The age of the respondents ranged from 19 to 64 years, with a mean age of 38.15 years (SD 7.46). They had between one and nine children (mean 2.57, SD 1.38).

One hundred and thirty-five respondents were married or living as married (75.4 per cent), 23 were single (12.8 per cent), and 21 were separated or divorced (11.7 per cent). Partners' ages ranged from 23 to 65 years of age, with a mean of 41.14 years (SD 8.18).

One hundred and seventy-nine respondents were white (95.2 per cent), five were Indian (2.7 per cent), one was Pakistani (0.5 per cent), one was Bangladeshi (0.5 per cent), two (1.1 per cent) were mixed race.

Sixty-nine respondents were employed (39 per cent); 22 were employed full-time and 47 were employed part-time. One hundred and ten partners were employed (80.9 per cent); 96 were employed full-time (83.5 per cent) and 14 part-time (12.2 per cent). Table 5.1 gives details of the socio-economic status of respondents and partners, based on present or previous employment (if not currently employed), using the five-category system of the National Statistics Socio-Economic Classification (NS-SEC). There were no significant differences between the samples from the seven services in socio-economic status.

**Table 5.1 Socio-economic classification of respondents and partners
(National Statistics Socio-Economic Classification (NS-SEC))**

<i>Class</i>	<i>Label</i>	<i>Percentage of people aged 16-74 in employment (England & Wales)¹</i>	<i>Percentage of respondents (n=115)</i>	<i>Percentage of partners of respondents (n=116)</i>
1	Managerial and professional occupations	38	47	45
2	Intermediate occupations	13	28	6
3	Small employers and own account workers	10	3	12
4	Lower supervisory and technical occupations	10	6	17
5	Semi-routine and routine occupations	29	16	20

¹National Statistics Socio-economic Classification Census 2001: <http://www.statistics.gov.uk>

Disability Living Allowance (DLA)

One family received the lower rate DLA for their child's care needs, 63 families (35.4 per cent) received the medium rate for care needs, and 105 families (59 per cent) received the higher rate for care needs. Thirty-eight families (21.3 per cent) received the lower rate for mobility needs, and 90 families (50.6 per cent) received the higher rate for mobility needs.

Service use

Respondents had used the key worker service for between six months and 16 years. The average amount of time families had used the service for was 3.33 years (SD 3.11).

Respondents were asked to report how many professionals they had seen in the last three months. Frequencies and percentages are shown in Table 5.2.

Table 5.2 Number of professionals seen in the last three months

<i>Number of professionals</i>	<i>Number of families</i>	<i>Percentage</i>
0	2	1.1%
1	12	6.9%
2	27	15.5%
3	27	15.5%
4	36	20.7%
5	23	13.2%
6	19	10.9%
7	19	10.9%
8	6	3.4%
9	3	1.7%

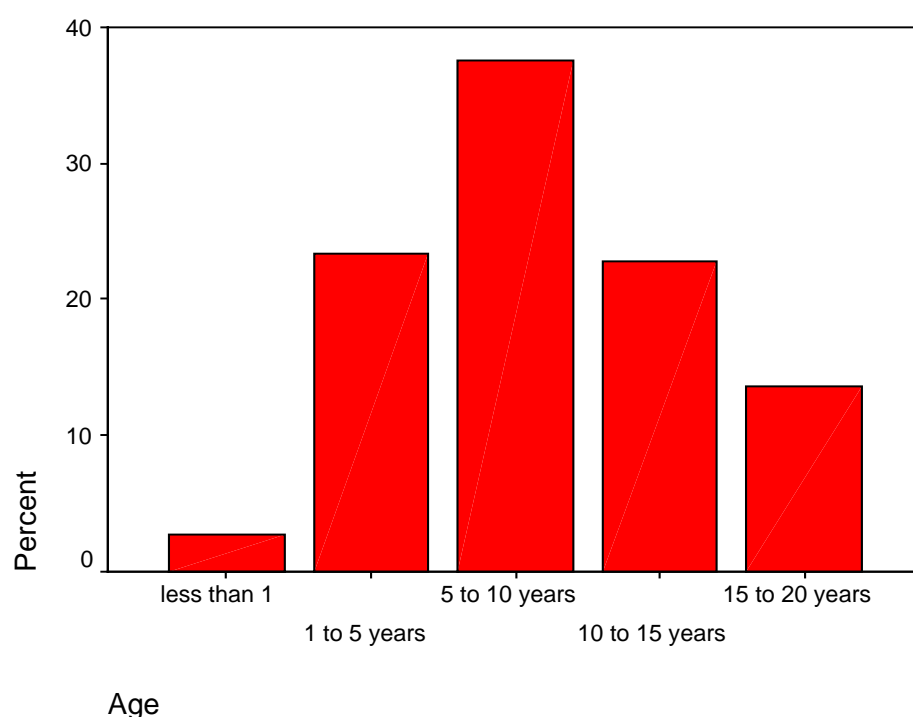
The mean number of professionals families had seen was 4.18 (SD 2.03, range 0-9, N=174). The seven services varied in terms of the mean number of professionals seen between 3.51 (SD 1.77) and 5.32 (SD 1.57). One-way analysis of variance showed that there were significant differences among services ($F=3.234$, $df=6,167$, $p<.01$) however post-hoc tests failed to show significant differences between individual services.

Respondents were asked whether their contacts with services had affected the amount of stress they had experienced in caring for their child in the past six months. Just over half (52 per cent) felt that services had considerably or somewhat reduced their stress, and 17 per cent felt contacts with services had increased their stress, with the remainder finding no effect.

5.1.2 Characteristics of children

Children's ages ranged from 6 months to 20 years, with a mean age of 8.06 years (SD 4.72) (see Figure 5.1). One hundred and twenty six children were males (66.7 per cent) and 63 were females (33.3 per cent). Three children were fostered (1.7 per cent), five were adopted (2.8 per cent).

Figure 5.1 Age of children in sample



Five children had been diagnosed before birth (2.9 per cent), 51 children were diagnosed at birth (29.1 per cent), and 119 children were diagnosed after birth (66 per cent). Among those who were diagnosed after birth, age at diagnosis ranged between one month and 15 years of age, with a mean of 1.96 years (SD 2.11).

The type and complexity of diagnosis was individual to each child. The most common diagnoses are given in Table 5.3. In addition, the sample included children with a range of rare conditions which each occurred in only one case, for example Fragile X syndrome, Pierre Robin syndrome, Williams syndrome, Hurlers syndrome. Most children had more than one condition.

Table 5.3 Most common conditions

<i>Diagnosis</i>	<i>Number of children</i>
Autistic spectrum	46
Cerebral palsy	35
Developmental or global delay	32
Epilepsy	31
Visual impairment	20
Down's syndrome	15
Hearing impairment	11
Dyspraxia	10
Muscular dystrophy	5

School

Fifty-four children were in mainstream school (30.7 per cent), 48 children were in special school (27.3 per cent), 33 children were in a special unit in mainstream school (18.8 per cent), 20 children were too young to go to school or nursery (11.4 per cent), seven children were in special needs nursery (4 per cent), six children were in mainstream nursery (3.4 per cent), four children were in residential school (2.3 per cent), two children were home-schooled (1.1 per cent), one child had finished their education (0.6 per cent) and one child was currently not in school (0.6 per cent). One hundred and forty children (80.5 per cent) had a statement of special educational needs.

Types and levels of disability

Families were asked to rate from one (not at all) to three (very much so) whether their child experienced difficulty in a number of fields such as communication, behaviour, learning and mobility. The percentage of children who experienced difficulty in these areas is shown in Table 5.4.

Table 5.4 Types and level of disability

	<i>Not at all</i>	<i>Moderately so</i>	<i>Very much so</i>
Communication	14%	28.1%	57.9%
Behaviour	29.5%	38.7%	31.8%
Learning	13.3%	24.3%	62.4%
Mobility	18.5%	34.7%	46.8%
Health	34.5%	41.4%	24.1%
Vision	58.5%	26.9%	14.6%
Hearing	74.4%	16.3%	9.3%
Continence	37.9%	23.6%	38.5%

Results showed that high levels of difficulty were found in the areas of communication and learning (over 50 per cent). Between 58 and 74 per cent of the children had no difficulty in the areas of hearing and vision. One hundred and forty-six children (91.8 per cent) had multiple difficulties (three or more).

A total score on disability items (disability scale score) was also computed. Responses were scored as one (not at all), two (moderately so) and three (very much so) according to the level of difficulty the child experienced on each item. The overall mean score was 15.98 (SD 3.17, range 10-24, N=159). One-way analysis of variance was run with the seven services as the independent variables and disability scores as the dependent variable. There were no significant differences between services.

5.1.3 Influence of the child's disability on employment

Families were asked whether having a disabled child had affected their employment. The majority of respondents (76.5 per cent) reported that there was an effect on their employment. Across services, the proportion who responded that disability had an effect ranged between 62.1 per cent and 87.5 per cent. There was no significant difference between services.

Families were also asked whether having a disabled child had affected their partner's employment. Here, the majority of respondents (63 per cent) reported that there was no effect on their partner's employment. Across services, the proportion of families who responded that disability had not affected their partner's employment ranged between 45.5 per cent and 74.1 per cent. There was no significant difference between sites.

5.1.4 Families' contacts with key workers

Number and duration of home visits to families

In a period of three months, the mean number of times families were visited by key workers was 2.84 (SD 3.69, range 0-24, N=168). Mean number of visits per site ranged from 4.44 (SD 3.84) to 1.35 (SD 1.66). The differences among services in the number of visits were not significant.

The mean duration of home visits was 1.04 hours (SD .71, range 0-5, N=151). Services varied in the mean duration of their home visits from 1.26 hours (SD 1.04) to 0.59 hours (SD .41). The differences among services were not significant.

Respondents were asked if they wanted to see their key workers more often, the same or less often: 29.2 per cent of families wanted to see their key worker more often, 68.5 per cent wanted to see them the same, and 2.4 per cent wanted to see them less often. The percentage of respondents who wanted more contact ranged across services between 9.4 per cent and 50 per cent. Although the one-way analysis of variance showed a significant overall difference among services ($F=3.625$, $df=6,161$, $p<.01$), post-hoc tests failed to show any significant differences between individual services.

Telephone contact with families

Families were asked how often they had spoken to their key worker on the telephone in the last three months. The mean number of telephone calls over three months was 4.42 (SD 7.18, range 0-60, N=161). Mean number of calls per service ranged from 6.71 (SD 4.46) to 2.12 (SD 1.87). The differences between services were not significant.

The mean duration of telephone calls was 10.36 minutes (SD 8.27, range 0-60, N=141). Mean duration per service ranged from 12.15 minutes (SD 6.31) to seven minutes (SD 5.22). The differences between services were not significant.

Respondents were asked if they wanted to talk to their key workers more often, the same or less often: 28.3 per cent of families wanted to talk to their key workers more often, 69.9 per cent wanted to talk to them the same, and 1.8 per cent wanted to talk to their key workers less often. The number of respondents who wanted more telephone contact across services ranged from 13.3 per cent to 50 per cent. Although the one-way analysis of variance showed a significant overall difference among services ($F=2.136$, $df=6,159$, $p<.05$), post-hoc tests failed to show any significant differences between individual services.

Pattern of contact between key workers and families

Families were asked whether the key worker generally contacted them or vice versa: 61.2 per cent reported that the key worker generally contacted them, 38.8 per cent reported that they generally contacted the key worker. The percentage of families reporting that the key worker normally contacted them varied across services from 86.4 per cent to 29.4 per cent. One way analysis of variance showed significant differences among services ($F=4.052$, $df=6,163$, $p<.001$) and post-hoc tests showed that in Service A the key worker was more likely to contact the family than in Service G (mean difference -0.5695, SE 0.150, $p<.05$). Furthermore, in Service C the key worker was more likely to contact the family than in Service G (mean difference -0.5392, SE 0.147, $p<.05$).

5.1.5 Key worker service context variables

As explained in Chapter Two, the seven services were coded according to eight service variables which emerged from the staff interviews. This coding was then applied to the parent questionnaire data according to the service providing the key worker for that family, and in the case of designated or non-designated key workers, the status of their particular key worker. Table 5.5 shows the percentage and number of families with key workers who have each of the service context variables.

Table 5.5 Descriptive statistics for service context variables

<i>Variable</i>	Yes		No	
	%	N	%	N
Training, supervision, peer support	47.4%	90	52.6%	100
Funding	85.3%	162	14.7%	28
Dedicated service manager	56.8%	108	43.2%	82
Parent representation	54.2%	103	45.8%	87

In 56.8 per cent (N=108) of families, key workers had a clear job description, 28.4 per cent (N=54) had a partial job description, and 14.7 per cent (N=28) had no job description. 39.2% (N=73) of families had a designated key worker and 60.8% (N=113) of families had a non-designated key worker.

5.1.6 Aspects of key working

Families were asked to rate how much the service provided them with ten different aspects of key working, on a scale from one (not at all) to three (very much). The mean score was 22.43 (SD 6.30, range 10-30, N=163; 95 per cent confidence interval for the mean 21.46 to 23.41). Mean scores among services ranged between 26.87 (SD 4.28) and 20.30 (SD 6.22). One-way analysis of variance showed a significant difference between services ($F=6.775$, $df=6,156$, $p<.0001$). Post-hoc tests showed that, Service A had significantly higher scores than Service B (mean difference 6.57, SE 1.57, $p<.01$), Service E (mean difference 4.80, SE 1.33, $p<.05$), and Service G (mean difference 9.67, SE 1.81, $p<.0001$). Service C showed significantly higher scores than Service G (mean difference 7.95, SE 1.95, $p<.01$).

Table 5.6 shows mean scores on each item of the scale. These means indicate that the aspects of the role that key workers performed the most were giving information about services, speaking on behalf of the families, giving advice and coordinating care. The aspects the key workers performed least were giving emotional support and information about the child's condition.

Table 5.6 Mean scores on aspects of key working items

<i>Item</i>	<i>M (SD)</i>
Information about services	2.41 (.65)
Speaking on behalf of the family when dealing with services	2.38 (.76)
Advice	2.38 (.65)
Coordinating care	2.32 (.78)
Improving access to services	2.28 (.74)
Help/support in a crisis	2.23 (.80)
Identifying the needs of all family members	2.19 (.79)
Addressing the needs of all family members	2.15 (.79)
Emotional support	2.11 (.76)
Information about your child's condition	1.97 (.77)

5.1.7 Relationships among service context variables and aspects of key working

Spearman's correlations were run among all among service context variables and aspects of key working (Table 5.7).

Table 5.7 Correlations among service context variables and aspects of key working

	<i>Training etc</i>	<i>Dedicated service manager</i>	<i>Parent rep.</i>	<i>Type KW</i>	<i>Aspects</i>	<i>Funding</i>
Job des.	.748**** n=190	.905**** n=190	Ns	.645**** n=186	.287**** n=163	.805**** n=190
Funding	.394**** n=194	.477**** n=190	-.382**** n=190	.338**** n=186	.271**** n=163	/
Aspects	.266*** N=163	.231** N=163	Ns	.166* n=159	/	
Type KW	.867**** n=186	.714**** n=186	Ns	/		
Parent rep.	.174* n=190	.351**** n=190	/			
Dedicated service manager	.827**** n=190	/				

****p<.0001; ***p<.001; **p<.01; *p<.05

Apart from parent representation on the steering group, most of the service context variables were highly related to each other. Parent representation was the exception, and it was unrelated to job description, aspects of key working and the type of key worker. Except for parent representation, the variable 'aspects of key working' showed moderate to strong relationships with the service context variables, indicating that key workers with training, supervision, peer support and the other service context variables, were more likely to carry out the various aspects of the key worker's role. Designated key workers were also likely to carry out more aspects of the key worker role.

5.1.8 Relationship between the service context variables and number and duration of visits and telephone calls

Analysis of variance was run with each of the service model variables as the independent variables and the number and duration of visits and telephone calls as the dependent variables. The relationships that were significant are shown below.

In services with some dedicated funding, key workers visited families for a significantly longer period of time (M 1.11, SD .73, N=128) than in services without (M .65, SD .48, N=23) (F=8.59, df=1,149, p<.01).

In services with some dedicated funding, key workers telephoned families for a significantly longer period of time (M 10.96, SD 8.59, N=118) than in services without (M 7.30, SD 5.62, N=23) (F=3.830, df=1,139, p<.05).

Services with a clear job description had key workers who visited for a longer period of time (M 1.13, SD .76, N=81) than services with no job description (M .65, SD .48, N=23) ($t=2.849$, $df=102$, $p<.01$). The service with a partial job description had key workers who visited for a longer period of time (M 1.08, SD .67, N=47) than services with no job description (M .65, SD .48, N=23) ($t=2.77$, $df=68$, $p<.01$).

These results indicated that in services where dedicated funding was available, contact with families lasted significantly longer, and in services where a job description was available for key workers, their contact with families lasted longer, possibly because the key worker would be more confident about what their role consists of and they would coordinate care in a wider range of areas.

5.1.9 Descriptive statistics for service process

The Measure of Processes of Care (MPOC) measures respondents' perceptions of whether they feel that they receive coordinated, enabling and responsive services (see Chapter 2). Whilst it clearly includes and is influenced by the key worker service, it is a more general measure of the pattern of services received than the measure of aspects of key working.

Families rated from one (never) to four (always) the quality of care they had received over the past six months, from the range of professionals working with their child. The mean MPOC score was 2.99 (SD .74, range 1-4, N=173; 95 per cent confidence interval 2.88 to 3.10). Services ranged in MPOC scores between 3.22 (SD .73) and 2.56 (SD .73). Differences between services were not significant.

Respondents were also asked whether having a key worker positively affected the way they were treated by services. Over half (53 per cent) felt that the key worker had a positive effect on other services often or always, 29 per cent felt that this happened sometimes, with 18 per cent responding that this was never the case.

5.1.10 Descriptive statistics for outcome variables

Descriptive statistics were calculated for the four outcome variables (QOL, Satisfaction with the service, Parent Unmet Need, and Child Unmet Need).

Descriptive statistics for parent unmet needs

The number of unmet needs per family was summed in order to obtain a total score of unmet need. Mean number of parent unmet needs was 6.47 (SD 4.85, range 0-20, N=129; 95 per cent confidence 5.63 to 7.32). Unmet needs ranged among services between 4.47 (SD 4.92) and 8.50 (SD 4.84). Differences between services were not significant. Table 5.8 shows the pattern of unmet need across the whole sample. The highest levels of unmet need (53 per cent) were for help in planning for

the child's future, followed by help with the child in school holidays (49 per cent). Conversely, over half the parents felt that they were getting enough help in having someone to show them what services were available and in having someone to talk to about their child, and almost half were getting enough help in information provision, and in planning the child's schooling. These are central aspects of the role of key workers and while it is positive to see that many parents felt that they were supported in these aspects, there were still significant numbers of parents who needed help.

Table 5.8 Parent needs

	<i>Unmet need</i>	<i>Getting enough help</i>	<i>Help not needed</i>
Break from caring for child	34.3% (60) ^a	36.6% (64)	29.1% (51)
More time with partner	36.1% (60)	17.5% (29)	46.4% (77)
More time with other children	32.3% (54)	17.4% (29)	50.3% (84)
Managing child's behaviour	28.9% (50)	21.4% (37)	49.7% (86)
Getting child to sleep better	16.4% (28)	22.8% (39)	60.8% (104)
Learning ways of helping child	33.5% (59)	44.9% (79)	21.6% (38)
Someone to talk to about child	22.9% (40)	52.6% (92)	24.6% (43)
Help with housework	22.9% (40)	16.6% (29)	60.6% (106)
Help with day-to-day care of child	20.7% (36)	23.0% (40)	56.3% (98)
Someone to show what services available	33.1% (58)	53.1% (93)	13.7% (24)
Meeting other parents of disabled children	21.4% (37)	33.5% (58)	45.1% (78)
Help planning for child's future	53.4% (93)	33.3% (58)	13.2% (23)
Money to care for child	29.7% (51)	43.6% (75)	26.7% (46)
Help with child in school hols	48.6% (84)	27.2% (47)	24.3% (42)
Care for child so can go to work	24.8% (41)	11.8% (19)	63.6% (105)
Improving child's mobility	19.8% (34)	40.7% (70)	39.5% (68)
Developing child's communication	38.2% (66)	45.1% (78)	16.8% (29)
Improving housing for child	28.0% (49)	20.6% (36)	51.4% (90)
Help with transport	19.7% (34)	30.1% (52)	50.3% (87)
Help getting information	29.9% (52)	48.3% (84)	21.8% (38)
Planning child's schooling	24.0% (42)	49.1% (86)	26.9% (47)
More time to spend with child	26.3% (46)	30.9% (54)	42.9% (75)
Obtaining aids and equipment	22.9% (40)	44.0% (77)	33.1% (58)

^a () = n

Descriptive statistics for child unmet needs

The number of unmet child needs was summed to comprise a total score of unmet child needs. Mean number of child unmet needs was four (SD 3.12, range 0-10, N=139; 95 per cent confidence interval 3.48 to 4.52). Child unmet needs ranged

among services between 2.43 (SD 2.73) and 5.08 (SD 2.31). Differences between services were not significant. Table 5.9 shows the pattern of child unmet need across the whole sample. In general, the figures for child unmet need were higher than those for parent unmet need, suggesting that the key worker services may have a stronger focus on parent needs. Over half the sample reported unmet needs for help in developing independence skills, communication, learning abilities and social skills. These are aspects of development in which key workers can play a part by facilitating access to relevant services and interventions but, unlike for example information provision, they are less likely to be services which key workers can themselves directly provide.

Table 5.9 Child needs

	<i>Unmet need</i>	<i>Getting enough help</i>	<i>Help not needed</i>
Learn independence skills	51.6% (98) ^a	32.6% (56)	10.5% (18)
Someone to talk to about being disabled	22.2% (35)	20.3% (32)	57.6% (91)
Moving about independently	31.3% (52)	29.5% (49)	39.2% (65)
Help with communication	53.5% (92)	32.6% (56)	14.0% (24)
Help developing physical abilities	47.9% (79)	30.9% (51)	21.2% (35)
Help developing learning abilities	50.9% (87)	42.1% (72)	7.0% (12)
Treatments to improve condition	36.8 % (60)	36.2% (59)	27.0% (44)
Meeting non-disabled children	21.1% (35)	40.4% (67)	38.6% (64)
Meeting disabled children	20.6% (34)	38.8% (64)	40.6% (67)
Help with behaviour problems	38.8% (66)	15.9% (27)	45.3% (77)
Help with social/relationship skills	50.6% (84)	22.9% (38)	26.5% (44)

^a () = n

Descriptive statistics for satisfaction with key worker service

Parents rated their level of satisfaction with the key worker service. Responses were rated from one (not at all satisfied) to four (very satisfied). The mean score for satisfaction was 3.23 (SD .88, range 1-4, N=187; 95 per cent confidence interval 3.10 to 3.35). Means for services ranged between 3.87 (SD .34) and 2.35 (SD .86). One way analysis of variance was significant ($F=8.64$, $df=6,180$, $p<.0001$) and post-hoc tests showed that families in Service A had higher satisfaction with the service than families in Services E (mean difference 0.85, SE 0.18, $p<.001$) and G (mean difference 1.52, SE 0.24, $p<.0001$). Families in Service C had higher satisfaction with the service than families in Service G (mean difference 1.26, SE 0.25, $p<.0001$). Table 5.10 shows the pattern of satisfaction across the whole sample, indicating that the vast majority of respondents (84 per cent) were satisfied with the service.

Table 5.10 Satisfaction with the key worker service

<i>Very satisfied</i>	<i>Satisfied</i>	<i>Not satisfied</i>	<i>Not at all satisfied</i>
46.0% (86) ^a	38.0% (71)	9.1% (17)	7.0% (13)

^a () = n

Descriptive statistics for impact of key worker on quality of life (QOL)

Families rated from one (negative impact) to three (positive impact) whether their key worker service had an impact on their quality of life. The mean QOL score was 16.61 (SD 2.64, range 7-21, N=173; 95 per cent confidence interval 16.21 to 17.01). Services ranged between 18.62 (SD 2.30) and 14.89 (SD 1.69) on QOL and one-way analysis of variance showed a significant difference among sites ($F=7.62$, $df=6,166$, $p<.0001$). Families in Service A had higher QOL scores than families in Service B (mean difference 2.86, SE 0.62, $p<.001$), Service E (mean difference 2.56, SE 0.55, $p<.01$), Service F (mean difference 3.73, SE 0.91, $p<.01$), and Service G (mean difference 3.75, SE 0.76, $p<.001$). Table 5.11 shows the pattern of impact on quality of life across the whole sample, with the greatest positive impact of key workers being on parents' peace of mind and emotional well-being.

Table 5.11 Impact of key worker on parent's quality of life

<i>Impact on:</i>	<i>Positive impact</i>	<i>Negative impact</i>	<i>No impact</i>
Physical health or well-being	32.2% (58) ^a	1.7% (3)	66.1% (119)
Emotional/mental health	49.4% (89)	4.4% (8)	46.1% (83)
Time for self	25.8% (46)	3.4% (6)	70.8% (126)
Relationships	23.7% (42)	1.7% (3)	74.6% (132)
Financial or material circumstances	44.7% (80)	2.8% (5)	52.5% (94)
Feeling of control over my life	43.3% (78)	2.8% (5)	53.9% (97)
Peace of mind	63.3% (114)	2.2% (4)	34.4% (62)

^a () = n

5.2 Relationships between employment and service variables

As might be expected severity of the child's disability was significantly related to impact of having a disabled child on respondents' employment: respondents with more severely disabled children were more likely to report negative effects on employment ($F=6.44$, $df=1,134$, $p<.05$). However, there was no significant relationship with impact on partners' employment. Chi-square tests were used to explore whether different models of key worker services had any effects on the impact of the child's disability on the employment of the respondent and of the respondent's partner. There were no significant relationships between service variables and effects on respondents' or partners' employment.

5.3 Path analyses of relationships between service and family context, service mechanisms, service process and outcome scores

The rationale behind the analysis of outcome measures is that the identification of factors related to better or worse outcomes of service provision for families can inform the development of key worker services which produce the best outcomes. The four areas of outcome considered are impact of the key worker service on parents' quality of life, satisfaction with the key worker service, level of parent unmet need and level of child unmet need. The first two of these variables are measures closely tied to the key worker service itself. However the latter two measures, focusing on unmet need, reflect the broader pattern of service provision to the family. The extent to which children's and parents' needs are met depends not only on the key worker service but also on the level of resources available in the area. Clearly key workers cannot access a service for families that does not exist in their area. However, one role of better coordination of services is to enable greater and more holistic understanding of need, and easier and more appropriate access to services. Thus it would be expected that the best models of key worker services would have a greater impact on unmet need.

The analyses of outcome measures were carried out as detailed in Chapter 2.

5.3.1 Path analysis of impact on parental quality of life (QoL)

The first stage of the analysis was to identify variables in Table 2.2 (page 25) which had a significant bivariate association with QoL scores. Correlations were run between demographic variables and QoL scores. None of the demographic variables was significantly related to QoL. Next relationships with service context variables were investigated. The correlation between length of time the service had been in operation and QoL was not significant. One-way Analyses of Variance (ANOVA) were run with each categorical service context variable and QoL:

- Parents in services which had regular training, supervision and peer support for key workers had higher QoL scores (M 17.31, SD 2.70, N=83) than those in services without (M 15.97, SD 2.43, N=90) ($F=11.90$, $df=1,171$, $p=.0.001$).
- Parents in services with some dedicated funding had higher QoL (M 16.89, SD 2.67, N=149) than those in services without (M 14.87, SD 1.68, N=24) ($F=12.86$, $df=1,171$, $p=0.0001$).
- Parents in services with a dedicated service manager had higher QoL (M 17.33, SD 2.68, N=98) than those in services without (M 15.68, SD 2.30, N=75) ($F=18.10$, $df=1,171$, $p=0.0001$).
- Parents in services with parental involvement in the steering committee (M 17.18, SD 2.75, N=93) had higher QoL than those in services without (M 15.95, SD 2.36, N=80) ($F=9.82$, $df=1,171$, $p=0.002$).

- Parents with designated key workers had higher QoL (M 17.06, SD 2.68, N=68) than those with non-designated key workers (M 16.19, SD 2.50, N=102) ($F=4.69$, $df=1,168$, $p=0.032$).

Significant differences were also found for services with and without a clear, written job description ($F=11.02$, $df=2,170$, $p=0.0001$). In this case there were three groups of services: those with a clear written job description, those with a partial job description and those without a job description. T-tests were used to compare the three groups on this variable:

- Parents in services with a clear job description (M 17.33, SD 2.68, N=98) had higher QoL than those in services without (M 14.87, SD 1.68, N=24) ($t=4.277$, $df=120$, $p<0.0001$).
- Services with a clear job description (M 17.33, SD 2.68, N=98) had parents with higher QoL than those with a partial job description (M 16.06, SD 2.47, N=51) ($t=2.81$, $df=147$, $p<0.01$).
- Services with a partial job description (M 16.06 SD 2.47, N=51) had parents with higher QoL than services without (M 14.87, SD 1.68, N=24) ($t=2.126$, $df=73$, $p<0.05$). As the greatest differences were between those with a clear job description and others, this variable was recoded into two categories for entry into the path analysis. The recoded variable showed 100 per cent overlap with having a dedicated service manager.

Relationships between Block 2 variables, that is, service mechanisms, and QoL were then investigated. QoL scores were significantly correlated with number of key worker visits ($r=0.23$, $p<0.01$), duration of visits ($r=0.28$, $p<0.001$), duration of telephone calls ($r=0.33$, $p<0.0001$), and aspects of key working scores ($r=0.68$, $p<0.0001$). Parents whose key workers were usually proactive in making contact were likely to have higher QoL scores (M 17.26, SD 2.39, N=99) than those whose key workers usually left it up to them to make contact (M 15.03, SD 2.22, N=60) ($F=34.33$, $df=1,157$, $P<0.0001$), and parents who did not want more frequent visits from the key worker were likely to have higher QoL scores (M 16.99, SD 2.47, N=109) than those who did (M 15.04, SD 2.22, N=47) ($F=21.64$, $df=1,154$, $p<0.0001$). Finally, QoL scores were also significantly correlated with the Block 3 variable, MPOC scores ($r=0.37$, $p<0.0001$). Table 5.12 summarises these results, listing the variables selected for inclusion in a multiple regression analysis on QoL scores, as the first step in the path analysis.

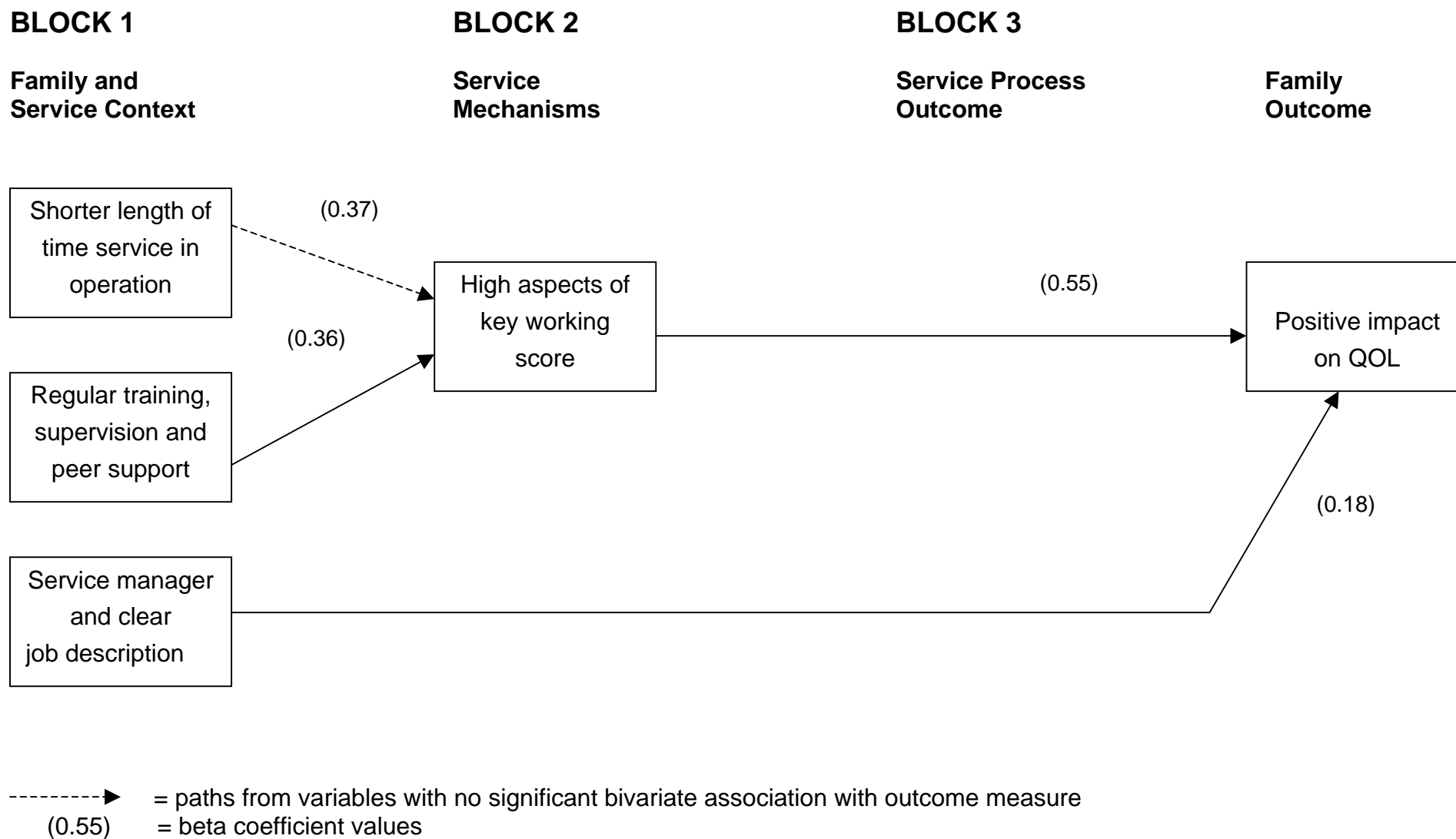
Table 5.12 Predictors of QoL scores: bivariate analyses

<i>Block 1</i>	<i>Block 2</i>	<i>Block 3</i>
<i>Service context</i>	Aspects of key working****	Measure of Processes of Care****
Dedicated funding****	Number of key worker visits**	
Regular training, supervision, peer support***	Duration of visits***	
Service manager and clear job description****	Duration of telephone calls****	
Parental involvement in steering group**	Appropriate number of contacts****	
Type of key worker*	Proactive contact****	

****p<0.0001; ***p<0.001; **p<0.01; *p<0.05

Figure 5.2 shows the results of the path analysis for impact on parental quality of life. The regression explained 47 per cent of the variance in scores (Adj $R^2=0.47$, $F=34.22$, $p<0.0001$), with two variables acting directly on the outcome measure. These were aspects of key working scores, and having a dedicated service manager and clear job description for key workers. Another two service variables acted as prior variables predicting aspects of key working – having regular key worker training, supervision and peer support, and the service having been in operation for a shorter length of time. This latter variable was not directly related to QoL, but was related to aspects of key working.

Figure 5.2 Path Analysis of Impact on Parental Quality of Life (QOL)



To interpret this result, the most positive impact on parental quality of life was achieved when key workers carried out all the different aspects of the key worker role with families and when they had a clear job description and a dedicated service manager who supported them. They were more likely to carry out all the aspects of the role when they had regular training, supervision and peer support and this facet of the service impacted on parental QoL through leading them to do so. 'Younger' services were more likely to have key workers who carried out more aspects of the key worker. This may be related to the fact that research defining the elements of the key worker role is relatively recent and younger services have drawn on this in defining the role. However, as noted in Chapter 4, one of the long standing services was experiencing considerable difficulties when we visited and there was doubt about whether workers in this service were still key working in any real sense with families. Nevertheless, the other longstanding service was not experiencing problems so time in operation per se does not seem to be the main influence on this finding.

5.3.2 Path analysis of satisfaction with key worker service

The analysis followed the pattern described above. Of the demographic variables, only child age was significantly related to satisfaction, with parents of older children being somewhat more likely to be dissatisfied ($r=-0.168$, $p<0.05$). Service context variables showed a number of significant associations:

- 'Younger' services were likely to have more satisfied parents ($r=-0.18$, $p<0.05$).
- Parents in services with regular key worker training, supervision and peer support (M 3.54, SD .72, N=88) had higher satisfaction than those in services without (M 2.95, SD .92, N=99) ($F=23.81$, $df=1,185$, $p=0.0001$).
- Parents in services with some dedicated funding had higher satisfaction (M 3.32, SD .84, N=159) than those in services without (M 2.71, SD .94, N=28) ($F=11.88$, $df=1,185$, $p=0.001$).
- Parents in services with a dedicated service manager had higher satisfaction (M 3.47, SD .73, N=106) than those in services without (M 2.91, SD .96, N=81) ($F=20.23$, $df=1,185$, $p=0.0001$).
- Parents in services with parental involvement in the steering committee (M 3.36, SD .82, N=103) had higher satisfaction than those without (M 3.07, SD .93, N=84) ($F=5.02$, $df=1,185$, $p=0.026$).
- Key worker job description was significantly related to satisfaction ($F=11.40$, $df=1,184$, $p=0.0001$). Parents in services with a clear job description (M 3.47, SD .73, N=106) had higher satisfaction than those in services without (M 2.71, SD .94, N=28) ($t=4.57$, $df=132$, $p<0.0001$). Services with a clear job description (M 3.47, SD .73, N=106) had parents with higher satisfaction than those with a partial job description (M 3.02, SD .97, N=53) ($t=3.28$, $df=157$, $p<0.001$). Again the greatest difference was between those with a clear job description and the other categories, so the variable was recoded as for QoL.

- Parents with designated key workers had higher satisfaction (M 3.48, SD .77, N=71) than those with non-designated key workers (M 3.05, SD .92, N=112) ($F=10.51$, $df=1,181$, $p=0.001$).

Satisfaction scores were significantly correlated with a number of Block 2 variables: number of key worker visits ($r=0.22$, $p<0.001$); duration of key worker visits ($r=0.33$, $p<0.0001$); number of key worker telephone calls ($r=0.28$, $p<0.0001$); duration of key worker telephone calls ($r=0.40$, $p<0.0001$); and aspects of key working ($r=0.79$, $p<0.0001$). Parents whose key workers were usually proactive in making contact were likely to have higher satisfaction scores (M 3.51, SD 0.64, N=104) than those whose key workers usually left it up to them to make contact (M 2.72, SD 0.97, N=64) ($F=40.76$, $df=1,166$, $P<0.0001$), and parents who did not want more frequent visits from the key worker were likely to have higher satisfaction scores (M 3.52, SD 0.62, N=117) than those who did (M 2.44, SD 0.94, N=49) ($F=39.72$, $df=1,164$, $p<0.0001$). Finally satisfaction scores were significantly correlated with MPOC scores ($r=0.54$, $p<0.0001$). Table 5.13 summarises these results, listing the variables selected for inclusion in a multiple regression analysis on satisfaction scores, as the first step in the path analysis.

Table 5.13 Predictors of satisfaction scores: bivariate analyses

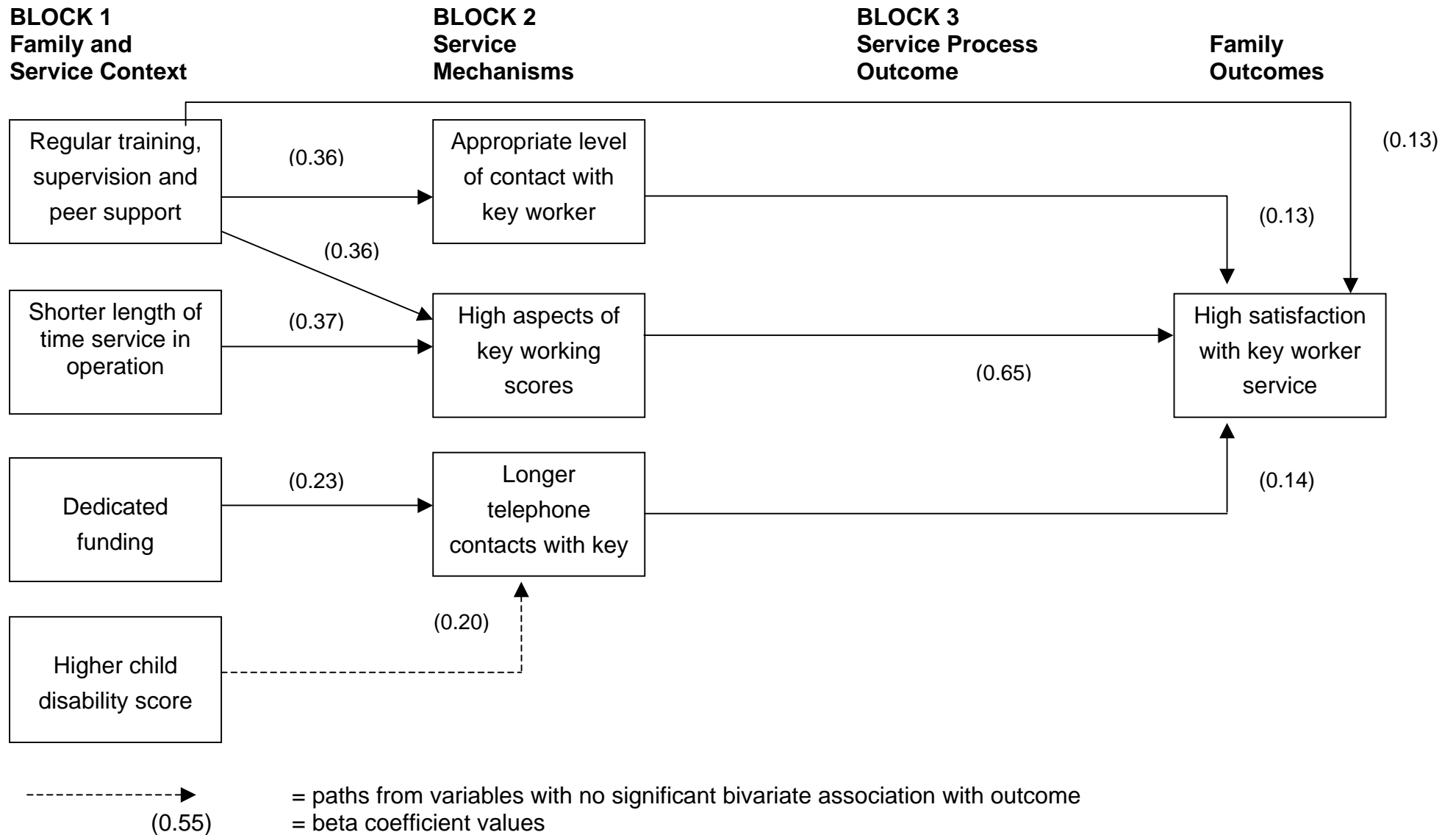
<i>Block 1</i>	<i>Block 2</i>	<i>Block 3</i>
<i>Family context</i>	Aspects of key working****	Measure of
Age of child*	Number of key worker visits***	Processes of
		Care****
<i>Service context</i>	Duration of visits****	
Length of time service in operation*	Number of key worker telephone calls****	
Dedicated funding***	Duration of telephone calls****	
Regular training, supervision, peer support***	Appropriate number of contacts****	
Service manager and clear job description****	Proactive contact****	
Parental involvement in steering group*		
Type of key worker***		

**** $p<0.0001$; *** $p<0.001$; ** $p<0.01$; * $p<0.05$

Figure 5.3 shows the results of the path analysis for satisfaction with the key worker service. The regression explained 70 per cent of the variance in scores (Adj $R^2=0.70$, $F=37.57$, $p<0.0001$), with four variables acting directly on the outcome measure. These were aspects of key working scores, greater duration of telephone contacts with key worker, appropriate amount of contact with key worker and the service providing regular training, supervision and peer support for key workers.

Another two service variables acted as prior variables predicting aspects of key working and duration of telephone contact –the service having been in operation for shorter length of time predicted the former and having some dedicated funding predicted the latter. Higher levels of child disability were also associated with duration of telephone contact. However this variable was not significantly associated with the outcome variable in bivariate analysis, indicating that the level of the child's disability is only relevant to satisfaction if it is associated with the amount of contact with the key worker. Finally, training supervision and peer support also showed two other paths to outcome through effects on aspects of key working and appropriateness amounts of contact. The total value of paths from training, supervision and peer support was $(0.36 \times 0.13) + (0.36 \times 0.65) + 0.13 = 0.41$, indicating that after aspects of key working, training, supervision and support is next strongest predictor.

Figure 5.3 Path Analysis of Satisfaction with Key Worker Service



The results suggest that positive effects on parental satisfaction were achieved through key workers carrying out all the different aspects of key working with families, having more contact with families (if only by telephone) and amounts of contact that were deemed by families to be appropriate to their needs, and key workers themselves having regular training, supervision and peer support. Key workers were more likely to carry out the key worker role if they had regular training, supervision and support and if the service was 'younger'. They were also more likely to make appropriate numbers of contacts if they had regular training, supervision and support. Where the service had dedicated funding, key workers were likely to have longer telephone contacts with families and satisfaction was likely to be higher.

5.3.3 Path analysis of parental unmet need

In the initial bivariate analyses, child age was significantly related to parental unmet need ($r=0.23$, $p<0.01$), the older the child, the more unmet needs parents were likely to have. Higher disability scores also showed a significant, though weak, correlation with unmet need ($r=0.18$, $p<0.05$). As with other outcome variables, service context variables showed a number of significant relationships with unmet need:

- Parents in services with regular key worker training, supervision and peer support had fewer unmet needs (M 5.47, SD 4.42, N=61) than those in services without (M 7.37, SD 5.07, N=68) ($F=5.05$, $df=1,127$, $p=0.026$).
- Parents in services with some dedicated funding had fewer unmet needs (M 6.05, SD 4.59, N=104) than those in services without (M 8.24, SD 5.57, N=25) ($F=4.22$, $df=1,127$, $p=0.042$).
- Parents in services with a dedicated service manager had fewer unmet needs (M 5.64, SD 4.24, N=70) than those in services without (M 7.47, SD 5.36, N=59) ($F=4.61$, $df=1,127$, $p=0.034$).
- Parents in services with a clear job description (M 5.64, SD 4.24, N=70) had fewer unmet needs than services without (M 8.24, SD 5.57, N=25) ($t=-2.413$, $df=93$, $p<0.05$).
- Parents with designated key workers had fewer unmet needs (M 5.42, SD 4.38, N=50) than those with non-designated key workers (M 7.14, SD 5.04, N=79) ($F=3.93$, $df=1,127$, $p=0.049$).

Parent unmet need scores were not significantly related to any of the variables measuring frequency and duration of contacts with the key worker, but carrying out fewer aspects of key working was related to higher levels of unmet need ($r=-0.21$, $p<0.05$) and parents who wanted more frequent visits from the key worker were likely to have higher levels of unmet need (M 8.75, SD 4.61, N=36) than those who felt they had an appropriate amount of contact with their key worker (M 5.53, SD 4.78, N=86) ($F=11.74$, $df=1,120$, $p<0.001$). Higher unmet need was also related to lower MPOC scores ($r=-0.39$, $p<0.0001$). Table 5.14 summarises these results, listing the variables selected

for inclusion in a multiple regression analysis on parent unmet need scores, as the first step in the path analysis.

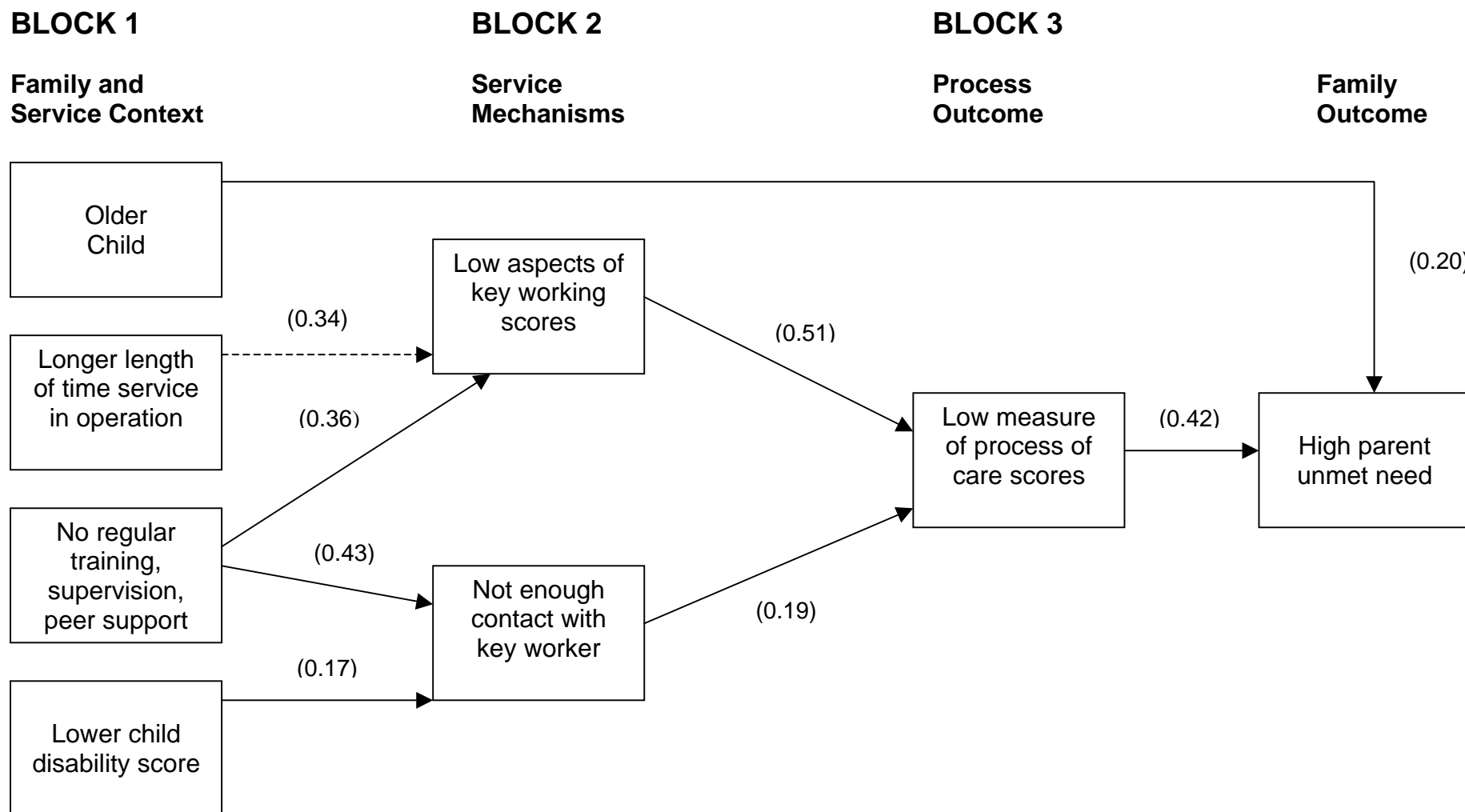
Table 5.14 Predictors of parent unmet need scores: bivariate analyses

<i>Block 1</i>	<i>Block 2</i>	<i>Block 3</i>
<i>Family context</i>		
Level of child disability**	Aspects of key working*	Measure of Processes of Care****
Age of child*	Appropriate number of contacts****	
<i>Service context</i>		
Dedicated funding*		
Regular training, supervision, peer support*		
Service manager and clear job description*		
Type of key worker*		

****p<0.0001; ***p<0.001; **p<0.01; *p<0.05

Figure 5.4 shows the results of the path analysis for parent unmet need scores. The regression explained 28 per cent of the variance (Adj $R^2=0.279$, $F=7.78$, $p=<0.0001$). Two variables, MPOC scores and age of child acted directly on the outcome measure. MPOC was itself predicted by aspects of key working and appropriateness of level of contact with the key worker. In turn, both these variables were predicted by key worker training, supervision and support. Length of time the service had been in operation also predicted aspects of key working and level of child disability predicted appropriateness of contact with the key worker.

Figure 5.4 Path Analysis of Parent Unmet Need Scores



-----> = path from variables with no significant bivariate association with outcome measure
(0.55) = beta coefficient values

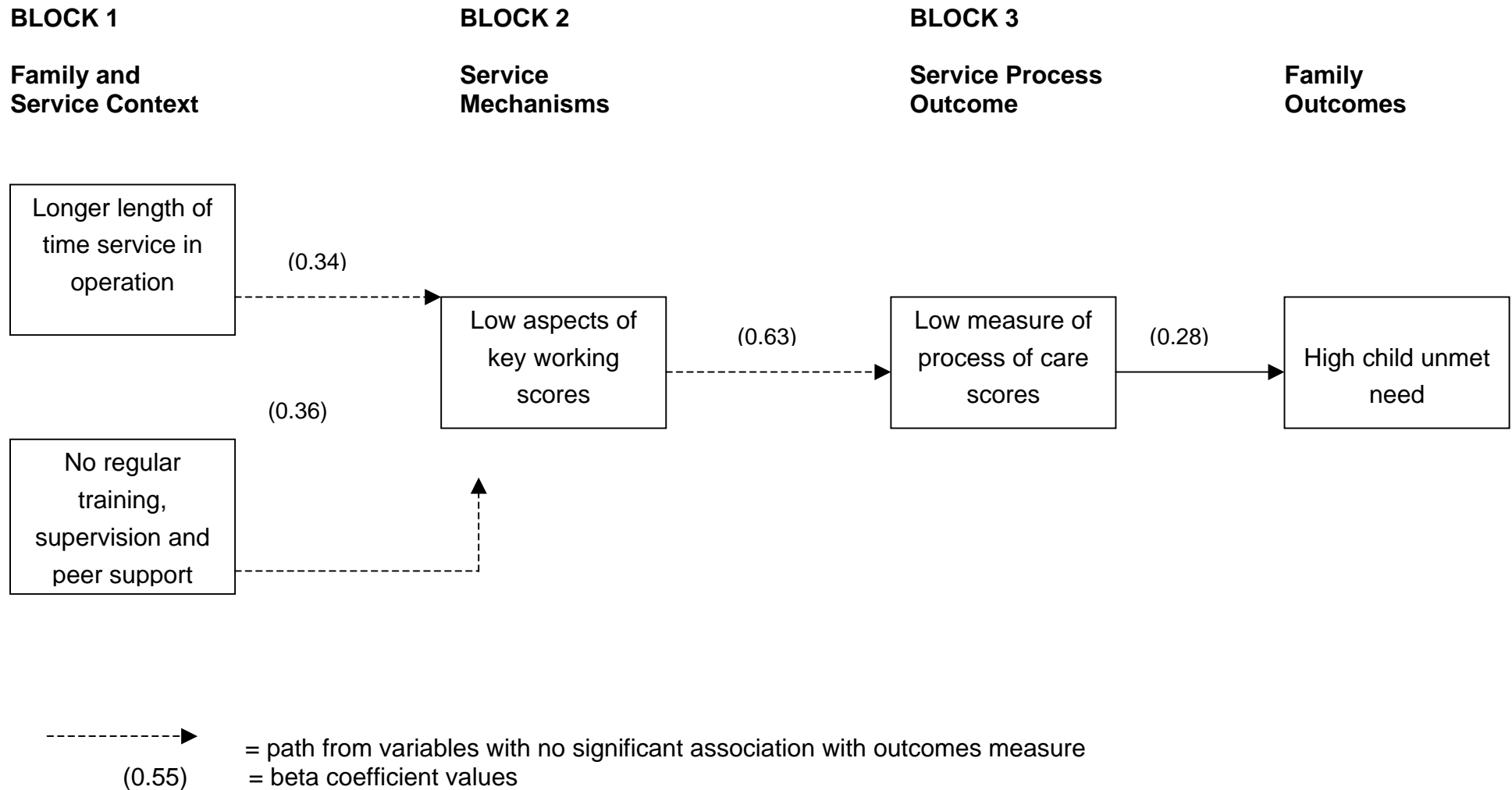
The results suggest that the strongest influence on reducing parent unmet need was through services in general providing information, a respectful, enabling, comprehensive and coordinated service, and working in partnership with parents. When the key worker carried out more aspects of the key worker role, this influenced parents' overall relationships with services (as reflected in MPOC scores), and appropriate levels of contact with key workers had a similar, although weaker, effect. Both these factors influenced unmet need. Key workers were more likely to carry out the key worker role if they had regular training, supervision and support and if the service was 'younger'. They were also more likely to make appropriate numbers of contacts if they had regular training, supervision and support and if the child had a higher level of disability. Finally, independently of all these factors, parents of older children were likely to have higher levels of unmet need.

5.3.4 Path analysis of child unmet need

Bivariate analyses showed that only a small number of variables were significantly related to child unmet need scores. The relationship between child age and unmet need was significant ($r=0.21$, $p<0.05$), the older the children the more unmet needs they were likely to have. Service context variables showed no significant associations. For service mechanism variables, children whose parents wanted more frequent visits from the key worker were likely to have higher levels of unmet need ($M\ 5.18$, $SD\ 2.97$, $N=39$) than those whose parents felt they had an appropriate amount of contact with their key worker ($M\ 3.56$, $SD\ 3.12$, $N=93$) ($F= 7.63$, $df=1,130$, $p<0.01$). MPOC scores were also significantly related to child unmet need ($r=-0.27$, $p<0.01$). These three variables were then entered into a multiple regression analysis as the first stage of the path analysis.

Figure 5.5 shows the results of the path analysis for child unmet need scores. The regression explained only six per cent of the variance ($Adj\ R^2=0.062$, $F=3.97$, $p=0.009$). Only one variable, MPOC scores, acted directly on the outcome measure. MPOC was predicted by aspects of key working, which in turn was predicted by training, supervision and support and length of time a service had been in operation. The latter three variables had no significant bivariate association with the outcome variable, indicating that these factors were only relevant to child unmet need when they were associated with general processes of care.

Figure 5.5 Path Analysis of Child Unmet Need Scores



This result suggests that when services in general provided information to families and worked in a coordinated, respectful and enabling way, in partnership with families, levels of disabled children's unmet needs were reduced to some extent. The ways in which key workers worked with families, influenced by the training and support they received, could positively affect such service provision. However, all these influences had only weak effects on meeting children's needs and other factors, such as the general level of resources for children, children's access to play and leisure facilities and their relationships with friends and peers, may be stronger influences on disabled children's unmet needs.

5.4 Descriptive statistics for the children's questionnaire

Thirty children completed the children's questionnaire. Scores ranged between one and 20. The mean score was 16.53 (SD 4.27), in the direction of higher quality of services. Responses per item are shown in Table 5.15. Apart from items seven and ten, all items were prefaced with 'my key worker'.

Table 5.15 Items on the children's questionnaire

<i>Item</i>	Yes		No	
	%	N	%	N
1. Makes my life easier	75.9	22	24.1	7
2. Helps me to become more independent and do things for myself	66.7	18	33.3	9
3. Understands about my illness or disability	86.2	25	13.8	4
4. Knows how to help and look after me	71.4	20	28.6	8
5. Asks me for my ideas and listens to what I have to say	72.4	21	27.6	8
6. Knows what I need	69	20	31	9
7. When I need something, I know my key worker will do everything to try to meet that need	82.8	24	17.2	5
8. Respects my religion or my family's custom	85.2	23	14.8	4
9. Gives me advice and information	72.4	21	27.6	8
10. I ask my key worker questions and she/he explains it to me	70.4	19	29.6	8

Approximately 70 per cent and above of children responded positively on the items concerning their key workers. Given the small numbers of respondents, no further analysis of these responses was carried out.

5.5 Summary

The results of the family survey showed a range of scores on outcome and service mechanism variables, with considerable variability in amount of contact with key workers, the ways in which key workers carried out their role and impacts on families. Mean scores for each service showed considerable variability, but there were few significant differences between individual services. This result should be viewed with caution, as low numbers of respondents per service meant that the analysis of differences between sites was not sufficiently powered and thus would be subject to Type II error. However, the purpose of the study was not to look for differences between individual services but to investigate which characteristics of service models were related to better outcomes for families. In this context, the exploration of results for individual services was simply a step to further analyses. The results of the path analyses provided more information on the important aspects of service models.

There was considerable consistency between the analyses for the four outcome variables, indicating that the extent to which key workers carry out different aspects of key working; the provision of regular key worker training, supervision focused on the key worker role, and peer support between key workers; and having a dedicated service manager and a clear job description for key workers are all central to the impact of the services on families. There was also an indication that key workers in 'younger' services were likely to carry out more aspects of key working and thus produce better outcomes for families.

The analyses explained more of the variance for outcomes measuring direct impact of key workers (satisfaction with key worker and impact of key worker on parental quality of life) than for the more general measures of parent and child unmet need. This indicates that other factors outside the key worker services are affecting whether families' needs are met. These results will be discussed further in Chapter 9.

The results of the children's survey suggest that key workers were viewed positively by the majority of children, but only 30 children completed the questionnaire so further analysis was not possible and these results should be viewed with caution.

Chapter 6: Unit Costs, Support Costs, Needs and Outcomes

6.1 Introduction

Two sets of tasks were set out in the proposal for this evaluation of key worker services. First, to use data from the CCNUK national survey to estimate the costs of providing key worker services for disabled children and their families. Second, to use data from the seven key worker services studied in depth to explore these costs further by looking at the cost implications of how children and their families use these services and any associations between costs and needs or use of other services. Thus, the project incorporates two linked approaches to cost estimation. First a *service-level* view which provides data helpful to planners who may want to develop this service or who want to know more about existing services. Second, we take a *user-level* view. This approach allows service managers to look at how the resources within a team are used. Managers may want, for example, to know the extent to which the service's front-line workers 'allocate' their time (a scarce resource) in response to the needs of the children and families served (do disabled children with higher needs get more of the service?) or whether higher costs (perhaps generated by provision of a more intensive service or from staff with higher qualifications) generate greater satisfaction for children and families.

6.2 Overarching methodology

The cost estimation approach underlying both of these sets of tasks takes the basic principles inherent in economics and applies them to the specific field of social care services (see for example, Beecham, 2001). Our interest is in obtaining the best approximation of the *long-run marginal opportunity cost* of the services. Key worker services have long been advocated in both policy and practice documents (Greco and Sloper, 2004) so we need to estimate the costs of expanding the service. Thus, the *short-run marginal costs*, which include only the costs of running the service on a day-to-day basis will underestimate the costs of providing *more* of the service. Our approach is to include these revenue costs as well as the overheads that accrue to the managing agency. Thus the full costs of providing the service are accounted for rather than the costs of squeezing just one or two more children into an existing service.

More details on the cost components are given in subsequent sections of this chapter; here we consider the second major element of cost estimation; that is finding an appropriate *unit of measurement* for the unit cost. Broadly speaking, unit costs can be envisaged in a number of ways. Costs per annum, for example, are a

common feature of social services accounting systems and provide a baseline for further calculations; the *unit* is a year. For many evaluations, however, because our interest is in the service users, our focus should be on estimating a cost that is commensurate with the way in which families and children use the service. Thus, children use residential or foster care as an overnight stay so the cost *per day* or cost *per week* would be common and appropriate currencies. Children may use a whole range of different day care or day activity services (perhaps a day nursery, or holiday club) for a number of mornings or afternoons each week thus the unit cost is sensibly measured as the *cost per session*. Children and families have hospital outpatient appointments, this unit cost is best conceptualised as a *cost per attendance*. Each of these has an inherent compatibility with the way the service is used. In estimating unit costs for peripatetic services, that is where the front-line worker is mobile and commonly provides support for the family in their own home, the situation is slightly more complicated. The notion of a *cost per working hour* is useful; that is, the total (per annum) costs divided by the total number of hours that the staff provide care and support. A peripatetic service may be a single worker or several workers organised into a team (as with these key-working services) so the total number of hours that the staff in that team provide care should reflect all care staff for which costs have been included. The total costs are obviously broader than just salaries. Key workers, for example, need a base (if nothing else they need a place to write case-notes or make telephone calls), some form of transportation, administrative and clerical assistance, supervision, etc.

This cost per working hour can then be 'weighted' for activities undertaken. Perhaps the data on the way children and families use this service are expressed as the number and duration of face-to-face contacts; say four visits over a month each lasting about an hour. We know, however, that key workers have to travel to the family's house to make that face-to-face contact; this has extra time implications, hence extra costs. Similarly, key workers will make telephone calls or write letters on behalf of that family and will update case-notes and may have user-related supervision. Identifying and quantifying the activities linked with or enabling face-to-face contact allows a *cost per contact* to be estimated. This will invariably be higher than the cost per working hour – perhaps more than doubling the amount of time spent actually seeing the family. For example, Carr-Hill *et al.* (1999) found that face-to-face contacts absorbed only 40 per cent of children and family social workers' time. Similarly, by combining the cost per working hour for several professionals and other staff and by identifying their time contributions to, say, a review meeting or an operation in hospital, a *cost per event* can be calculated or a *cost per process* such as finding a placement for a child (see, for example, Ward *et al.*, 2004).

Although the *unit of measurement* may be different for any given unit cost and there may even be a different scope of costs included, its estimation is most easily undertaken by following four simple stages; describe clearly the components of the service (or event, process, etc) for which costs are required, identify the activity and

unit (or units) of measurement, estimate the cost implications for each component, and finally calculate total and unit costs (Beecham, 1995 and 2001). These four stages underpin the activities undertaken to estimate the costs of the key worker teams.

We should also be interested in the variation in costs. We should not expect services – even those with similar titles – to cost the same; producing social care services is not like, say, a production line for cars. The provision of services occurs within different policy, organisational, and practice contexts across England. Moreover, the service is relational, that is, it is provided for people by people. These are not easy elements to standardise so we should expect that key worker teams will have different compositions of staff, different ways of working and the like. It is this variation that makes cost estimation and analysis interesting for it leads us to ask *why* costs vary. Again, in this research we try to address this question at both the service-level and the user-level using simple descriptive statistics as well as multivariate analysis.

6.3 Service-level costs: the costs of providing key worker services

6.3.1 Methodology

One aim of this research was to explore the extent to which data collected from a national postal survey would allow us to comment from a wider perspective on the way resources are used to co-ordinate care for disabled children. For this reason, broad cost-related questions based on previous cost estimation research, were included in the national Care Coordination UK survey (see Chapter 3).

Although integrated into the survey questionnaire, the cost-related questions contained an implicit hierarchy of the information required to estimate costs. Of course, ideally, we would like full and detailed information on the service's income and expenditure over the past year but to improve response rates we asked for broader information on annual expenditure for a set of standardised cost categories likely to fit with accounting practices (QA18, see Appendix 1). These categories were: care staff salaries and on-costs, manager salaries and on-costs, clerical/domestic salaries and on-costs, service costs (such as staff or user travel, office expenses), building costs (for example, power, maintenance), rent or capital charges, overhead costs or charges to the managing agency, charges made to the scheme for services, and other costs. Alongside these expenditure data, information on the service outputs was requested allowing us to assess what would be sensible 'units of measurement' and to quantify them. Again, we needed to match ideal requirements (how much time have key workers spent with each of the families using this service) against the likely availability of information. We asked about numbers of

families supported, typical caseloads and proportion of time spent on key-working activities; data that would be easier to access at this service-level.

In case expenditure data were not forthcoming, we also included questions asking about the full staffing profile of the key worker service (QA15 and QC4). Staffing absorbs the major part of the total costs in this type of service (possibly as high as 80 per cent) so our 'default' position was to estimate salary costs from these data and add costs for the other categories from a variety of reliable sources. Thus our 'margin of error' for the total cost calculation would not be too wide. Of course, without the service output information these costs are less useful for we cannot compare the costs of say, a 20-person team with a 3-person team, unless the data on activity levels (families seen, etc) are also reported.

6.3.2 Availability of data

In a large postal survey such as this a complete set of cost-related data for each of the schemes surveyed is, for a variety of reasons, rarely forthcoming. Even in previous studies of services where (arguably) the service boundaries are clearer, such as residential care, day activity services, or children's psychiatric inpatient services, the results suggest that after the main survey a considerable amount of research time is required to chase, persuade and cajole service managers and finance department personnel into providing expenditure data (Beecham *et al.*, 1998; 2003a and b; Chisholm *et al.*, 1997). There were no resources for these activities in this research project but even so, one of the most common issues for this kind of research is that financial data are considered confidential or commercially sensitive and therefore are not made available to researchers.

Greco and Sloper (2004) point to the limitations of a postal survey for generating information, in particular that postal surveys may not generate reliable information nor identify the full sample of teams. Putting these issues aside for the moment and looking within the data collected we can identify some areas in which the service managers found costs-related information difficult to come by.

In our sample of 30 care co-ordination schemes with key workers, all but six were able to provide some information about which agencies contributed to the funding for the service although this was complicated by the fact that some projects received direct financial contributions and in others, contributions were made through seconded or 'donated' staff where there was no financial transfer to show on the balance sheets. Of the 24 schemes providing funding information, only eight were funded from a single source; half social services and half health Trusts. Ten were funded through three agencies, commonly health, education and social services. Two or four contributing agencies were less common (four and two schemes respectively). Voluntary sector organisations contributed resources to only four key-working schemes. This complexity of funding arrangements means that the service

manager may only have access to partial budget information, perhaps only for the agency that manages the service. In fact, budget or expenditure information was provided by ten schemes and in most cases this was partial data – either for a single agency's contribution or an identifiable budget for the scheme's manager and their support where key workers were seconded or donated from other agencies.

Similar problems in reporting data, but perhaps to a lesser degree, haunted the return of data on staffing inputs. While 26 of the schemes could provide information on the team's staffing mix, only 15 could provide information on how much time was spent by these staff on key-working activities. Obviously this was more problematic where key workers were dispersed across several agencies and, a common scenario, where they came from several teams or services within each of those agencies. This spread of workers across agencies and the dispersed line-management arrangements also appeared to make caseloads difficult to assess. Only 22 schemes were able to provide information on the number of families supported and only an approximate figure could be given for five of these schemes.

Of the 30 areas that returned CCNUK questionnaires stating they provided key workers for families, sufficient data in the right combination made service-level cost estimation possible for 14 teams (47 per cent). While this response rate is disappointing in that this is one of the first opportunities to obtain realistic national costs for key-working services, it should be set in the context of the completion rates for the other research surveys cited above. In these surveys, extra data collection through direct contact with the services and related finance departments meant unit costs for 92 per cent of facilities in the residential care survey could be estimated, 79 per cent of respondents in the day activities survey, and 88 per cent for the survey of children psychiatric inpatient services (Chisholm *et al.*, 1997; Beecham *et al.*, 1998; Beecham *et al.*, 2003a and b). In this research, there were only sufficient resources to obtain extra data from the key worker services participating in the second, more detailed phase of the research; and indeed, even this in-depth approach failed for two of the services.

6.3.3 Key worker team costs

For seven teams the estimated average cost per family per year is between £1,300 and £2,000. About half these teams have designated workers (Table 6.1). For a further five services, the average annual costs per family are between £2,300 and £3,000. The penultimate team on Table 6.1 is quite a new team and the data show how changes in the output (here, number of families supported) as the service develops will change the unit cost. Debates about the number of clients a key worker should support have been ranging since the early 1990s (see for example, UK700 Group, 1999 for a brief summary of discussions around caseloads for care management teams working with adults with mental health problems). For the teams returning data for this survey, Table 6.1 shows total caseloads vary between 16 and

60. The schemes led from within the health sector tend to have higher costs per family but with such a small sample we cannot know whether this represents a real difference or is a function of sample bias. The final scheme on Table 6.1 appears very expensive compared to all other schemes but it is likely that this service has a residential component, possibly for respite care, and it has not been possible to identify and disaggregate these joint costs.

The data in Table 6.1 exclude the costs associated with the Steering Groups set up to oversee each team as few teams could provide sufficient data on the grade, job title, or time commitments of the Groups' members. However, the associated costs could be quite high. Six services provided some information. There were between three and 17 members of these Steering Groups, commonly including at least one manager from education, health or social services. For team G, three social services managers, one manager from education, the administrator, and a parent met each month for two hours. The costs of attendance, excluding the costs to the parent, could easily amount to an additional £3000 per scheme per year. Steering Groups with larger memberships tended to meet only three or four times each year.

Table 6.1 The costs of key worker schemes using data taken from the national survey

<i>Location code¹</i>	<i>Lead</i>	<i>Designated Key workers?</i>	<i>Manager w.t.e</i>	<i>Key worker staff w.t.e.</i>	<i>Lead agency /scheme costs p.a.²</i>	<i>Donated staff w.t.e³</i>	<i>Costs for donated key workers p.a.⁴</i>	<i>Total cost of scheme p.a.</i>	<i>No. families currently supported⁵</i>	<i>Average annual cost per family</i>
708	SSD	Yes	1.0 wte	11.5 wte	£413,740			£413,740	300	£1,380
042*	Multi	Yes	0.5 wte	1.7 wte	£97,278	1.0 wte	£46,650	£143,930	92	£1,560
453	Educ	No	1.0 wte	0	£54,000	1.0	£31,220	£86,020	55	£1,565
443	SS	No	0.5 wte	2.5 wte	£96,560			£96,560	60	£1,610
013*	Multi	Yes	1.6 wte	2.9 wte	£273,770			£273,770	160	£1,710
098	Vol	No	0.8 wte		£24,810	0.35 wte	£11,760	£36,570	21	£1,740
508	Vol	Yes	1.0 wte	9.0 wte	£724,790			£724,790	370	£1,960
030*	Vol	Both	1.0 wte	1.0 wte	£48,480	1.0 wte	£30,780	£80,570	35	£2,300
016	Health	No	1.0 wte	0.0 wte	£45,060	0.6 wte	£16,990	£62,050	25	£2,482
660	Educ	No	0.0 wte	0.5 wte	£20,480			£20,480	8	£2,560
006*	Health	No	1.0 wte	0.0 wte	£51,900	1.56 wte	£63,140	£115,040	44	£2,615
080*	Health	No	0.25 wte	0.0 wte	£8,640	4.0 wte	£188,110	£196,750	67	£2,935
090	Vol	Yes	0.6 wte	2.1 wte	£68,300			£68,301	15 rising to max. of 90	£4,550 £760
New team										
528	SS	Also respite?			£892,700			£892,700	83	£10,755

Notes

1. An asterisk indicates that this scheme was also part of the second phase of the research.
2. Includes salaries and on-costs, other revenue costs such as office expenditure, training, travel etc, any management overheads (excluding the Steering Group), and indicative capital costs that accrue to the host organisation, but *exclude* specific costs associated with the scheme's Steering Group.
3. Donated staff refers to people, usually key workers, who are (part-) seconded to the care co-ordination scheme from an organisation that is not the main lead or budget holding organisation. Wte figures are estimated from data provided by the schemes' managers. Staff time commitments are often made in lieu of financial contributions.
4. Costs for donated staff are taken from nationally applicable unit costs data (see for example, Netten and Curtis, 2003) and include the salary on-costs, overheads and the like that will accrue to their home organisation.
5. Most schemes have a waiting list or one is just developing, therefore, the number of families currently supported represented the scheme's capacity at any one time. This number is used to estimate the average annual cost per family in the next column.

6.4 User-level costs: supporting children and families

6.4.1 Methodology

In this section we look at the costs of the key worker service in relation to the way that children and families use this form of support. Rather than estimating an average cost per family per year, we are interested in the different amounts of key worker support families get and the costs associated with that level of contact.

The survey of families in the seven services (see Chapter 2 and 5) included a number of questions relevant to the way they used services over the previous three months. (This retrospective period was chosen as a good compromise between getting a clear picture of the variations in service use across a range of provider organisations and the reduction in accuracy that comes if respondents are asked to cast their minds too far back.) Four questions were central to this part of the work.

- How often have you seen your key worker?
- Typically, how long do these visits last?
- How often have you spoken to your key worker on the telephone?
- Typically how long do these contacts last?

To attach costs to the key worker service use data we have calculated the cost per working hour for each team using the total cost as described above. However, despite the development of good working relationships between the researchers and services' staff and the services' stated willingness to participate in the research, data that would allow cost estimations equivalent to those shown above was not forthcoming for two services and broader estimations were used (see Appendix 6 for details).

The average cost per working hour is estimated as the total cost of the service divided by the total number of hours for which staff members undertook key-working activities. This unit cost is, therefore, weighted for the staff-mix on each service. It is worth noting here that only eleven key workers from three teams could provide information on how they used their time. It is unlikely, for example, that the only activity undertaken by key workers is visiting families. As we know from Chapter 4, key workers have to travel to families' homes, liaise with other services by telephone, letter or by personal contact, they have to write case-notes and reports, and attend meetings. Ideally, we would want to be able not only to identify the amount of time key workers spent in contact with families, but also the time over and above this spent on other client and non-client related activities. This would give a better estimate of the costs of *providing* the service, rather than, as presented below, solely the costs associated with the family *receiving* the service. Table 6.2 summarises the unit cost information used in this part of the report.

Table 6.2 Costs per working hour for each service

Service A. £26.00	Service E. £38.00
Service B. £42.00	Service F. £32.00
Service C. £36.00	Service G. £24.00
Service D. £38.00	

6.4.2 The costs of key-working services

The data shown in Table 6.2 have been multiplied by the frequency and duration with which each family use the service. Thus, not only does the *cost per family* vary depending on which key-working service is being used, but also because the families use the key-working service at different intensities; seeing the key worker more often, for longer visits means relatively higher costs.

Table 6.3 presents some information on the way the key-working services were used and the associated costs. We have repeated some of the data presented in earlier sections of this report because this is useful context information for the costs data. All 190 families on the database report that they have a key worker. Of these, 173 reported the length of time they had a key worker as between 6 and 192 months; on average 6.3 years. Twenty-two people did not report how often they had seen a key worker and a further 38 people reported no contact with their key worker in the previous three months. Twenty-seven people did not report how often they had spoken with their key worker on the telephone in the previous three months, and 25 people had not spoken with their key worker by telephone².

² Reflecting the data conventions adopted in the earlier analysis, where data are given on the typical duration of face-to-face visits but the number of contacts is missing (five people with visits, no-one with telephone contacts) we have assumed one contact in the previous three months. Where data on the number of contacts is present but the duration is missing we have assumed one hour for face-to-face contact (median and modal visit time is 1.0 hour for those seeing the key worker) and ten minutes for the telephone call (median and modal time is ten minutes for those having telephone contacts).

Table 6.3 Use and costs of key worker services in three months prior to survey

<i>Service</i>	<i>No. families reporting visits¹</i>	<i>Mean No. visits (range)</i>	<i>Mean cost for face-to-face contact (range)</i>	<i>No. families reporting tel. calls¹</i>	<i>Mean No. tel. calls (range)</i>	<i>Mean cost for tel. calls (range)</i>	<i>Cost of visits and telephone calls (mean, median, range)²</i>
A.	21	2.9 (0-8)	£101.72 (0-394)	21	6.7 (1-16)	£36.14 (4-105)	£143.32 £124.88 (9-399)
B.	30	2.7 (0-24)	£145.32 (0-1498)	30	5.0 (0-60)	£38.38 (0-416)	£185.02 £90.18 (0-1540)
C.	21	3.6 (0-10)	£144.21 (0-582)	18	5.4 (1-30)	£29.66 (3-182)	£189.41 £141.05 (6-637)
D.	18	1.9 (0-12)	£ 84.04 (0-454)	18	2.5 (0-12)	£24.16 (0-151)	£108.21 £59.88 (0-457)
E.	51	2.8 (0-20)	£134.45 (0-760)	48	4.6 (0-50)	£48.12 (0-633)	£183.86 £113.97 (0-1393)
F.	9	4.4 (0-12)	£100.59 (0-384)	10	2.5 (0-12)	£ 9.01 (0-32)	£110.60 £74.64 (3-392)
G.	17	1.4 (0-6)	£ 31.85 (0-214)	17	2.1 (0-6)	£ 7.43 (0-32)	£39.28 £23,75 (0-226)
Total/Av	167	2.8 (0-24)	£115.81 (0-1498)	162	4.4 (0-60)	£33.16 (0-633)	£151.43 £87.08 (0-1540)

Notes

1. Excludes families where data are missing.
2. Difference between groups: Anova p=0.241; Kruskal-Wallis p=0.002.

We have been able to calculate the total time of face-to-face contact with the key worker (frequency of contact multiplied by typical reported duration of contact) for 167 respondents and made similar calculations for telephone contacts for 162 people. Adding these totals gives us a sample of 160 families for whom we have data on both their reported visits and telephone contact with the key worker, although as evidenced by Table 6.3, each of these types of contact, and indeed the total, could amount to zero (no contact in the previous three months). However, we have excluded one family. The costs of key worker support for this family were estimated at almost £4,000 over the three-month period, more than twice the cost of supporting the second most expensive family. In reviewing the questionnaire it became clear that the frequency and duration information given included time spent supporting the child that was not associated with key working.

Table 6.3 shows that across the whole sample of 159 respondents, the average cost of contact with the key workers was £151 although there was considerable variation around this mean. Assuming this level of contact to be constant over 12 months, annual average contact costs would be £700, around 38 per cent of the average cost per family estimated across the 12 schemes identified in Table 6.1³. Although comparisons between cost information calculated from 'top-down' and 'bottom-up' perspectives are susceptible to estimation error, we can, with considerable caution, suggest that the contact to other activity ratio is 1:2.6. This means that for each hour spent in contact with the family, two and a half hours are spent on activities such as travel, liaison, meetings, etc. The 11 key workers reporting time use in this project supported this estimation suggesting that between 25 and 50 per cent of their time was spent on visits, although the high figure included travel. Given the key workers' role in co-ordination, such a high level of non-contact time is not surprising. We can compare this figure of 38 per cent with data from professionals who work with adults. Social work case managers spend 20 per cent of their time in face-to-face contact, for social work assistants the figure is 27 per cent, family support workers working with people with schizophrenia spend 29 per cent of their time in face-to-face contact, and for intensive case management with elderly people the proportion is 18 per cent (Netten and Curtis, 2003).

Returning to the data in Table 6.3, we see that there was also considerable variation between the seven services with average contact costs for service G at around £40 per person for the three months prior to the survey and service C showing an five-fold increase at an average contact cost of around £190 per person. There are also wide cost variations *within* each service. Figure 6.1 shows the distribution of these costs data, plotting the number of families against contact costs. Figure 6.2 shows the skewed distribution remains (albeit reduced) even when the nine highest cost families are excluded.

³ Excluding the last two teams in Table 6.1, which we believe are least reliable, the total cost for all schemes is £2,250,270 and the total caseload is 1,237. Thus the average annual cost per family across these schemes is £1820.

We found that:

- 13 families had no contact with their key worker in the past three months (£0);
- key worker contact for 38 families cost between £1 and £49.99;
- key worker contact for 36 families cost between £50 and £99.99;
- key worker contact for 36 families cost between £100 and £199.99;
- key worker contact for 27 families cost between £200 and £499.99;
- key worker contact for seven families cost between £500 and £999.999; and
- key worker contact for only two families cost more than £1,000.

Thus, the contact costs for nearly three-quarters of the families seeing their key worker were less than £200 for the three-month period prior to questionnaire completion.

Figure 6.1 Distribution of total costs of key worker visits and telephone contact, all families in cost sample

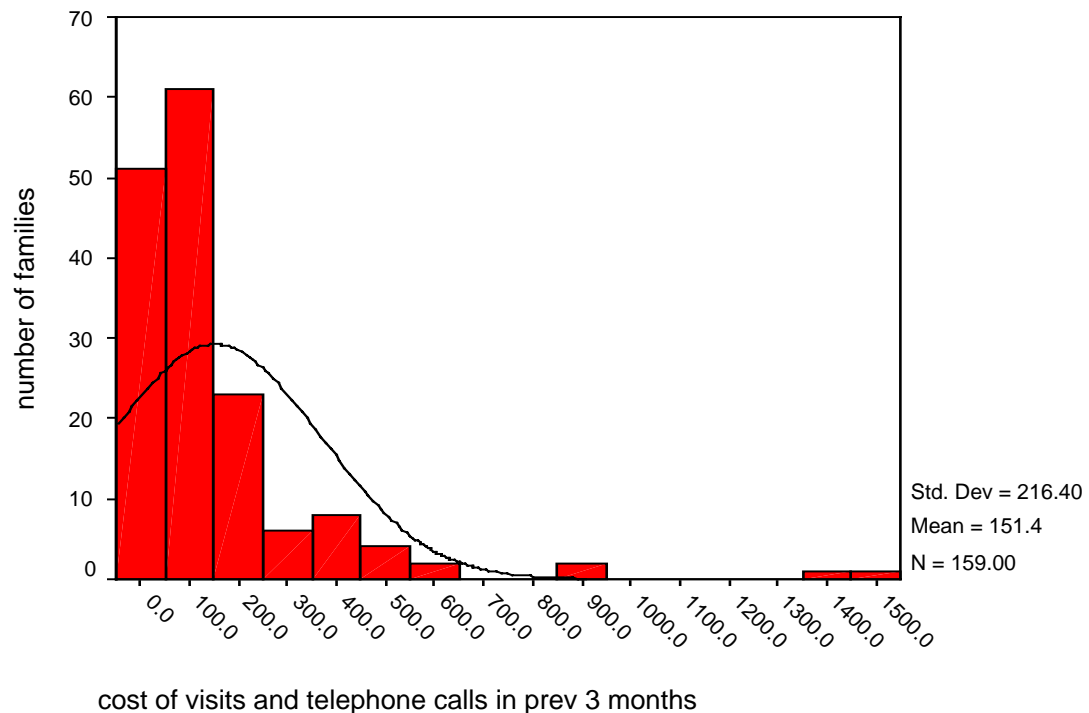
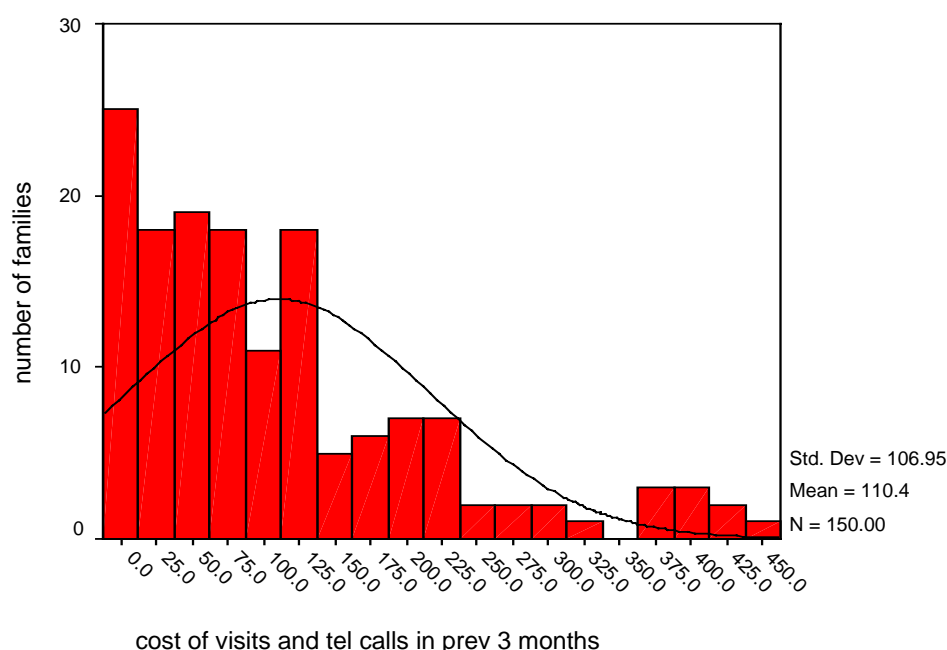


Figure 6.2 Distribution of total costs of key worker visits and telephone contact, excluding families whose support costs are higher than £500



6.5 Cost associations: bi-variate analyses

The costs of telephone contact amounted to 20 per cent of the total costs of key worker contact. There was a statistically significant ($p < 0.000$) and positive, fairly strong correlation between the costs of visits and the costs of telephone calls ($r = 0.435$) indicating that more face-to-face contact was associated with more contact by telephone. When the most expensive people were excluded (those with contact costs of over £500), the correlation remained significant but the association was weaker ($r = 0.318$, $p < 0.000$).

Using simple t-tests, we found no associations between the cost variables (cost of visits, costs of telephone calls from the key worker, total of these costs) and the socio-demographic variables such as the child's gender, age, whether they were found to be disabled before or at birth, or age at which they were found to be disabled. None of the family demographic data were associated with the cost measures either; interviewee's marital status, employment status (both or either working), or the number of children in the family.

Table 6.4 shows the results from the bi-variate analyses where significant differences were found. Here, variables have been recoded into simple yes/no values and the association with the total cost of visits and telephone calls from the key workers shown. This table shows the results from three statistical tests for each of the variables. In the second data column, a positive cost difference means that people

with the characteristics listed on the left of the table had significantly higher costs than those without it. The confidence interval (CI, fourth data column) from the bootstrap analysis⁴ confirms the findings of the t-test where the figures do not pass through zero. Because the children and families served by the key workers come from seven services with each of them (potentially) supporting a different client group in different ways, and supported by a different array of services it was also important to test whether this 'clustering' of the research sample in different services had an impact on any of the observed associations. Thus the final column of this table shows the confidence intervals when the data have been adjusted statistically for receiving key worker support from a particular site.

Table 6.5 shows the significant cost associations for the continuous variables using a similar format.

⁴ Bootstrapping tests the mean cost difference under consideration on randomly selected samples (here 1000) from the dataset. This to ascertain that the difference is valid for the whole dataset, helping to overcome problems associated with small sample sizes and/or skewed data. Confidence intervals from these analyses are reported. If the confidence interval does not pass through zero the t-test has produced a valid result.

Table 6.4 Bi-variate cost associations: indicator variables

<i>Characteristic</i>	<i>No. with this characteristic</i>	<i>Mean cost difference</i>	<i>P value</i>	<i>CI (bootstrapped, 1000 reps)</i>		<i>CI (adjusted for service membership)</i>	
Measures of need/service use:							
Child's difficulties with continence	97	+ £69	0.024	16.58	127.14	-35.46	173.30
Seen hospital doctor in last 3 mths	80	+ £64	0.062	1.65	132.91	22.77	105.41
Key worker related							
Having KW <i>never</i> positively affects way treated by services	26	- £102	0.030	-159.61	-39.32	-193.16	-11.53
Interviewee <i>very</i> satisfied with KW	67	+ £99	0.006	28.69	168.87	-45.44	243.23
Interviewee wants to see KW more	48	- £118	0.000	-169.83	-63.98	-189.73	-46.93
KW makes contact with parent	95	+ £108	0.002	39.48	169.40	56.17	160.21
Service-related							
Family supported by a service that has							
dedicated funding	133	+ £105	0.000	-157.74	-53.49	36.77	172.35
parent rep' on Steering group	82	- £64	0.070	8.30	144.86	-126.01	-1.43

Table 6.5 Bivariate analyses: continuous variables

<i>Characteristic</i>	<i>No.</i>	<i>Coeff</i>	<i>Unadjusted</i>			<i>Adjusted for service membership</i>		
			P value	CI		P value	CI	
Measures of need/service use:								
Total disability score ¹ (Higher score = more severe)	141	+£10.53	0.035	0.76	20.30	0.034	1.12	19.93
KW improved interviewees':								
Total quality of life score (Higher score = better quality of life)	145	+£23.97	0.001	9.77	38.17	0.052	-0.22	48.15
Key worker related								
Total MPOC score (Higher score= parents perceive it to be more co-ordinated etc. service)	153	+£53.01	0.027	6.21	99.81	0.10	-13.0	119.02
Total number of support aspects provided (Higher score = more provided)	136	+£11.35	0.000	5.25	17.44	0.03	1.48	21.22
Total satisfaction score (Higher score=more satisfied)	156	+£68.49	0.000	30.42	106.55	0.007	26.54	110.43

Few of the measures of the child's disabilities, or surrogate measures of need, such as contact with services, were associated with costs. Those not associated with the cost measures included most areas of the child's disability⁵, receipt of higher or lower levels of the Disability Living Allowance mobility or care components, contact with most of the health, social care or education services in the previous three months (see Table 6.6 for service utilisation rates for this sample), or number of professionals seen⁶. Table 6.4 shows only the measure of whether the child had difficulties with continence and whether they had seen a hospital doctor were associated with costs; higher costs in each case. Table 6.5 shows that the total disability score is also positively associated with cost. Chapter 2 describes how this measure was calculated. The figures show that for each additional unit of measurement of disability, the cost increased by about £10.

Table 6.6 Service use in three months prior to interview¹

Service	% (n) using		Service	% (n) using	
Health care			Social care		
General practitioner	61%	(115)	Social worker	24%	(45)
Psychologist/Psychiatrist	12%	(22)	Voluntary worker	11%	(20)
Speech therapist	56%	(105)			
Occupational therapist	37%	(69)	Other service	13%	(24)
Physiotherapist	50%	(94)			
Community nurse	21%	(39)	School/Education		
Health visitor	21%	(40)	Portage/home liaison	9%	(17)
Hospital doctor	47%	(90)	Behaviour support in school	5%	(10)
Community paediatrician	34%	(64)	Learning support in school	27%	(51)
			Classroom assistant	24%	(46)

Notes

1. 177 families answered questions about health and social care services, 135 families answered questions about education or school-based services.

The next group of variables includes those concerning the interviewees' attitudes to the service and four main outcome variables: total quality of life score, total parental unmet need score, total child unmet need score, and overall satisfaction with the service. The method for calculating these variables is given in Chapter 2. Table 6.5 shows that higher costs were associated with better quality of life for the respondent. In fact, parent-reported improvements in six out of the seven component quality of life measures⁷ were significantly associated with higher costs; physical health, emotional health, relationships, financial/material circumstances, control over their

⁵ Communication, behaviour, etc coded as very much or moderately = 1 (yes), not at all = 0 (no).

⁶ Mean and median number of different types of health and social care professionals in contact with families was four (range 0-9). For education/school professionals the mean was 0.8 and the median was one type of professional (range 0-3).

⁷ Recoded: 1 = positive impact; 0 = no impact or negative impact

life and peace of mind ($p < 0.039$). The total scores for unmet parental or child needs were not associated with costs, nor were changes in the interviewee's stress levels.

The third set of variables includes those related to key worker activities, including the total MPOC score, a measure of the extent to which parents feel they were getting a coordinated multi-agency service. Table 6.4 shows that higher costs are associated with the key worker making contact with the family (rather than vice versa) and high levels of satisfaction. (This is a yes/no variable derived from the satisfaction scale and counts only the families who were very satisfied with the service.) The interviewee wanting to see more of the key worker and where the key worker has no impact on other services reduced the contact costs. Three other key worker-related variables are shown in Table 6.5. A higher score on the MPOC and on the overall satisfaction measure were both associated with higher costs. Each additional unit on the total 'aspects' score (see Chapter 2 for the calculation of this score) also generates extra costs of around £11. Eight out of the ten individual components⁸ of this total score were found to show significant cost differences. Higher costs were found to be associated with the worker providing support or help in the following areas: emotions, information, advice, identifying and addressing the needs of the whole family, speaking on behalf of the family, coordinating care, and providing help/support in a crisis. The length of time the family had been supported by a key worker was not associated with costs.

Our last set of bi-variate analyses explored the associations between the costs of providing key worker support to families and the characteristics of the services: presence of training, supervision, peer support, presence of a dedicated service manager, type of key worker, length of time over which the service has been in existence, parent representation on the Steering Group, and whether service has dedicated funding. These are characteristics of the service but were applied to each person supported by that service. Each person supported by Service B for example, was ascribed the same value for any of these variables. Only the last two variables in this group were found to be associated with costs. Table 6.4 shows that dedicated funding for the service was associated with higher costs; services F and G had no dedicated funding. Parent involvement on the Steering Group is associated with lower costs; only services B and E had no parental involvement on their Steering Groups. The correlation between dedicated funding and parental involvement on Steering Groups was -0.318 ($p < 0.00$).

Looking across the two tables the final columns show that the site from which families receive their services affects four of the variables: whether the child has difficulties with continence, whether the parent is very satisfied with the key worker service they receive⁹, the total MPOC score, and the total quality of life score. In

⁸ Recoded: 1 = some or very much; 0 = not at all

⁹ Note however, that the influence on cost of the total satisfaction score remains significant; Table 6.5.

each case, the association is no longer significant. This means that these characteristics 'cluster', or are more common, in certain sites. For example, site E supported nearly a third of all children recorded as having any continence difficulties (33/105) and between them, sites D and F supported only 10 of the 86 families who reported they were very satisfied with the service they received.

6.6 Cost associations: multivariate analyses

The results of the bivariate analyses were taken forward to the two sets of multivariate analyses. The first of these uses linear multiple regressions to explore the overall impact of the four groups of variables set out above on key worker contact costs. The second replicates the path analysis shown in Chapter 5 but uses the contact cost variable in Block 2 to summarise the two input variables (frequency and duration).

6.6.1 Overall cost impact

The influence on contact costs of each of the variables within the groups laid out in Tables 6.4 and 6.5 was tested using linear regression with the result confirmed using bootstrapped confidence intervals. Table 6.7 shows the results of the final equation and the 'next best' alternative. Equation I shows that the measure of the child overall disability is positively associated with contact costs; the greater the child's needs as measured on this instrument the higher the costs (more intensive key worker contact). The p value is just outside 0.05. The measure of the number of aspects of work that the key worker provides is also positively associated with costs. The final variable in this equation is whether parents are represented on the services' Steering Group; where there is parental representation, the contact costs for any user are lower. This result is less intuitive and less easy to explain as it shows that the mean costs for the two sites *without* parental involvement are among the highest (services B and E, Figure 6.3). However, this variable remains a powerful predictor. If it is excluded from the equation, the adjusted R^2 drops to 14 per cent but as Equation II shows, the identifier for site E enters the equation as having a positive and significant association with contact costs. This second equation, although explaining very slightly less of the variation in contact costs is perhaps more easy to understand; once the impact of family and service characteristics have been taken into account, service E provides a higher cost service to the families it supports than all other teams. This service supports three of the four families with contact costs higher than £800.

Figure 6.3 Mean contact costs by service

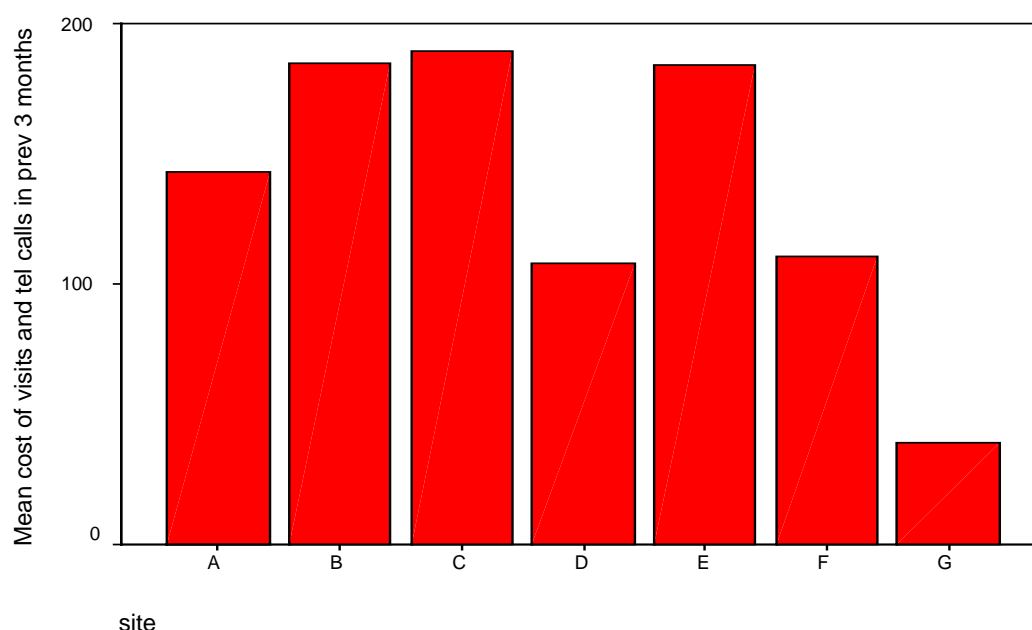


Table 6.7 Cost function analysis: predictors of contact costs

<i>Characteristic</i>	<i>Equation I¹</i>		<i>Equation II²</i>	
	Co-efficient	P	Co-efficient	P
Constant	-216.43	0.032	-277.99	0.006
Child's disability score	+9.88	0.057	+9.59	0.066
Total number of support aspects provided	+11.40	0.000	+11.32	0.000
Supported by service with parental involvement in Steering Group³	-82.07	0.013	-	-
Site E³	-	-	+77.23	0.030
	N=123, F=10.014 (p=0.000) R ² =0.200, Adj. R ² =0.180		N=123, F=9.429 (0.000) R ² =0.191, Adj. R ² =0.171	

Notes

1. The standardised residual from this equation was not normally distributed. When tested using a logarithmic transformation for contact costs the adjusted R² was raised to 43 per cent and the constant and all variables were significant at p<0.015.
2. The standardised residual from this equation was not normally distributed. When tested using a logarithmic transformation for contact costs the adjusted R² was raised to 41 per cent and the constant and all variables were significant at p<0.004 except for Site E, which was not significant.
3. Measured at the service level and applied to each person using that service.

6.6.2 Path analysis

Here only two pathways are explored. As indicated by the results of the bivariate analysis, no associations were found between contact costs and parent unmet needs or the child unmet needs and indeed, Figures 5.3 and 5.4 also show there were no associations between the separate measures of frequency and duration of key worker contact and these outcomes.

The bivariate analyses point to possible underlying associations with contact costs.

- *Block 1 family and child context:* level of child's disability.
- *Block 1 service context:* service has dedicated funding, service has parent involvement in the steering group.
- *Block 2 service mechanisms:* number of aspects of key worker role, appropriate level of contact, proactive contact.

In Block 3, the previous path analysis showed that the process outcome (MPOC total score) is not associated with either of the outcome measures of concern here, although it is associated with contact costs. Our interest, therefore, is the path of associations between Block 1, Block 2 and two family outcomes: total quality of life score and total satisfaction score for which higher scores denote more positive impact of the service on quality of life or greater satisfaction.

In repeating the path analysis for the quality of life total score (Figure 5.1) the costs variable was not a significant predictor when the variable describing the number of aspects of key working remained in the equation. Contact costs and the key worker aspects score are correlated (0.302; $p < 0.000$) but when entered into the equation together the key worker aspects score is the stronger predictor.¹⁰ Entered into the equation on its own, the contact cost variable 'explained' just seven per cent of the variation in the total satisfaction score ($R^2 = 0.072$; adjusted $R^2 = 0.065$).

A similar set of findings held true as we repeated the path analysis for the total satisfaction score, again using the contact costs variable instead of the separate variables on frequency and duration of contact (see Figure 5.2). There was a significant association between contact costs and parental satisfaction but the proportion of variance explained was small ($R^2 = 0.075$; adjusted $R^2 = 0.069$). Using the backward regression function the contact cost variable dropped out of the equation leaving the key worker aspects score and the measure of appropriate levels of contact as significant association as reported in Figure 5.2 ($R^2 = 0.679$; adjusted $R^2 = 0.674$)¹¹.

¹⁰ For this sample, the beta (standardised) coefficient for the key worker aspects score is 0.672 and the adjusted R^2 is 0.448.

¹¹ For this sample, the dichotomous variable 'would you like to see more of your key worker' (coded yes=1 no=0, see Table 6.4) changed the p value of the constant from 0.065 to < 0.000 and generated a similar adjusted R^2 (0.677). The Beta values of the two independent variables remained similar.

What can we conclude from these analyses of user-level contact costs? The bi-variate analyses showed a number of significant associations between the families' and services' characteristics and the contact costs. Three factors were broad measures of the child's needs, five were measures of the parents' attitudes to their key worker, a further two were service mechanisms that are directly in the control of the key worker (the types of support provided and whether they make contact with the family), and the final two variables were measures of the services' characteristics. However, many of these variables did not appear in cost function results reflecting the composite nature of some of the measures, their inter-correlation, as well their impact on contact costs. This set of regression analyses explored the extent to which the multiple influences on costs could be identified and how much of the variation in families' contact costs could be 'explained' statistically. The proportion of variation explained is quite low at 18 per cent, leaving more than three-quarters of the variation unaccounted for, but this level of explanation is not unusual in cross-sectional analyses for care services. More importantly, we are only assessing variation in the costs of one service received by these families rather than the more common approach of exploring the costs of a comprehensive care package. We know that in the three months preceding completion of the survey families saw, on average, four types of health or social care professionals but the range was wide, from no contact with services to nine different types of services, but we have no measure of the intensity with which they used these services. The level of support from other services – and indeed from friends and relatives – is likely to influence the level of support from the formal care sector.

6.7 Summary

This chapter presents the findings from our exploration of the service- and user-level cost estimations for key worker services for families with disabled children. These two levels are closely linked, for without data on the former, the latter cannot be estimated. This study benefited from two stages of data-collection: a national survey of key working services and a more detailed study in seven areas. In both stages questions linked to the economic component were carefully integrated into the main data collection mechanisms.

In estimating service costs, our hierarchical approach to collecting financial, staffing and caseload information meant that we could estimate service level costs for nearly half the key worker services responding to the national survey. Of course, the further one moves away from 'ideal' data (full annual income and expenditure accounts and accurate work load information) the less well our estimates will reflect the exact cost profile of any given service. However, these data provide important information for planners contemplating adding this type of support to the current panoply of services already provided to families with disabled children. They clearly lay out the costs associated with particular staffing profiles and the outputs (caseloads) that are

commonly managed by these teams. Average cost information for key working services provides data with which planners and commissioners can estimate the likely budget requirements given knowledge about the number of families who would benefit from such support in their area.

Seven services were selected to participate in the second stage of the research. Cost data at this level begin to address question about how scarce resources *within* a team are dispersed between its users. This is information that service managers require in order that their scarce resources are allocated in the best manner possible. Variation in user-level costs should be considered the norm for just as users' circumstances and needs are different so should be the types of support that they receive and the intensity with which they receive it. Of course, here only the costs associated with face-to-face or telephone contact between key workers and the families in the survey are considered. In reality, these supports are not only set within the context of other activities undertaken for the families by their key worker but also within the range of services available in the local area.

Our analysis found that only a fifth of the variation could be explained statistically with higher levels of disability in the child and provision of a broader set of activities by the key workers both raising costs. These are logical findings for we would expect higher needs and a higher quality service (here as perceived by the parents) to be associated with higher costs. Interestingly, if a service had parents involved in the Steering Group this reduced costs. The underlying reason for this finding is less clear as only one or two parents took part in each service's Steering Group and our sample is 159 parents. It should not be assumed that parental involvement reduces contact costs. It is likely that this variable is picking up the generally lower costs per user for these services rather than a causal link between parental involvement in the Steering Group and lower costs. Our second equation is perhaps easier to understand, although less cost variance is 'explained'. The identifier for users of service E was associated with higher contact costs, all other factors considered.

Our last set of analyses was also informative. Although costs were associated with both the outcome measures considered – the quality of life score and the total satisfaction score – this was weaker than the association between the numbers of aspects of the service the key worker provided for the family. Although path analysis cannot prove causality, it would appear that the way key workers provide support has more of an impact on these outcomes than how much they receive *per se*: service quality may well be more important to parents than overall quantity. Estimating costs is not a quick or easy task. It requires considerable amounts of data that are not easily available, and then time to assess the quality of the data and seek out appropriate estimates where data are missing. Analysis of costs data is often made more complex by skewed data or small sample sizes. Problematically, because costs findings often arrive on decision-makers desk as one easy-to-understand figure, it is all too easy for such results to be used with less caution than

a researcher would advise. Here, as with findings from any other cost-related study, findings should be used to inform decision-making not to make decisions.

Chapter 7: Key Worker Services and Education

The purpose of this chapter is to examine the relationship between the key worker services in the seven case study areas and the Local Education Authorities (LEAs) and the schools within those areas. A separate chapter focussing specifically on Education is provided because research (see, for example, Townsley *et al.*, 2004; Webb and Vulliamy, 2001) suggests that LEAs and schools often face particular challenges in fully participating in multi-agency initiatives. This is of special interest and concern given the increased role of Education in the government's inclusion agenda.

This chapter describes the nature of the contact that key workers had with schools and the range of issues they addressed in order to enable schools to better meet the needs of disabled children and their families. It documents the benefits and drawbacks for families of key worker involvement in education and explores the implications for LEAs and schools. It concludes with consideration of the advantages and disadvantages of teachers themselves taking on the role of key workers.

Research for this study of key worker services took place at the time when schools were required to implement new duties under Part 4 of the Disability Discrimination Act 1995 (DDA) as amended by the Special Educational Needs and Disability Act 2001. Since September 2002 it has been unlawful to discriminate, without justification, against disabled pupils and prospective pupils in all aspects of school life. Additionally, since 1 April 2003 all schools and LEAs have been required to have in place accessibility plans and strategies for increasing over time the accessibility of schools for disabled pupils. *The Code of Practice for Schools* issued by the Disability Rights Commission (DRC) and *Accessible Schools: Planning to increase access to schools for disabled pupils* (DfES, 2002) explains these duties and assists schools and LEAs to draw up the necessary plans and strategies which are monitored by OFSTED. While LEA and school progress on these duties is outside the scope of the research reported here, the issues and constraints identified that face teachers and parents in meeting the needs of disabled children clearly have implications for the successful implementation of Part 4 of the DDA. In documenting the contribution key workers made to the educational provision for particular disabled children, this chapter indicates ways in which key worker services could assist schools to successfully fulfil their statutory obligations to their disabled pupils and prospective pupils.

The findings reported in this chapter are derived from three data sets: the interviews with professionals (key workers and managers) in the seven case study areas; the interviews with parents/guardians in those areas and visits to 14 schools with pupils on roll who were recipients of care co-ordination by key workers from services A

(designated and non-designated key workers), C (designated key workers) and D (non-designated key workers). School data were derived predominantly from semi-structured interviews with school SENCOs and/or headteachers. As an exploration of key worker services and Education was not a central aim of the research, questions on Education were not included in the questionnaire survey to parents and the statistical analysis, therefore generalisations based on quantitative data cannot be made. However, analysis of the qualitative data identifies, and reveals patterns in, the difficulties experienced by parents and children in meeting the children's educational needs and the help provided by key workers and gives insights into these through examples.

7.1 Choosing a school

Children spend a large proportion of their time in school and consequently their school experiences have a major impact on their happiness, self-identity and their future life chances. The parents interviewed were extremely aware of the importance of securing an appropriate education and went to considerable lengths, including moving house from one LEA to another, in order to obtain places for their children in schools that they regarded as particularly suited to meeting their needs. A stimulating and suitable education in a caring context was not only beneficial for the child but also extremely reassuring for parents. Conversely where the school situation was perceived to be unsuitable and therefore upsetting for the child, this caused parents considerable ongoing anxiety and additional stress.

A small minority of parents had to find out about appropriate schools without any assistance from either a key worker or another professional involved in the care of their child. This was particularly the case where parents were dissatisfied with the school their children were attending and wanted a change of placement. For example, the mother of one five year old girl described how her daughter had attended the local primary school which kept her in the nursery class when she should have gone into the reception class and wanted to retain her in the nursery for a further year when her peers were entering Year 1. Her mother decided this was inappropriate provision and thought that her daughter would benefit from special schooling. She took advice from agencies used to working with special schools and from her family and 'managed to make my own way in the end, it took a few months but we got there'. Her experience was in sharp contrast to that of those parents who received considerable support and practical help from a key worker. For example, one mother learned at the end of the Summer Term that the school nursery her daughter was to attend in September had not carried out the recommended adjustments including providing level access. Consequently, another school had to be found at the last minute. In her case the key worker was immediately proactive in speedily resolving the situation by obtaining a placement in another school and organising temporary attendance for the daughter at an agency run nursery until the

school had appointed a one-to-one care assistant for her - thus considerably reducing the potential stress of the situation for the mother.

The levels of disability awareness of some teachers were viewed by several of those involved in care co-ordination as responsible for the problems encountered in obtaining placements for disabled children. Key workers were regarded as having an important role to play in countering negative attitudes and promoting inclusion through facilitating links between the home and the school:

Well recently we had a child who was sort of post-meningitis and was about to start school. And there were barriers there about the child starting mainstream school because of her illness and disabilities following that. It was just about setting up links between the school and the family and getting the child back into school a lot quicker. There's been a few issues like that where there's been perhaps a little bit of a barrier for whatever reason, and it's that going in and just sort of doing a bit of negotiating really, and getting children back into school.
(Key worker Service Manager)

Teachers also spoke of the valuable role key workers could play in helping parents to choose a school best suited to meeting their child's needs. For example, the Head of a Secondary Autistic Centre described his most recent contact with a key worker to address parents concerns that their eleven year old could all too readily leave the Centre without staff knowledge, as it was on a large shared site and had a number of entrances and exits:

The key worker stepped in and helped to arrange viewing of different schools in different settings to give the parents an opportunity to have a look around and see if they might be happier with some other placement. That's how I see the role of the key worker, to take some of the burden off the parents, to make those phone calls, to get in contact because the key worker often knows people in education, comes out of that sector so will have contacts already in certain schools and can make contact then with the head teachers in various schools and say 'Look, you know, I've got these parents, can they come around, can we have a look, can we have a chat and sit together and see what you've got to offer'.

Several key workers also described how early initial contact with schools, prior to children taking up their placements, meant that they could advise teachers about a disabled child's abilities and needs and the steps they could take to prevent any anticipated difficulties from arising. For example, one key worker contacted a school to brief them about a boy's epilepsy and arranged for an epilepsy specialist nurse, who did outreach work, to visit the school with the mother. Another had organised a similar meeting between teachers, the family and a dermatology expert to enable the needs of a boy, who had very severe eczema, to be met within school. A third had arranged for the school, where a boy with an insulin deficiency was enrolled, to receive advice from a diabetic specialist and sign up to written procedures.

7.2 Easing transition

Transition from one phase of education to another can be difficult for children and parents. As the data demonstrate, this can be considerably alleviated by key worker involvement.

She had to go from junior school to secondary school so I coordinated visits and made sure that everybody knew her condition and problems with the uniform - because of the condition she had to have a different uniform. I was probably ringing twice a week and visiting once a week for that transition period but because I kept sort of a very close supervision on what was happening I think probably that's why it went so smoothly. So it did work very well.

(Key worker)

The interview data from parents revealed that parents valued the key worker providing information on potential schools. For example, a designated key worker had taken this further and actually produced information packs on pre-school, school and after school choices and facilities and used these as a basis for providing relevant information to disabled children and their families. Parents also found it helpful to have key workers accompany them on school visits to make introductions and to ask questions that they might not have thought to ask and to monitor the placement in its early stages:

Well when we first started to think about the next step [the key worker] gave me a brochure with details of all the different colleges which was incredibly helpful, so we had a look right through and we went to visit three of them. So her role was really information giving and then once we had selected the college and sort of started to go ahead with that placement, [the key worker] then was very involved in the transition review inviting the careers officer, also inviting someone from the local FE college to come and she's been instrumental in sorting out the funding and just advising on how to go about it and monitoring it.... [the key worker] has had her fingers on the tabs if you like so that everything seems at the moment to be going quite well.

(Parent)

However, parents were keen to stress that the choice of school was, and should be, entirely their decision and that any attempt to influence this decision would be resisted - a perspective of which most key workers were aware.

While much has been made of transition between institutions and phases – nursery to primary school, primary to secondary school and secondary school to higher education – there has been relatively little consideration of the effect on children of transition points within phases. However, some teachers were acutely aware of the challenges posed for children when they moved from key stage 1 to key stage 2 which were likely to be more keenly felt by those with special needs:

The other one that I sometimes think as a school we overlook is transition between key stage 1 and key stage 2. There's a huge gap and I don't think as professionals we really realise that's a huge transition for these children and these parents because generally you meet a completely different number of staff, you're meeting a different curriculum, different playgrounds in this school and it's hugely different so we've started to focus on that here.... in key stage 2. It's also very different 'cos we move the assistants around quite a bit. One of the policies in this school is that we don't have one child one assistant as it can be bad for the child and bad for the assistant so once they get to key stage two we tend to move them around so they're ready to move to the high school where they won't have one person with them all the time.
(SENCO, primary school)

The change from having one care assistant to being supported by several tended to occur during transition points thus exacerbating any difficulties resulting from the move between phases. Certainly, this issue was raised as a cause for concern by several parents, who, while aware their child could develop an over-reliance on one person, generally preferred the consistency of such a situation and found it easier where there was only one support assistant for them to get to know and with whom to liaise.

7.3 School knowledge of the key worker service

Two headteachers had been involved to varying degrees in the setting up of the key worker services and were therefore aware of the rationale underpinning the schemes and the way they operated initially. Another headteacher explained that she had gained her understanding of the service through having worked previously with a number of those involved in setting it up. Three teachers interviewed in special and secondary schools, who had been in post when their area's key worker service was launched, were invited to an initial meeting where the service's intentions and procedures were outlined.

Only one headteacher claimed to have received documentation on a scheme and to have found that helpful:

They issue very good information leaflets to anyone involved including parents, and then we can access it by consulting with parents. 'Do you think a key worker would be useful to you?' If the person is without a key worker and then we can make a referral on their behalf to the service and then be allocated .. they'll, well the parents'll be allocated 'cos it is a parent based service, you know, they're there for the parents not for us, you know.
(Head of Autistic Unit)

Schools receive an enormous quantity of documentation. Consequently, documentation sent into schools seems unlikely to be read by, and available to, teachers at the point when they might need it.

One SENCO claimed 'Normally services you find out within an area, you find out by accident' and this seemed to be the predominant mode by which teachers found out about the key worker services. For example, the SENCO at an Infant School described how she got to know of the service:

When the parent came in and said 'You haven't filled in my book' and we said 'What book?' because we didn't know anything about it at all....So it came from the parent and it was a big shock because we didn't know anything about it and we didn't know how it worked and we didn't know what this book was or anything. She had been in school four or five weeks, something like that. She came from another school and we weren't aware of it from the other school either.
(SENCO, infants school)

As is discussed in the following sections, key workers' contacts with schools were often initiated in response to parental concerns over issues arising or upsetting events. An outcome of this was that schools with only very few, or perhaps only one child with a key worker, were unaware of the existence of key workers until they contacted the school to introduce themselves in order to discuss a problem or accompanied parents to their child's annual review meeting. However, as acknowledged by several key workers, working with schools was facilitated and speeded up if teachers were aware of the service prior to a need arising for key worker intervention:

It's easier if they've met you before and they know who you are, if you go to a school and nobody knows who you are and they don't know your background or anything it takes a long time to sort of be able to help. It had been suggested that we perhaps took a little information sheet with us to give to the school saying 'This is me and this is what I can do sort of thing', but we never have, we don't play it like that.
(Key worker)

However, having an explanatory sheet to hand when a first visit to a school is made could prove useful.

Key workers complained that schools often suggested to them that other children would benefit from having a key worker but that these children generally did not approach meeting the criteria necessary for a referral to be made. Teachers were very aware that they did not understand referral criteria and called for these to be made explicit to schools:

The issue I have is, is referral and who refers and, and criteria and parameters for it cos I don't think I've got full understanding of that ... I mean somebody said to me it's when there are two agencies involved and we have loads of children where there are two agencies involved or more,

and the two children with cerebral palsy you'd think would be prime candidates for service co-ordination but none of the services involved with them have suggested that we do that, so I'm now thinking well really do I contact [the service coordinator] and say 'Are these children who'd be appropriate for the service co-ordination scheme, cos I think they would be?' So no, I'm not clear, it's been useful for the one child who's on it bringing everybody together but I'm not clear what the criteria are. (SENCO, infant school)

Perhaps, because of lack of understanding of the referral criteria, schools were only instrumental in obtaining a key worker for a child in a small minority of cases. For example, the SENCO in a primary school found that she was co-ordinating the increasing level of care provided by a number of professionals for a seven-year-old boy with dyspraxia, mobility and continence problems. Consequently, the need for care co-ordination was raised at his annual review and having obtained information on the key worker service the school made a successful application for a key worker.

7.4 Securing in-school support

The provision of a nursery nurse, learning support assistant (LSA) or one-to-one care assistant to support children in school can make an enormous difference to the quality of their school experience. Interviewees described how in addition to reducing anxiety and assisting with implementing a child's Individual Education Plan (IEP) or equivalent, LSAs and care assistants also enabled children to participate more fully in the life of the school, including joining in with school trips, sports and other activities and enabled them to interact with their peers at play times and lunchtimes. For example, one parent described how a care assistant helped her 17 year old daughter, who attended a special unit within a large comprehensive school, cope with the difficulties created by being in a large crowded busy institution. In particular, she had converted an old storeroom into a little room where they could talk and work quietly together.

There were a number of instances in the data where key workers enabled parents to obtain the kind of in-school support that they wanted to meet their child's particular needs:

There were three staff to eight children I think, which seems quite a lot, but I mean if you've got a couple of them having seizures it isn't, and I came home one day and I said to [the key worker] 'You know, I'm not happy with her in school without a one-to-one' and she said 'Leave it with me' and she actually went, took on the Education Department for me and got her the one-to-one. So I mean she has a one-to-one now so she goes to school and she has the one-to-one there and I mean that was [the key worker] that got that because I couldn't get it, you know. I really couldn't, I was up against a brick wall with the Education and they said 'No, you don't

need a one-to-one, it's as simple as that'. But [the key worker] managed to get her it, so she was pulling the right strings.
(Parent)

Key workers also addressed difficulties that occasionally occurred in relation to care assistants, such as adjusting the timetabling of the hours for which support was provided so that the assistants were available when the children's needs were greatest and/or to co-ordinate with parental provided support when parents assisted their children at the beginning and or end of the school day or for a particular activity.

7.5 Routine contact with schools

Most of the parents interviewed felt that they had good communication with their children's schools. The majority of schools sent notes home each day in a home-school book and were accustomed to ringing the parents if they had any concerns or queries and were used to receiving regular calls from the parents. Several parents increased the level of contact that they had through being involved in the life of their child's school through fund raising or as governors, members of parents' associations or in roles such as dinner supervisors. Where the schools were situated locally, parents usually collected their children to and from school. This enabled them to maintain regular contact with the care assistant, the classteacher or the headteacher or occasionally all three. Where parents lived at a distance from the school a few drove over to bring the children home once a week and/or made occasional visits.

As the majority of parents routinely communicated with school staff, only a few commented on the value of the key worker maintaining regular contact with schools:

She'll pop in to check that she's all right and she's phoned me, I think it was about three days after [her daughter] went back to school for a full day, and she phoned me up she said 'Oh' she said 'I, you know, I was in school today and I just popped into check and here she was sitting on the floor and, you know, playing with this' and she, you know, was really excited that she was doing well, but that was nice as well.

(Parent)

Some parents felt that maintaining regular contact with the school should be their responsibility and a few were against the notion of the key worker visiting or contacting the school without having consulted with them first and got their agreement to do so. They seemed somewhat resentful of the unrequested intervention of a third party:

She does make spot visits, you know, which she's obliged to do. She can just turn up out of the blue and see how things are. And it, the ironic thing is I very often don't know she's made those visits till afterwards which sometimes you think well, you know, I'd liked to have known you were

going to see him but I suppose that's the nature of the beast with that one really, that's why they're called spot visits I suppose isn't it.
(Parent)

A minority of parents spoke of the considerable anxiety caused by poor relationships with their child's teachers and negative communications from school suggesting lack of understanding of the child's condition. For example, a parent whose child was continually being punished by the school for swearing and inappropriate behaviour, which the parent considered he did without realising it, described how:

It's more stress added in because the teacher keeps phoning us every little willy-nilly thing that he has done and I think well that's what he's there for, you know, sort it out don't keep ringing me, you know. It just makes pressure on me and I want to say to them 'Look, you can't do this, you can't do -', you know, and they don't understand, they really don't understand, they don't. A lot of teachers have given me a lot of stress over the years they really do, they really, really do.
(Parent)

The involvement of a key worker in such situations has the potential to help address the issues of concern for both parties and facilitate improved relations for the benefit of all concerned.

The schools appeared to have considerably more contact with the key workers than the parents either realised or acknowledged. The teachers interviewed claimed to make regular contact with most key workers in order to talk over issues and to seek information and advice, particularly in relation to children's medication and ongoing medical treatment:

I mean probably on average once a week for various reasons. I suppose the fact that there were two boys involved and there, they were going through a period where there were quite a lot of changes. So, for instance, we were talking about the need for oxygen for him and the issues around that .. there were quite major changes to medication, with both boys that's been an ongoing concern. When you've got issues like that running then you do have to gain information and the key worker's the place to go really for that.
(Acting head, special school SLD)

The only exception to this was a three to nineteen special school for children with severe and complex learning difficulties where the headteacher considered that apart from at annual reviews 'We don't have a lot of involvement with them [key workers]'.

Most key workers viewed themselves as in regular communication with schools once the initial contact had been made and felt that this communication was particularly important in helping teachers to understand children's family background:

They [parents] don't read or write and the school use me to negotiate with the family because dad is anti-school, terribly anti-school and they were actually very concerned about the little lad because dad will come in and

take him and not speak to anybody....they were saying 'He's frightened of dad', and I was saying 'No he's not frightened of dad, what he is frightened of is you and dad in the same room 'cos he probably knows what you feel about dad and he certainly knows what dad feels about you and he's frightened that you two are going to kick off and he's in the middle'. He has a lovely relationship with his dad and of course I know that so they tend to use me.
(Key worker)

Teachers also strongly endorsed the importance of having background information on a child's home context and family situation and any particular events likely to have an adverse effect on the child's attitude to, and behaviour in, school:

Sometimes by phone, sometimes they'll come in. You see we have an issue with a little girl at the moment, she goes to respite and she gets very disorientated about when she goes and she likes to know in advance that she's going. Parents find it difficult to tell her because she gets distressed when she goes, although she, she enjoys it when she gets there and no problem, she goes through the door, she's fine but a very good set-up she has there. She stays at weekends once a fortnight so we've set up a photographic and symbol schedule for what she does and when she goes and they have one at home which leads up to the time she's going to go to respite. ...we get liaison directly about what's gone on at home from the key worker especially if, if things change where we think she's going, that's her weekend to go and something's happened that she's not going. We need the information immediately in order to be able to deal with it.
(Head of Autistic Unit)

Teachers recognised key workers could have a unique relationship with parents, who regarded them as allies. They therefore considered that parents would be much more willing to express their concerns and to confide in key workers than would generally be the case with teachers.

However, a minority of key workers explained how they had experienced problems in getting schools to liaise with them:

For instance, the family I've visited just recently had an issue with the school so I said 'Right, I'll contact the school now after half term and the physiotherapist' and when I spoke to the physiotherapist about a meeting, she said 'Oh the school have already arranged one but the family couldn't come to it' but the school didn't contact me and they know I am the key worker, so sometimes it's a one-way communication and we don't always get feedback.
(Key worker)

7.6 Coping with crises and resolving problems

Parents regarded the intervention of key workers as particularly welcome when crises arose, especially when these were the result of their children's problematic

behaviour. In such situations parents felt that the key worker would explore the school situation that had given rise to the behaviour and not allow blame to be attributed solely to the child:

When he hit a child with a rolling pin at school, [the key worker] was the first one in the school, phoned me while she was on her way, phoned me to tell me there'd been an incident and, you know, be prepared to be there at half past three. She went in and, you know, sort of said, not stuck up for him but sort of said there must have been something to have -, you know, she said.
(Parent)

Key workers were also frequently asked by parents to go into school to discuss issues that required tactful handling and careful negotiation which they, given their emotional involvement, would find hard to do:

Once I did ask her to because again we had a problem with, you know, nappy, soiling her nappy and once she came with - her top was all messed up with soil and all the rest, which wasn't nice, which I told [the key worker] about but she went to the school personally to see how they're doing everything up there. So she, if I ask her to go she will go.
(Parent)

He's got very severe eczema and there were issues about being comfortable in school and getting the right amount of liquid in school and being able to have a drink on his desk. The school had its own rules and there was just a breakdown within, between the school and the mum, nobody's particular fault really but we had three meetings in total with the school, with the mum, with the Dermatology Outreach about what this little boy needs and what would help to make him more comfortable and want to go to school.
(Key worker)

Parents also felt that when points were reiterated by key workers they were taken much more seriously by teachers than when they were made solely by parents. For example, one parent explained that until the key worker intervened the school did not accept the importance of her son's diet in the management of his autism:

I just felt that they weren't necessarily taking it seriously enough, that they were a bit sort of like 'Yes -' just indulging me a bit. And I said 'It's very important to us', and she was actually able to support and talk to the teacher in charge of the unit. I just noticed the attitude totally changed towards me, once I'd had a word with her about it and I was really grateful for that, because it was getting to be a bit of an issue.
(Parent)

If parents had cause to raise a number of issues with a school or to pursue a particular issue over time, they thought that this could result in them and their child being perceived very negatively by the school. For example, one parent, who was unhappy about the nature of the support being given by the LSA, had to continually

raise the issue with the classteacher to the point where the parent felt that she had become 'the big bad person' in the teacher's eyes. If the key worker intervened, this facilitated a speedier resolution to problems, defused potentially confrontational situations and helped prevent the deterioration of home-school relationships.

The teachers interviewed also gave numerous examples of the key workers acting as intermediaries between parents and the school and viewed this as a major benefit of the role for themselves as well as for the families:

If you've got a difficult parent as some of them sometimes can be difficult the key worker can be the intermediary. Yeah, they come in and you can say to the key worker 'Well look, I can't say that to the parent directly but this and this and this is happening, can you sort of sort this out in a roundabout way' and they'll do it which is good. ...it can refocus the parents because quite often parents can say 'Oh well it's the school's fault that this has happened', and the key workers kind of say 'No, no, in this particular case the child was playing up' or 'It's not quite how it's been presented'.

(Learning support teacher, comprehensive school)

To be successful in their role as mediators and negotiators and to work productively with schools, teachers considered certain qualities were vital for key workers. These qualities were to 'have empathy not sympathy' with the parents, 'be approachable', 'maintain a very balanced viewpoint', be 'unprejudiced', 'to be calm, non judgemental and level headed', 'a good listener' and 'a good communicator', able to 'use initiative' and have 'a sense of humour'.

7.7 Understanding children's disabilities

The majority of parents interviewed did not consider that the key workers had assisted school staff in understanding their children's disability. When the children were in special schools or special units attached to mainstream schools, this was predominantly because parents felt that the staff already had the appropriate knowledge and that this was quickly supplemented by personal knowledge of their children as individuals. However, in a very few cases where parents considered that teachers' actions suggested that they lacked sufficient understanding of a particular condition, they were sometimes viewed by parents as reluctant to admit this and to accept advice from the parents and/or key workers:

I think [the key worker] tries, I'm not sure how open the teachers are to hear (pause) we did put together a portfolio describing [her daughter] and what she likes and dislikes and I think that helped sort of identify her as an individual. But I think [the key worker's] very gracious in her approach and what [her daughter] wants and needs and what we want, but I think it is a bit of resistance with the teachers, which is natural.

(Parent)

A few parents of children particularly in mainstream schools considered that key workers had played an important role in informing staff about their children's disabilities and had changed aspects of the ways in which they were treated:

During his first couple of years in secondary school they always wanted us to pick him up, after a seizure they'd want us to pick him up and bring him home and sometimes he'd recover after about twenty minutes. So again through [the key worker] he has his own room where he can rest in school and then, if he's recovered he'll stay in school, because he used to play on it a bit. If he'd had a seizure, after well he'd know then they've phoned dad now and I'll go and pick him up and so, you know, that was harder for us because he wouldn't, didn't want to go to school then, he'd know he could come home, you know, and we were tied then to picking him up. So that's, that's been stopped.

(Parent)

As with views on the extent to which key workers were in contact with schools, parents' perceptions differed from those of teachers who generally considered that through information sharing and the provision of staff training key workers had considerably assisted them in understanding children's disabilities.

The implications of this increased understanding for the education of disabled children is demonstrated in the following portrayal of the provision made by a large inner city primary school for a boy who was diagnosed with a severe degenerative disease just after he moved into Year 5. About a fifth of the children at the school were on the SEN register and the school had a full-time and a part-time SENCO. The school was concerned about the physical problems the boy appeared to be experiencing and with the parents' permission the SENCOs had been proactive in securing through the family's GP a full neurological assessment which produced the diagnosis. Once the diagnosis was made the SENCOs began contacting the Physiotherapist and Service for the Visually Impaired to secure additional provision for the boy.

At this point the school became aware of the key worker service when the key worker assigned to him, as a result of the diagnosis, first sent a letter to the SENCOs explaining her role and then followed this up with a telephone call and an introductory school visit. She immediately carried out an extremely thorough assessment of the boy's needs which was written up in a detailed report that informed the child's care co-ordination plan. The SENCOs found the report extremely informative and were able to use it to secure funding for a full-time Special Needs Assistant (SNA), some further adjustments to the building, such as the provision of a toilet for disabled children, and later for a statement for the child in order to gain a place for him at the end of Year 6 at a special school for physically disabled children.

The key worker had been extremely helpful in providing information on his condition and discussing it with the SENCOs and the SNA and had also talked to the other

school staff and to the children in the boy's class. Crucially she had greatly assisted in anticipating and making recommendations about provision for his deteriorating condition as he became increasingly disabled to the point where he could only communicate by moving one leg:

It was a massive shock to the family and to school really and because we were determined to keep him here because all his friends are here – he'd gone right through the school with all his friends – so we wanted to keep him in mainstream as long as we could, especially until they moved onto high school ... and we've kept him right through. We've had times when it's been really difficult and we thought we wouldn't be able to manage it but then something has happened that's sort of improved the situation again [the key worker] has come and helped.
(SENCO A)

She has supported us when we got to the lowest point really
(SENCO B)

The SENCOs described how they tackled each issue as it arose, for example feeding had presented particular challenges for the teachers in the earlier stages of the disease although ultimately as his illness necessitated a feeding tube this had been resolved. The full-time SENCO had also accompanied the key worker and family to see the consultant. Throughout, the SENCOs had had a great deal of contact with the parents especially as the boy's father took his son to and from school each day. They described the trauma the parents had been through as they came to terms with the implications of the diagnosis and moved house to one with more space for a wheelchair and adaptations. Consequently the SENCOs appreciated the enormous amount of moral support and practical help, especially in relation to modifying the house, the key worker had provided for the family. They also stressed the distress experienced by the family owing to their loss of privacy and independence 'because they've not wanted this intrusion but they know they've got to accept it, it's so difficult ... so to have one person pulling it together I think is the only way they can do it really'. The SENCOs' knowledge of the family and experience of meeting their son's needs made them extremely supportive of the key worker service.

7.8 Organising and providing training

Several parents expressed concern as to whether teachers had adequate training for the range of disabilities that they might encounter, particularly in mainstream schools. In mainstream schools this was acknowledged to be an issue as with the pressure of government reform there was little time for whole school meetings or INSET on such matters. However, LSAs were sent on training in relation to the particular needs of the children that they supported, and, when a new child with disabilities enrolled at the schools, classteachers and subject teachers were alerted to the particular implications of the disability. In secondary schools SENCOs produced and circulated guidelines and notes for collation in a staff file. In primary schools, because of their

small size and the central role of the child's classteacher, such information was shared informally. However, as expressed by one primary school SENCO, supporting the education of a disabled child could be a very positive learning experience that 'was a real opportunity for sharing information on all sides of [the disabled pupil's] life.

In several instances key workers had personally provided or organised training for school staff. In some instances this was at the request of teachers such as the training on lifting and handling disabled children provided at a secondary school. However, more usually training was instigated by parents or the key workers:

As a school nurse she's obviously, she's doing that for children in school anyway. I did ask for some training to be put in place for the staff, because she's at risk of a heart attack. And I just wanted staff to be aware of what the signs would be for a young child. Because it's not something you normally think about as being a problem with a child. It wouldn't be your first thing. So she did, she arranged that and went in and talked to all the staff.

(Parent)

We were taking a child into school who has epilepsy and a lot of staff were not really sure what to do so she suggested it might be a good idea if we actually got the nursing service in to give every member of staff, and by that I also mean the dinner ladies, anybody who was working with this child training, which in fairness she did, she sorted it out for us... with teaching one had to be after school and one at lunchtime...but we had said it was a priority for this little girl so that was a real positive, you know, it was very helpful.

(SENCO, primary school)

7.9 Liaising with other agencies

Teachers considered that the personalities of the various professionals involved and the time that both they themselves and those professionals had been in post were the main factors responsible for promoting good inter-agency relationships based on mutual respect and information sharing:

I happen to know all the people that are involved in all the other services because I mean I've been in special needs in [county] for quite a few years. When I first moved down I worked in a special school, then I was in a peripatetic special needs service and worked in a language unit and then into autism so I know all the people involved.

(Head of Primary Autistic Unit)

However, all schools found key workers enormously helpful for accessing information from agencies, particularly the Health Services, as Consultants and General Practitioners were thought to be generally reluctant to share information with the Education Service:

What we've used the key worker for is much more to gain information about what was going on in the round .. so as a conduit if you like for information from other agencies and other people ... So instead of parents having to worry that if the child was on oxygen that the protocols for oxygen went to the school and to respite and to the hospital and to wherever else it went, that was the kind of role that the key worker took on. So we would get information like that from the key worker but they would get it directly from the GP. So in a sense almost bypassing the parent which sounds wrong, but that's what she wanted because she...I think there's so much pressure, particularly where you've got a child who has got a progressive condition, who's deteriorating and is spending lots of time in hospital.
(Acting Head Special School SLD)

This view was substantiated by parents as they also considered that the key workers had assisted school staff to liaise with other agencies particularly Health Services.

While teachers' experiences of key workers and care co-ordination were generally very positive, as one Primary School SENCO emphasised:

When it goes wrong I think it really does go wrong because I think a lot of reliance can be put on key workers and you think they are doing something about it and they're not....there's been a bit of a problem with one child that I can think of where I felt more was being done and then I found out it hasn't been...from one meeting to another you would read out and say 'Well you said – 'Oh well I haven't –' and you think 'Oh'.

The SENCO went on to describe how the stress and frustration experienced by one family were considerably exacerbated by a situation created through a key worker not fulfilling her brief and the agencies involved making the assumption that recommended actions were taking place when in fact these recommendations had not been followed through.

Teachers believed professionals from all the agencies to be 'driven by the needs of the children'. They acknowledged the need to capitalise on this commitment through close inter-agency cooperation and viewed key workers as ideally placed to promote such cooperation. However, they thought that long established differences in values, agendas and attitudes to information sharing needed to be overcome if schools were to be in a position to work fully in collaboration with other agencies. Research by Webb and Vulliamy (2003) demonstrates the constraints on cooperation between Education and Social Services exerted by the stereotypical views of each other held by teachers and social workers. Such views surfaced in this research and seem equally likely to hinder effective key working:

Parents get really, really angry with the school – and then you are trying to help to mediate, to help to see a clear picture of what's happening. I think you're having to do it all the time, especially with inclusive education because the education system is so rigid isn't it, I think it's an unnatural system really, education. I mean you rarely move into an employment

situation where there are a thousand people or where you get thirty people in a room who all have to conform. You know, I think it's very, quite, unnatural and to expect people with learning disabilities, who have their own forms of socialising which don't conform with the norm, to fit in is unrealistic so all the time you are having to liaise and to mediate.
(Key worker)

7.10 Adjustments and resource allocation

A central role of key workers is to monitor the implementation of the multi-agency care plan agreed for each disabled child. The data provided a number of examples of how key workers carried out this role in relation to schools. They helped to negotiate adjustments to school buildings and checked that they took place, for example, a key worker negotiated with the LEA and the school to have a ramp put in to enable access to a primary school when a child had to begin using a wheelchair. Key workers also liaised with the various professionals, particularly the physiotherapist, the speech therapist and the educational psychologist, to ensure that children were receiving the help to which they were entitled. Many key workers were also health professionals and able to play a valuable role in liaising with schools in relation to children's health needs. For example, often, key workers were present at the medical examinations that occurred in school and checked on the administration of medication, particularly when this was changed, and on the availability of specialised medical equipment:

She co-ordinates making sure that he's got a spare G tube and any spare equipment and what have you that he needs at school. She makes sure that all of that is in place as well. ... Because of him being in a different Education Authority to Health Authority, it's the Health Authority that are supposed to provide the financing for the equipment but yet it's a different area, so she makes sure that it's all in the right place at the right time.
(Parent)

Key workers also ensured the special resources were available that were necessary both for the comfort of the child while learning and to promote that learning:

He has to have a special chair to sit on ... and he also has to have things such as a reading board, special pencils to use and all that will be in place because [the key worker] will have made sure it is, so I haven't got to worry about that whereas I'd be worried about that, getting him there and will he be able to cope when he gets there but yeah, so she's doing all that for him, so.
(Parent)

Teachers also valued this aspect of the key worker's role as it alerted them to what was available to meet the child's needs and informed them of the care being provided by other professionals. Also, if they had queries or concerns related to the special care being provided these could be raised with those professionals by the key workers and the response fed back.

By achieving building adjustments and resources for an individual disabled child, key workers were sometimes able to make a general contribution to a school's provision for disabled children particularly in mainstream schools. For example, the renovation of the shower and medical facilities and the provision of new changing facilities in a primary school nursery to increase accessibility for a particular child were viewed as enabling other disabled children to be offered a nursery placement. However, even in special schools, by helping to co-ordinate input from various agencies key workers could help extend provision and move thinking forward in ways that might benefit other children:

Certainly they were helpful over the protocols around oxygen and sorting that out which is not something we'd had to have for other children, so I mean you could say the fact that we now have protocols for that, we now have storage of that, we have that kind of facility that might be used. I mean for instance we're having a new child in September who may need oxygen and we've already gone through those, jumped through those hoops and got it sorted.

(Acting head, special school SLD)

7.11 Transport to and from school

Parents regarded a calm smooth passage to school as important for a positive start to the day. Getting their children to and from school was an issue for the majority of parents whose choice of mainstream or special school was some distance from their home, especially if it was not the school suggested by the LEA. While the majority of parents had not needed help from the key worker in getting transport to and from school, several of them had been glad to have key worker support. When in a small minority of cases children went to school on public transport generally they were provided with an escort and usually an escort was also provided when the children were collected by taxi or by special school minibus. If an escort was not available, this was a source of anxiety for some parents. For example, when the escort for one child who attended a specialist nursery seventeen miles from home suddenly gave up the role and the LEA were unable to find a replacement, the mother had to provide the transport herself. This was particularly difficult as her other two children attended the local school in the village where they lived and she had just returned to work. She described how it took four months for the problem ultimately to be resolved by the key worker. Another example was given by the parent of an autistic child who was also transporting her child to and from school. She decided to do this because she considered that the firm providing the taxi service for her child and others with autism did not exercise sufficient care given the children's condition. She described how with the key worker's support she was 'battling' with the LEA to get an appropriate mileage allowance to cover rising petrol costs.

Teachers also acknowledged that transportation issues were frequently a cause of parental concern and that key workers could be very helpful in making the case for changes:

We have transport problems sometimes because ...they had two kids in a wheelchair on one minibus and there wasn't sort of an escort with the driver. So the driver was having to strap in the wheelchairs and there was no escort and there were other children on the bus as well so ... things like that which we have to sort out which sometimes people don't realise. So I have to get on to transport, in this case [the key worker] and I were getting, we managed in the end but we both had to lobby transport at County Hall to explain what the situation was, then they had to get onto the bus company.

(SENCO, Comprehensive)

7.12 Statementing and annual reviews

The approaches of LEAs to statementing differ considerably from one LEA to another. In one case study area, LEA funding in order to facilitate inclusion and generate resources was no longer tied to obtaining a statement. However, teachers regarded a statement as important in order to protect the provision made and in case the family moved areas.

The majority of the parents interviewed had been through the statementing process. Some had received help from Parent Partnership/SNAP Cymru services (see Section 7.15). In many cases key workers had already been involved with families when the statementing process started so they played some role in this process. For parents without firsthand knowledge of the education of a child with special educational needs (SEN) this process could be a complex and confusing one. Consequently, some found the key workers particularly helpful in explaining the purpose for, and procedures involved, in SEN assessment and statementing:

She was very good with that, took a lot of the pressure off us, you know, and well I didn't know how to do it, so I mean she had the knowledge of how to go about doing the statement. I think as a parent, when you've never had a special needs child, you're not aware of how to do the statement and someone does need to help you and she was very good at doing that.

(Parent)

Schools held annual meetings to review the progress of those children with a statement and considered that in these meetings key workers played a valuable role in providing moral support for parents and ensuring that they fully understood the discussion:

We've always asked the key worker to be there... because sometimes with education we use jargon I feel, and parents don't understand and they don't want to say 'I don't understand' especially in meetings where you've got lots and lots of people. I think it can be quite daunting for

parents so at least then they can go away and ask the key worker without feeling a fool.

(SENCO, primary school)

Parents agreed that preparing them for, and supporting them during, annual review meetings was a crucial part of the key worker's role:

[The key worker] will give me a ring a few days before 'Now is there anything that you can think of now that perhaps you don't feel you can bring up but I'll bring up for you or is there anything' - so she's there, she's there at the meeting, we haven't got a problem with that, her being there, because she can always think of other questions to ask than perhaps we can think of, so she will be there at the meeting. She rings me to let me know she's had the date before the school does, you know, to make sure I'm OK with that date, in case we need to change it for some reason.

(Parent)

Parents described how key workers could express concerns 'in such a way that I didn't feel I was complaining' and 'bring up slightly more delicate issues'. Where parents did not attend key workers represented their views and provided feedback for them on how the review went and the outcomes.

Meetings to review care co-ordination plans and annual statement review meetings usually involved several of the same professionals and had overlapping concerns. In several cases the meetings were combined in order to reduce the number of meetings both for parents and professionals and to capitalise on having a range of professionals available to address the issues raised. As one Infant school SENCO explained, this was:

Very useful because all the information comes together at one point and you've got the expertise of the medical services, who all come together, and mum comes, is there as well, you know, we translate everything. So I think everybody comes out with a whole picture so it's very, very useful.

In addition the existence of the key worker service and combining the reviews was found to considerably increase the effectiveness of school communications and resultant action compared to that more normally experienced:

One of the things that I've got, everything I've asked for has come. It's just really good. I've been amazed 'cos I've gone on with some children, in fact I did an annual review yesterday of a child who I've had on the special needs register for six years – he's now got a statement – and I think in February was one of the first times I'd got a hospital report from the consultant involved and he's been going back for six years.

(SENCO, Primary School)

Key workers also cited a further advantage of combining reviews was that the school could be used as a venue for review meetings, especially for families 'who didn't want professionals trailing into their house'.

However, in most cases the reviews tended to take place separately because combining them led to very lengthy meetings and a large number of competing agenda items to be covered. While combining reviews could bring together more professionals and facilitate inter-agency cooperation, the larger the number of professionals involved the more difficult it was to get everyone together on one occasion, particularly Health Service professionals. Also, it was considered potentially overwhelming for parents if there were too many people involved and too many issues to be resolved. Nevertheless, most schools tried to combine review meetings to look at specific needs that directly affected children's education, such as speech and language reviews, and annual reviews. Primary school SENCOs also stressed the value of classteachers attending such meetings in order to 'take ownership of the child' and because of the knowledge that they had of children's interactions and behaviour on a daily basis. However, they acknowledged this was often difficult to arrange unless they took the teacher's class.

7.13 Accessing the curriculum

The interview data suggested that in addition to the processes involved in drawing up a statement of SEN, individual education plans (IEPs) or their equivalent were also often inadequately explained to parents and subsequently a further source of confusion. A minority of key workers, usually those with an education background, assisted parents' understanding of, and their input into, their child's IEP.

Key workers could also offer suggestions to schools on how curriculum access might be improved and represent parents' concerns:

He has seizures and they stopped him doing PE for a time and, you know, they would try and, and sit him in a class and let him read a book rather than go out and do PE which is what we've always fought against, and, you know, they fob you off and fob you off and you just get tired of arguing with them, but then [the key worker] doesn't, she'll carry on and on until something, she gets a result and that's, that's what helps us, it takes the pressure off us.

(Parent)

However, while key worker persistence over curricular matters generally achieved the desired results, sometimes they were unsuccessful. For example, in her interview one parent complained that the school had given the family no advice when they tried to find out about the kinds of computer software their son used at school. They needed the information in order to describe his experience of computer use in a grant application for a home computer and to purchase software for him to use as stimulus and entertainment at home. Both themselves and the key worker had been unsuccessful in trying to get advice.

Parents and teachers also described how key workers had increased the breadth of children's experience and helped make school a more positive experience by:

- Assisting with tailoring aspects of the school's Personal and Social Education to the needs of the child.
- Providing a list of suitable accommodation for educational visits.
- Involving youngsters, who were having difficulties integrating with their peers, in youth projects.
- Raising funds for transport home to enable participation in after school clubs.
- Assisting in identifying friends and mentors, particularly to provide companionship and interaction at playtimes.
- Intervening to prevent bullying and in one case negotiating a change of class.

7.14 Teachers as key workers

Teachers of children with complex needs and SENCOs in mainstream schools viewed a considerable amount of care co-ordination as an integral part of their work and saw themselves as in many ways informally fulfilling a key worker role (see, also Webb and Vulliamy, 2002). Some of the support that they provided for parents was clearly outside of the work expectations of a teacher, for example, the Head of a Primary Autistic Unit described how she went to a tribunal with a child's parents to support them in their claim for a Disability Living Allowance.

A few of the parents interviewed also described how teachers had taken on care co-ordination responsibilities:

School's very good, as I say the teacher for the deaf she .. I mean I would suggest that she is more of a key worker and is more on the ball with his needs than anybody, you know. She's had the visual impairment teacher come into school to do an assessment and to see him and they've had lines put on the steps, 'cos of all the steps into the playground from each of the classrooms, so they've had white lines painted. They take on board, you know, the height of the chairs to his computer keyboard, things like that that weren't really -, you know, they all play a part.
(Parent)

Key workers with a background in Education had particular knowledge and skills to bring to care co-ordination. For example, a designated key worker with a background in nursery nursing, special schools and early years education felt her earlier work had contributed considerably to her ability to fulfil the role:

A knowledge of child development and working with families – and families under stress – working with other professionals and seeing the weaknesses in trying to work with other professionals, chairing and attending meetings and also through the education side the statementing process and all that.

A non-designated key worker, who was a teacher in a special school, considered her appropriateness for the role was also derived from her detailed knowledge of the

children, which was second only to that of the parents, through being with them each day:

I know the kids incredibly well. When the parents talk about the amount of time it actually takes to care for their child, the emotional strains it puts on them when they're in hospital, all those things, I know that because I'm caring for the kids during the day. So I think it's a strength in a way not to be an outsider, a person coming in.

Non-designated teacher key workers also frequently met with parents who lived locally as they usually fetched their children to and from school and often became involved in school activities.

However, those teachers interviewed, who had not personally experienced being appointed as a key worker to a child, considered that key workers from the Health Services had most to offer children with complex needs and their families. As documented in earlier sections, teachers welcomed the additional alternative knowledge and skills that key workers from other agencies could draw on to resolve problems encountered in schools. This expertise seemed to them unlikely to be provided by a teacher in a key worker role:

I think probably you need to look at individual circumstance because .. if you're looking at a key worker for a child that has got a lot of medical issues then it's much better that it be a medical person, simply because they know the routes into the various services that would be appropriate to support the child. I mean Education in a way is a very minor aspect of managing a progressive condition, it's a very, very small part, and probably the least important part if we're honest.
(Acting head, special school SLD)

A few teachers thought that if they were key workers the role could place them in a very difficult position if parents complained to them about their colleagues and that a close relationship with the family might complicate their interactions with the children concerned in a classroom situation. Also, they felt if any Child Protection issues arose with any of the families this would cause tension between the two roles and make a supportive relationship with the parents exceedingly difficult to maintain. A teacher of children with profound and multiple learning difficulties, who was a key worker for two children, acknowledged such potential tensions. In order to emphasise to parents when she was acting in her care co-ordinator role and to enable them to raise issues they might not readily voice to a teacher, she made a point of going to their homes for regular visits and in particular for the six monthly review.

The main constraint on teachers acting as non-designated key workers raised by both those in the role, and other teachers considering its feasibility, was insufficient time to devote to co-ordination tasks:

I think that the main difficulty is the time element. It's how much time it takes and really I'm on the edge of what I can cope with, with it with everything else.... I spend lunchtimes and after school whizzing around and that's OK but I think if you had a number of children in this situation – we're possibly going to have another one – it becomes more of an issue then and that's one of my concerns really that we are going to get more and more children with complex needs into mainstream schools and, you know, where does this role then go to....If I could have release time, you know, it would make – the school just can't afford that kind of finance for it really – even half days when it was coming up to review time to make sure we'd put everything together would make quite a big difference.
(Teacher key worker)

The other main constraints cited by teacher key workers were:

- Lack of access to a child's medical files.
- Having to contact the service manager whenever information on medical matters was needed.
- Insufficient knowledge of specialist and voluntary agencies, the support that they could offer and how to access it.
- Lack of opportunities for training.
- No supervision related to the role or opportunities to offload the emotional demands that it made.
- Lack of understanding of medical and technical terms associated with a child's disability.

Closely linked to the final point were difficulties experienced in understanding the nature of the care coordination being provided and the discussion about it that took place between professionals from very different disciplines:

I actually found the meetings quite difficult. Because there are people there from different disciplines, the language was different and I took a long time to clue in to what was actually being said. ...I found it difficult to understand the perspectives of the different people. OK not everybody, but certainly people from perhaps say a Social Services or a Health perspective. I found it difficult to participate. I felt, if I'm brutally frank, that I was attending the meeting but it was all going over my head so it took me a while to clue in and to find my voice.
(Teacher key worker)

Such experiences mirrored those often experienced by parents in inter-agency meetings. They could make key workers feel ineffectual and considerably reduced their ability to influence the proceedings.

Perhaps unsurprisingly, given these constraints, particularly those of time and training, recruiting teachers as key workers was found to be difficult. However, school involvement was important for inter-agency co-operation and effective care co-ordination:

When we started we tried to get schools on board but schools didn't really know what we were talking about and didn't see the point and anyway it costs £150 to let a member of staff out for a day's training from the school, you know, to cover for the supply so we didn't really get schools involved. So the Education input has always been LEA based rather than school based although obviously the LEA and schools do talk to each other but it's a different stream. Now of course what's happening is heads are saying 'Well what are these joint agency teams and what is happening?' and if school-based SENCOs are being asked to be key workers there's a bit of difficulty over that because schools are saying 'Well we weren't involved', and of course the message is 'We wanted to involve you but it wasn't possible'.

(Education Manager)

7.15 Key worker services and the LEA

Examples in the data of key workers assisting parents in negotiating with LEAs are relatively few. This appears to be predominantly because, wherever possible, parents and/or key workers preferred to make direct contact with schools for information, to make requests and to address queries and concerns. Also, help with negotiations with LEAs was provided by the children's schools and by other agencies, such as voluntary organisations and Parent Partnerships.

The Special Educational Needs and Disability Act 2001 amended the Education Act 1996 to place a legal duty on LEAs to make arrangements to provide information and advice on SEN matters to the parents of children with SEN in their area. Such arrangements may be provided at arms length by the LEA or by a 'bought-in' service from another provider, usually a voluntary organisation, or a combination of both options. These services, known as in England as Parent Partnership services (PPS) and in Wales as SNAP Cymru (SNAP), aim to encourage partnership between parents, LEAs, schools and agencies and so empower parents to play an informed and active part in their child's education. The intention is that the PPS/SNAP assist parents with issues such as SEN assessment, statementing and curriculum access detailed in the earlier sections of this chapter. However, a specific question on the PPS/SNAP in the parent interviews revealed that the majority of parents had not had contact with or were unaware of these services and only eleven of those interviewed had been in contact with them. In discussing their work with disabled children and their families, only three key workers (from three different services) mentioned liaising with PPS/SNAP and one mentioned having information about SNAP as part of their key worker training. Teachers did not mention PPS/SNAP when discussing issues related to their experiences with key worker services.

Parents' experiences of interactions with LEA personnel generally appeared to be negative:

Education I would say that's been the worst, I tend to have more problems getting in touch with people there and getting responses, I'm forever leaving messages for people and they never get back to me.
(Parent)

Accounts by parents of their contact with LEAs over securing school placements and resources and/or obtaining or changing statements were full of battleground metaphors as it seemed everything required had to be fought for.

The stressful incidences described that resulted from negotiations with LEAs often seemed to have occurred prior to the family having a key worker. However, where key workers were involved in such negotiations, they were viewed as a source of knowledge and strong influence. For example, a parent explained how her son's key worker obtained a place for him at the school of their choice:

Education itself, not the school, the actual Education Department didn't want him to go there. Money probably 'cos they have had to adapt it and whatever else. She [the key worker] came and virtually quoted all his rights and said you can't say no virtually and didn't really give them a lot of option.
(Parent)

Teachers readily acknowledged the difficulties and frustrations encountered by parents of children with complex needs in their negotiations with LEAs and occasionally expressed fears that this could induce negative attitudes towards schools:

If they [parents] are looking for special accommodation for the children, for special equipment, they always have to fight. There's always a battle.... it gets very difficult for parents to separate the teacher in the classroom, who's doing something for the children, and the person who sits in the office and says no all the time to all the demands they're having. So it makes it very difficult because the letter headings are all the same. You know, we all work for the same people. We work in Education for these authorities so it makes it very difficult for the parents to separate us...parents do not realise that often teachers on the ground also battle with the authority, you know, and even the people who are sitting in the authority, you know, the next person up, special needs advisors, anybody who sits there, they battle with the next person.
(Head of Secondary Autistic Centre)

However, such fears as those expressed above did not seem to be borne out in the data, as parents made distinctions between the LEA, which they referred to as Education, and schools. As illustrated in the previous sections, while parents experienced numerous problems in relation to their children's schooling they also made many positive comments on the work of teachers.

Teachers attributed the conflict between LEAs and parents to arise predominantly from a combination of parents' awareness of, and willingness to pursue, their rights,

which meant they would ‘fight’ for their children to go to the school of their choice rather than the one offered by the LEA, and the government’s inclusion agenda which they regarded as grossly underfunded.

Education Departments— particularly in three of the case study areas - also incurred criticisms from those involved in the provision of key worker services for contributing less time, effort and/or financial assistance to those services than the Health Services and the Social Services – the two principal agencies maintaining the key worker services and from which the service managers were drawn:

Generally education has always been slow to take on and embrace the idea of care coordination. It has been, and it still is, a bit of an uphill struggle.

(Manager, Social Services)

I think Education hasn’t really, I guess, played its part. They seconded one of the key workers, who worked in an Early Years Centre, to come over and work as a key worker and I suppose there was somebody from education on the Steering Group and involved in the recruitment process, but as for like everyday, day to day functioning, not a great deal of input really.

(Key worker)

The situation above described by the key worker was attributed mainly to two factors in the way in which the service developed. First, Social Services had provided the framework for assessment and the line management for the key workers. Second, initially the Health Services had dominated the Advisory Group. These factors led to education being marginalized from decision-making about the service even though they provided financial support though the secondment of a key worker. Other explanations offered across the sites for perceptions, as one education manager acknowledged, that ‘education are not participating’ were that children with complex needs for whom the key worker services were set up were a tiny minority of the children provided for by education; the steering group and meetings to discuss referrals and allocate families to services were poorly attended by the education representatives; and it was difficult for LEAs to secure teachers as non-designated key workers for the reasons outlined in the previous section.

7.16 Summary

The approach to introducing key worker services to schools appeared rather *ad hoc* and unsatisfactory in the schools visited and data from parents and key workers in the other areas suggested that this was the case across all the sites. Also, the tendency for key workers to wait for a problem to arise at school before making contact could lead to key workers initially experiencing difficulty in establishing positive relationships with teachers and being reactive rather than proactive. Given the amount of documentation going into schools, periodically circulating information

about key worker services by traditional or electronic means seems unlikely to improve the situation. However, as one Primary SENCO stressed 'If a family has a keyworker I really do feel they should introduce themselves to the school straightaway'. Key workers were best placed to introduce a key worker service as part of their first visit and at that point the distribution of brief documentation outlining the main aspects of the service to the staff involved could prove helpful. Teachers also thought if children at one school could have the same key worker, or maybe more realistically two or three key workers might be attached to a cluster of schools, this would facilitate communication and collaboration. The findings also suggest that links between PPS/SNAP and key worker services were variable and could be strengthened by a more proactive approach.

Key workers helped parents to improve their children's education and school experience by:

- Helping in the identification of appropriate schools.
- Easing transition from one phase of schooling to another.
- Securing in-school support.
- Securing improvements in transport to and from school.
- Negotiating building adjustments and resources.
- Communicating parents' views particularly on sensitive and/or contentious issues.
- Crisis management and resolving problems.
- Increasing schools' cooperation with other agencies.
- Explaining and contributing to statementing and annual reviews.
- Increasing access to the curriculum and extra-curricular activities.

Little comparison can be drawn between designated and non-designated key workers in relation to the extent and effectiveness of their involvement with schools. In part this is due to the fact that mainstream teachers in particular were unsure whether or not key workers were fulltime in their role or combining it with work from the agency with which they were associated. The personality of the key worker, their familiarity with and confidence in working with schools and the importance that they attached to this aspect of key working were clearly crucial factors in influencing teachers' attitudes and schools' provision - possibly more important than their full or part-time status. As one headteacher expressed it:

I suppose the one that is designated you would notice that perhaps. She will focus on certain elements a little bit more because she's probably got a bit more time to do it I would say. I mean she is the one that has taken on board the epilepsy and has got in in terms of doing that but that's a particular background of hers. The other ones, they do it as part of their role and are perfectly I think adequate in terms of what they've done for the children. You know, there's no difference in that sense.
(Head Special School)

Teachers considered that key workers in addition to their primary role of supporting children and families greatly assisted schools in providing a better education service for disabled children through:

- Promoting understanding of particular conditions and their implications.
- Helping schools cope with regressive conditions, where contrary to the usual expectations progress could not be achieved.
- Bringing together the information and advice offered by different agencies.
- Identifying, speeding up and improving agency provision and resources.
- Raising teachers' awareness of home factors influencing children's attitudes and behaviours.
- Mediating between families and schools.
- Helping resolve problems experienced in school and/or in getting to and from school.

These findings also serve to demonstrate the potential of key workers to play an important part in assisting schools to meet their responsibilities under the DDA 1995. In the words of one secondary Learning Support Teacher 'I think they're excellent, please can we have some more'.

Chapter 8: Interviews with Families

“She's just, she's the first person to come and look at my child as a whole...”

In this chapter we report the findings from 68 interviews with parents and guardians of disabled children and nine children who were users of the seven key worker services. Parents were asked about a variety of topics, for example the various aspects of the key worker's role, how the key worker service could be improved, and the quality of the services they received from the three statutory agencies. Children were asked questions such as: if they knew their key worker, what they liked and disliked about their key worker, and whether their key worker listened to them (see Chapter 2 for more detailed information about the interviews). Results of the interview data analysis are reported below in three sections concerning 1) parents' views on the key worker service, and 2) other services, and 3) interviews with children.

8.1 The key worker service

8.1.1 Professional backgrounds of the key workers

The professional backgrounds of the key workers with whom the families were in contact varied. These were the following: nursery nurses, teachers, health visitors, nurses, speech and language therapists, occupational therapists, social workers, workers in voluntary agencies and care workers.

8.1.2 Choosing or being assigned a key worker: advantages and disadvantages

Families in designated key worker services were usually assigned a key worker. Families in most non-designated services were asked to choose a key worker from the professionals with whom they worked closely. The parents interviewed were asked to discuss the advantages and disadvantages of how they had received their key worker.

Those who had chosen their key worker were generally already happy with the way that professional worked, they already had a good relationship with them, they were familiar with them, they knew they got along with them, and their child already knew them. These parents felt that it “made sense” to have as their key worker someone who already knew the child and was familiar with the family:

... she knew us, she knew the family, we knew her, we were comfortable with her, why have another stranger come into the house when we're

already comfortable with her. So she approached us and I fully accepted it.

However, the family's choice of key workers may be limited, because only few professionals have the capacity to take another family on their caseload.

Yeah, well I suppose so and really your choice is actually limited when you think about it, because there's only certain really, certain people particularly if it's an add-on to your role that actually have got, well in a way they haven't got the capacity cos they've already got heavy caseloads.

On the other hand, parents who had been assigned a designated key worker were generally satisfied with that arrangement too. They expressed that the designated key worker had more specialised training and more time to perform their role:

I'm happy to have somebody assigned to you cos you know they're in that role, they're specifically for that role, rather than say "Well we'll have the physio as the key worker to co-ordinate everything" it's better to have somebody outside of that that might have more specialised training...

8.1.3 Parents' understanding of the key worker service and role

The key worker service was generally introduced to the family through professionals (for example, the health visitor, physiotherapist or paediatrician) who worked closely with the family. Some of these professionals would later become the family's key worker. The professionals would briefly describe the service to the family and ask if the family was interested. Then, the key worker service would get in contact with the family and a key worker would be chosen or appointed. Subsequently, the key worker would more fully explain to the family what the role was. Although two thirds of parents interviewed expressed that they had received a clear enough explanation of the key worker service and the key worker's role, a third of parents felt that they had received vague or insufficient information.

The level of information initially provided to the parent as an introduction to the service varied widely amongst services and also within some of the services. Two services consistently provided the families with leaflets and explained the key worker's role to them. When asked to describe the key worker's role, all families within those sites were able to provide an adequate description of the role:

The key worker's role in general... to ensure that we had every possible service available to us that we were entitled to, to maintain the smooth running of these services once in place and also to provide emotional support if and when required.

In five services, parents' understanding of the role varied, as did the amount of information they had been given. For example, within the same service, some families had not received much information, while others said that their key workers had carefully explained their role.

No, it wasn't. No, they didn't, they just said that a key worker would be replacing the social worker basically to a degree, I mean I don't think everybody's been allocated a key worker, certainly friends of mine haven't, so. But no, it hasn't been explained.
(Family 1)

Yes, she explained herself, she explained what she was there for, every meeting we had about every, up to about nine meetings we had after that, she explained in a row what she can do and what she can't do and what she can intervene with and what she can't...
(Family 2)

When families had not received an adequate explanation of the role, many were confused about it, and some families had very high expectations of the service, which then led to disappointment, while other families had no expectations of the service at all. Many of the parents who initially had not been given a clear presentation of the key worker's role had gradually understood it over time, as they watched their key worker provide a service to the family.

8.1.4 Ability to coordinate care

Most parents reported that their key worker was able to help them across the range of services and agencies. One designated service comprised a multi-agency team located in the same building and some of the parents referred to them as a place where they knew that someone would be able to help them: if not the key worker, then one of her colleagues. The parents in all services were generally aware that key workers were not knowledgeable in all areas, however they appreciated it when key workers would do their best to collect the necessary information and get back to them.

When asked if their key worker was able to work across agencies and coordinate care by liaising with different professionals, all families in two services said that they felt their key worker was doing so. In the remaining services, families' responses varied depending on the key worker. Only in one service did the number of families that felt that their key worker did not coordinate care outnumber the families whose key worker did coordinate care. In this site, only two families reported that their key worker was working across fields and agencies and the remaining families interviewed did not.

Often, when the key worker was not coordinating services appropriately, families would attribute that to their lack of knowledge in those fields:

...for example (child)'s care co-ordinator has been very, has been great with things which are her remit which is things like perhaps respite... but if it came to something, if I had a particular medical issue that was

something entirely different, she wouldn't particularly know that much about that.

8.1.5 Contact with the key worker

Most families expressed that their key worker had enough time for them. Families appreciated when the key worker made them feel important and their visit was not rushed:

She never ever looked at her watch or, she just took what, I'm sure she, in, inside her she was very aware of her next appointment but she never let us feel that she didn't have time for the last question or, or, yeah.

A few families said that their key worker needed more time for them to carry out the key worker role.

Most of the time, the key workers were easy to get hold of. Families usually had both an office number and a mobile phone number for contact. In two services, all the parents felt that the key workers were easy to get hold of. Often parents would leave a message on an answer-phone and the key worker would get back to them in a fairly short period of time. In the other five services, parents who deemed their key worker not easy to get hold of ranged between one and three parents per service. In all cases, this occurred when the parents only had an office contact number (rather than a mobile telephone) and the key worker was rarely available in the office.

There was a wide variation in the frequency of contact between the key workers and the families. Frequency of contact also depended on what the family was experiencing at the time and how much they needed their key worker. Therefore, when setting up the services they needed, key workers would visit the family more often, while later leaving more time between appointments. In between appointments, the family was told they could telephone the key worker if necessary.

In two sites, most of the families responded that they were in contact with their key workers between once every two weeks and once every two months. In other services, there was a wider variation among families: between once every two weeks and once a year. In five out of seven services, at least one family responded that they saw their key worker once a year.

Both key workers and families initiated contact. Generally families would make contact when a problem arose. On the other hand, key workers would make contact routinely to check how the families were doing and to inform them of any breakthroughs and successes in providing for the family's needs:

She normally, she normally calls us every couple or two or three weeks she calls us, if we get a problem we phone her... just leave a message and she does ring back within an hour, as soon as she gets the message she rings us straight back.

8.1.6 Characteristics of a good key worker

Families were asked what they thought were the abilities and characteristics of a good key worker. The following skills and personal characteristics were identified:

- Knowledgeable, informed and knows where to find the information necessary.
- Knows what it is like to have a child with a disability (possibly is a parent of a disabled child).
- Organised.
- Able to chair a meeting and speak on parent's behalf at meetings.
- Able to liaise between different services, agencies.
- Able to communicate information at different levels: to families and to professionals.
- Is good with the disabled child.
- Includes the whole family.
- Available at the other end of a phone.
- Treats all that is said as confidential.
- Respected by other professionals.
- Calls the family regularly, will call back when contacted.
- Is persistent, demands that things get done, pushes things forward.
- Friendly, approachable.
- Compassionate, caring, enthusiastic.
- Has tact, diplomacy.
- Listens and is not judgemental.
- Respectful of the family, doesn't make them feel like they are exaggerating situations, treats them like 'experts' on their child.

8.1.7 Training

There was a general acknowledgement and acceptance of the fact that the key workers could not be experts in every field. Most families expressed that when the key worker was not informed, they would find out and report the information back to the family. Hence, some lack of knowledge on behalf of the key worker was acceptable as long as the key worker would find the information and get back to them promptly:

No, I mean nobody can know everything and it's very foolish to expect somebody to know everything but I mean where, when I've asked something, if she doesn't know anything about it she's gone away and found out and come back to me. So I don't feel that there's a particular skill or, or, you know, part of the service that is lacking in any way.

All services had at least one parent who felt that their key worker needed more training. Between one and three parents per service said that the key worker needed more training. The child's disability was mentioned more than other training areas as

something the key workers could learn more about. The other areas where additional training was desirable were: the key worker's role, education, benefits, social services, direct payments and occupational therapy.

8.1.8 Empowering parents

Families were asked if they had learned something from their key worker. Some families reported that they had not learned anything particular from their key worker. In these cases either the key worker had been assigned to them when the family was already familiar with services or the key worker had not been very pro-active in liaising with services.

Other parents' views concurred with those of key workers (described in Chapter 4) that they had learnt from their key workers modelling strategies for accessing services. They had gained awareness of the different kinds of services available to them. Along with this awareness, came the tendency to fight for their needs to be met and being more confident in demanding what was needed:

Her attitude is, you know, you've got to keep fighting for what you want and I've picked up a lot of that off her as well.

This awareness included the concept that their children had rights which should be respected:

I didn't know he himself had any rights, I didn't know none of the disabled rights which (key worker) promoted more to me, she let me know all of them, yeah, definitely I didn't...

Other ways in which key workers had contributed to parents' learning included modelling ways of organising the large amounts of information families collect on their child and the services they receive and learning from the help key workers provided in dealing with forms which had to be filled in to obtain services:

I've learnt how to fill in forms (laughs). That's something, all these complicated forms. Yeah, I'd probably say forms more than anything but I mean, you know, because I do, I get so many forms that I do have to fill in and some of them are quite complicated but, you know, and she does help me fill them in and, but I'm getting used to them now.

8.1.9 Stress levels before and after having a key worker

Most families said that their key worker had reduced their stress levels considerably. This was due to the services provided to them (for example, respite care or help with housework), and spending less time looking for information, writing letters and making telephone calls. Meeting the extra care needs of disabled children is time consuming for parents (Roberts and Lawton, 2001) and trying to find time to 'chase up' professionals in addition to this is stressful for parents. By taking on that role, key workers relieved stress:

... we have a mental list of people to phone, things to do... and it's very difficult sometimes if you've got a child with special needs to think, right, well I'm going to make a phone call now... or to take a phone call, you might be in the middle of feeding, you might be in the middle of doing some physio stuff and sometimes it's very difficult and... you try to phone somebody and they're not in 'Can you phone back in half an hour?'... and sometimes it's just something you can pass over to (key worker) and... she'll do that for you...

In two services all parents said that their key worker had reduced their stress. In all the other services, there was at least one parent per service who felt that their key worker had not reduced stress. Generally this was attributed to the lack of a proactive attitude on behalf of the key worker, and these families still had unmet needs or were still coordinating care largely on their own:

In a very minor way as in when we've needed services, you know, getting the final OK to them, but a lot of the, a lot of the sort of admin being done by me.

8.1.10 Repetition of the family's story

There were high numbers both of families whose key worker had helped reduce the number of times they repeated their story to other professionals, and of those who said that this had not occurred. Amongst those who expressed that their key worker had not reduced the number of times they told their story, some said that particularly medical professionals want to communicate only to the family rather than to the key worker:

... (Key worker) has been on quite a lot of the visits to the professionals when we've been having problems and things she's come along but it's, they always want to speak to the parents, do medical profession anyway, so no, I don't think she could have done, no.

One key worker had drawn up a brief history of the child that they could give to professionals involved with the child. By doing this, parents were not required to repeat the same information many times. After reading this, professionals could come back to them with specific questions:

But one thing that (key worker) did that was really useful was she made a, like a brief history of (child)'s kind of life and if we were getting involved with a new professional she'd send it on to them so that they'd have that information. But I mean of course they'd want to know bits and pieces from us anyway but I did find that really useful.

Some families believed that the care plan review meeting, rather than the key worker, was particularly effective in reducing the number of times they told their story. At the meeting, the new professional would learn about the child and family by listening to other professionals discuss their care.

Particularly when the key worker was not working very closely with the family, they were repeating their story to professionals:

...and I wouldn't really expect it to because, you know, she'd have to be involved with us a lot more closely for me to be able to hand over that... I couldn't delegate, you know, that type of thing to someone who... I see (key worker) once every four months...

8.1.11 Effect of the key worker on the number of professionals seen

Having a key worker did not automatically reduce the number of professionals the family interacted with; most families reported that they interacted with the same number of professionals. However, whilst key workers did not reduce the number of professionals, they made sure that the family was seeing the right professionals:

I think it's, it's interaction with the right professionals now and the ones that we actually require.

Some professionals were closely involved with the family's care and the family had to interact with them regularly regardless of the key worker. These were for example the physiotherapist, the occupational therapist, or medical staff:

...but it's never going to take away the number of appointments that you need with, you know, and the specialist or, it doesn't take those away because that's who you have to go and see and your care co-ordinator can't replace that person.

A few families also expressed that they were happy to have been in contact with more professionals since having a key worker:

...I've met more professionals since (key worker) had a finger in the pie sort of thing than I would have normally because I would have had to rely on (hospital)... and I don't think I would have pushed myself if she hadn't of been there to give a helping hand because, to be honest, I wouldn't have known where to go for half of the stuff that she's been able to sort out for us.

8.1.12 Relationship between the child and key worker

Although many parents expressed that their child had limited understanding of the key worker's role, it emerged that many children had a general understanding that the key worker was someone who was there to help. Other times, they knew the key worker in her main professional role but not the key worker role. Even when children had no understanding at all of the key worker's role, either due to age or disability, parents appreciated when the key worker would spend some time with the child, for example, sitting down and talking to them rather than not noticing the child and speaking directly to the parent:

...she will make a point of coming over and sitting by him 'Hello (child), how are you today?' Whether he knows, well I sort of know you but I don't know who you are, he wouldn't know who she was, but it's not just a case

of 'Oh hello (child) and off' she sits, even if it's just for two or three minutes, she'll sit there to talk to him.

Parents valued when the key worker communicated to the child in a way the child could understand, for example using simple language. If the child did not have verbal communication, they appreciated when the key worker made an effort to learn how to communicate with them (for example, Makaton). By making the effort to communicate, the key worker was acting more like a friend than a professional:

...she can use Makaton sign language and she can communicate with her on that level and she's just, I don't know how to describe her, she's, she's not like a professional, you know, she'll just come in and see (child).

One mother said that she valued the fact that her key worker would always identify herself when speaking to the child, who was visually impaired and had brain damage. This made it easier for the child to know who she was:

...so she's obviously picked up some skills from that, that when you walk up to a child you don't just say 'Hiya (child)' you know, you say 'Hello (child), it's (key worker)' so he knows who it is basically.

However, when key workers contacts with families were infrequent, some children very rarely saw their key worker.

8.1.13 Key workers' roles with other family members

Most often, the mother was the person whom the key worker visited. However, many key workers would commence the visit by enquiring about the different members of the family and this was highly valued:

... if I would have rang her or something 'Oh hello, how are you? How's (child)? How are you doing? How's your partner? How's the children? How's the other daughter who lives in (place)?' you know, she would ask about the whole family.

Parents cited a number of examples of key workers taking a holistic approach and supporting other family members. Some key workers would involve the other sibling or siblings, for example, by playing with them or talking to them during their visit. Some key workers had also arranged counselling or siblings groups for siblings to attend. One mother had expressed her concerns about the sibling being dyslexic and the key worker posted her some information on dyslexia, indicating that the key worker was interested in the family as a whole:

I said "You know I'm sure she's a little bit dyslexic and this that and the other." The next minute in the post there was information for me, she didn't have to do that but she did off her own back.

One key worker had organised marital counselling for a couple that were experiencing marital problems after the child's diagnosis. In another case, the key

worker knew that the child's father was finding it difficult to accept the child's disability, and provided support for the father and child to do things together:

Whereas (father) totally blanked it, wouldn't accept it and she said 'What he needs to do is he needs to realise that he can do things still' and she arranged... for (child) and (father) to go fishing, she said 'Think of something that (father) enjoys' well (father) enjoys fishing and she said 'Well that's something that (child) can still do with him' and they went to a big pond somewhere and she, she arranged all that...

Although not the majority, there were some key workers who did not enquire about the family or see the family as a whole. These tended to be the situations where key workers were not coordinating care appropriately on the whole and parents were dissatisfied with the service. For example, one parent said that the key worker would do something for the family only if they asked her to and another said the key worker spent too little time with them to consider the whole family's needs.

8.1.14 Assessment and review meetings

Meetings were generally held six-monthly or annually either at the family's home, at the hospital, at school, or at nursery. There were advantages to having the meeting outside the home; for example there was enough space for everyone and meetings in these locations tended to be more central and therefore more accessible. The children did not usually attend, except for those situations when the parent specifically wanted them to. For example, as her child had got older, one mother had started to bring him to the meetings rather than just letting him read the reports afterwards. Generally, all the main professionals who had contact with the child were invited, however not everyone would be present at the meeting. Particularly parents reported that paediatricians and GPs would not be able to attend and would send a report or a letter about the child. In many cases, after the meeting, the key worker would type up her notes, which contained the minutes of the meeting, a report from each of the professionals, and an action plan where professionals would commit to taking action before the next meeting. This paperwork would then be signed by the key worker and by the family, and sent to the family and all the professionals involved.

Most parents appreciated the meetings where all professionals involved with the care of their child would meet to assess and review the child's needs and the progress they had made in meeting those needs. Parents felt that people had made time to gather to discuss the family's needs and they also appreciated the sharing of information across fields and areas of knowledge:

I mean I've really enjoyed the co-ordination scheme for having those meetings every six months if for nothing else. I think those have been brilliant because for an hour/an hour and a half, you know, we've got like so many individuals all in one room, all who know (child), and talking about him and his needs. And I find that invaluable...

Services varied in the amount of support the key worker provided during these meetings, from full support to the parents to little or no support. In two services key workers appeared to consistently chair and organise the meetings and support the parents during those meetings. In these services, the key workers spoke on behalf of the parents and pushed other professionals to deliver services. In another two services many parents had complaints about the level of support they were receiving from their key worker, for example, the key worker was not at the meeting, they did not speak on behalf of the family, they made excuses for why the child was not receiving services, and key workers had failed to organise a new meeting. Support varied in the remaining services. The following two quotes show how differing levels of key worker support are possible before and during a meeting:

Yeah, she actually co-ordinates it, she's chairperson, whatever, and before it I have a meeting with (key worker) on my own and put any relevant points that I've got to say like say I've got a problem with... the physio, I'll tell (key worker) and they go round then into school and see if there's any problems... same as physio, occupational therapy, who else comes, Social Services..., social worker, they, they all come and any problems I've got I've already pre-discussed with (key worker) cos I forget, halfway through the meeting I trail off into a different conversation and I'll come home and oh I never mentioned this. So I always have half an hour with (key worker) prior where she notes everything down for me.
(Parent 1)

(Key worker) really, has a supportive role. She comes along and she doesn't really contribute verbally to the discussion but she is there and she will just help beforehand if I've asked for say the educational psychologist to be present at a meeting she will arrange that.
(Parent 2)

In the sites where key workers supported families most, in consultation with parents, the key worker would prepare a list of the professionals invited and then would liaise with them about the meeting and who was able to attend. Families were most satisfied when, prior to the meeting, the key worker asked them what issues they wanted to bring up and what goals they wanted to achieve and then ensured that relevant professionals attended the meeting:

...and then she'll usually run past me who's been invited and then I'll say something like well why's nobody there from so, so and so, so she'll make sure they'd come along. You know, it's that sort of thing really. There's a few phone calls going backwards and forwards, you know.

The key worker's support during the meeting was necessary because parents felt that it can be intimidating to speak in a room full of professionals, particularly if they have something unpopular to say. Parents wanted to know that the key worker was on their side, and appreciated when the key worker acted as an intermediary between the family and the professionals. One parent said that her key worker knew

her so well that she would intuitively recognise what she was thinking or feeling like during the meeting:

She is my representative so to speak, because they may be saying things that I'm thinking oh I don't quite understand what they want there, but (key worker) would stop that meeting and she will say 'Now can you make that a little bit clearer?'

Parents enjoyed an informal meeting, where they felt comfortable to speak and to express their opinions. Families valued when the key worker would ask professionals to commit to taking action. While the key worker can press a professional to commit to a deadline for getting the work done, the family may not feel comfortable taking on that role, or they may not achieve the same results as the key worker:

...and (professional) will say 'Oh I can get in touch with the incontinence nurse for you' and (key worker) will say 'OK'... and she'll say 'When are you going to do it?' and (professional) will say 'Well I can do it as soon as I go back to the office.' 'So you're committed to doing that this afternoon are you, you'll definitely do it today?' And I think she pressures them into doing it today, whereas if I phoned her up and said 'Can you get in touch with an incontinence nurse for me' she goes 'Yeah' and six weeks later I'll probably still be sat waiting.

In four services, at least one parent had attended a meeting without their key worker. In one of these, one parent said that she regularly performed the role of organising the meeting. This parent was not aware this was the key worker's role.

8.1.15 Characteristics of the service parents appreciated the most

Families were asked to comment on the characteristics of the service that they appreciated the most. Families appreciated:

- The availability of the key worker.
- The key worker meeting the family's needs.
- That key workers were good listeners.
- Having someone who was 'on their side'.
- The access to information.
- Relief from stress and extra work.
- Not repeating their story many times to different professionals.
- The care plan and review meetings where all professionals gathered together.

8.1.16 Problems with the key worker

Parents from two services did not have any problems. Parents from five services identified problems with the key worker service they were receiving. In two of these, about half of the families who were users of the services had one or more problems.

In the other three services, one or two families per service had problems. Two main themes in the problems concerned the key worker not being proactive and not having enough time for families.

One of the most common problems was that the key worker was not proactive enough in meeting the family's needs and coordinating services. Some key workers limited themselves to giving the family advice, rather than actually chasing up other professionals and making sure the family's needs were met. For example, a key worker would suggest that parents do a search on the internet for information about a service they needed, rather than obtaining that information themselves and then bringing this information back to the family, or key workers would provide parents with another professional's telephone number, rather than making the telephone call themselves. Some key workers would not take any action for the family unless the family suggested it themselves and some families had learned that if they did not take action themselves, nothing would ever get done. Some families had a nominal key worker who was not coordinating care at all. These families were coping alone or had found other professionals who could help them informally:

Yes, but she's not proactive apart from things that are within her area, but she would do something if I asked her to do it, but I would be the one who would be saying that, not her.

Parents also commonly expressed that to perform the key worker role to its full extent, the key worker would need to spend a considerable amount of time with them, which they did not have due to a heavy caseload. Parents were aware that non-designated key workers already had a caseload of children for their main professional role and some parents felt that the key worker role should be a job in its own right:

I think it's a job in its own right and it's a specialist job in its own right. I don't think it should be tagged on to somebody's job.

Apart from proactivity and time, there were also other problems. For example, some parents had been waiting for months for a replacement key worker and had not received one. In the mean time they had outstanding needs that had not been met.

Parents who had never received a definition of the key worker role were confused about what to expect from their key worker. In some cases, the family originally had high expectations, and not receiving a sufficiently pro-active service had caused some disappointment:

I think the main thing you've got here is that nobody quite understands what that, what that service is and what it should be, quite possibly even the people doing it

Some parents expressed that the key worker lacked any power to make decisions. For example, parents had understood they were going to receive a service and then realised that the key worker had to go back to their line manager or a 'panel' before

any action was taken. Parents were frustrated by the fact that people who did not know them were making decisions on whether they should obtain a service or not. Parents were aware that there were limited resources for the number of children needing them, that they were competing for a service they all equally needed, and they felt that this was unfair:

I feel that she's there to represent us but she doesn't really have much power... She then has to persuade the panel, whoever this panel is and she's constrained by knowing that there are other people who need things and there's only so much money to go round.

8.1.17 Suggestions on how the service can be improved

Parents were asked how the service could be improved. Most of the suggestions came from those services where families had experienced problems (see 8.1.16) and suggestions tended to reflect the kinds of problems families had experienced. In the two services where no problems had been reported, most parents said that they could not think of any improvements, some said that more families should be receiving a service, and one family said that key workers should receive more training in all areas. In one of these two services, the key worker service was time-limited and one parent suggested they should have the service for a longer period of time.

In the other services, many of the suggested improvements reflected the areas that parents perceived to be more problematic. Of these, the two more prevalent complaints concerned time for the key workers and funding for both key worker and other services. Suggestions were:

- Key workers should have more time for families.
- More funding should be put into both key worker and other services.
- Key worker role should be very clear to families.
- Key workers should have more authority to demand families receive services.
- Parents should receive a key worker before or at time of diagnosis.
- Key workers should be given more training.
- Families should receive more information about services.

8.1.18 Length of time families needed a key worker

Only a few of the families who currently had a key worker expressed the view that they would not need the service in the future. Two families (from different services) said that as time went on they were more knowledgeable about the system and eventually would be able to relinquish the service:

As (child) grows up you learn how to find a lot of things out for yourself and you, and you know the people that you should go to for this, that and the other...

One of the services operated by assigning key workers to families for a period of approximately six to 18 months. The aim of this service was to empower the family and help set up the services they needed until they were able to cope on their own. Out of the ten families interviewed in that service, seven had exited the service by the time of the interview. Four of those who had exited the service were coping well on their own and felt that it was only fair that other families should receive a key worker service. Three families expressed that it was not the same without their key worker. One of these had moved to a new area and was experiencing a lot of difficulty finding information about services. Two now had a social worker, but did not have the same relationship with them:

Well I've rung him, it took me about four days to get hold of him... and when he did ring me back, he just said, I told him what I'd done and he said 'Oh well, you're doing all the right things, if that doesn't work, ring me back' which, whereas (key worker) would kind of straight away said 'Right, fine, what do you want me to do?'

8.1.19 Advice to other families who were considering having a key worker

When asked what advice they would give to other families who were considering having a key worker, most interviewees advised other families to 'go for it'. Most of the families who had chosen a non-designated key worker advised other parents to make sure they chose the right key worker for their family. For example, it was important to choose a professional who was already doing their professional role well, who was proactive in their professional role, and whom the family felt comfortable with:

I think it's got to be someone that you get on with, someone that you feel comfortable with as well isn't it, someone that's approachable and you know you can trust as well, trust and confidentiality, there's lots of things. But I think it's got to be someone that you like and they like you, you know, and that they, they do get on with the children, that they're used to dealing with disabled children.

8.2. Other services

Families used a wide variety of services. These included respite services, playgroups, leisure activities, sitting services, holidays, physiotherapy, occupational therapy, speech and language therapy, benefits, housing, transport, counselling, educational psychology, siblings groups, and groups for parents of disabled children. Key workers coordinated services from health, social services, education, and voluntary agencies.

8.2.1. Family's greatest need in terms of services

When asked what their greatest need was, the most common answer was a need for respite care. Some families had been or still were on a long waiting list for respite care:

It's only now I've got the respite, I mean he's 13 years old and we've been asking for respite since he was about eight or nine.

Other outstanding needs were: very long waiting lists and oversubscribed child and adolescent mental health services, lack of counselling services for parents, waiting lists for housing adaptations, and lack of activities for the child such as after school clubs, the need for more speech and language therapists, and long delays in provision of equipment.

Parents also spoke about disjointed services. Particularly, they felt frustrated by professionals using different budgets to access services, causing confusion and delayed access to services. For example, a family was looking for specialist equipment. They had found two pieces of equipment, which were funded by different agencies. However, obtaining a combined piece of equipment with joint funding was very difficult:

...we've got a seat stander and there's one department that would provide the funding for a specialist chair for him and a different department that would provide the funding for a specialist stander for him. But we wanted a piece of equipment that did both jobs because we've got a limited amount of space and plus there's a limited amount of handling, we didn't have to lift him from a chair to a stander, which is easier on him, easier on us... But the fight, the battle that we had on to get a combined funded piece of equipment from two different departments was ludicrous really.

8.2.2 Families' experiences with specific services

Respite services

Families required carers who were appropriately trained to look after their child and respite services which allowed them to relax and to spend time with their other children. Families across all sites mentioned a number of issues concerning respite care that were problematic. Some families had waited for long periods of time, sometimes years, for respite care. Some children had been matched with inappropriate families in family-based short-term care schemes, and sometimes there was a lack of continuity in respite carers. Sometimes the respite provided was not suitable for the child. For example, a respite facility that was very noisy and chaotic would be disorientating to a child who was blind. Another issue concerned having respite when the family needed it most, for example when the child was ill or during an emergency. Most often, respite was available when most convenient to the carer. Carers could cancel respite at short notice and generally it was not

possible to obtain their help at short notice or during an emergency. Sometimes respite care was too far to reach geographically and therefore the child could stay there only a week at a time. Other times social services would offer respite care that was far away and transport was not included. One family complained about the absence of male carers. Another family said they could lose their respite care too easily, for example, if the carer retired or moved to another area:

...it doesn't take much for that whole system to collapse cos all you need to do is for her to be ill or something like that and then you've lost it.

Although across sites there were complaints about respite care, there were differences among sites in the ways that key workers dealt with the above-mentioned issues, the most common area of difference being the availability of respite. With regards to availability, in the services where the key workers were more proactive, even when it all first appeared that respite care was not available, some key workers were able to put pressure on until it was provided. On the other hand, in those sites where key workers were less proactive, parents felt that key workers were more prone to accepting the status quo concerning the absence of respite care.

Benefits

Parents expressed that three main issues concerning benefits were the complexity and length of the Disability Living Allowance (DLA) forms, the family's underestimation of the benefits they should be receiving, and the need for clear information on the benefits they are entitled to.

Many of the families interviewed commented that the DLA forms were too long and complicated to fill in:

...they are, a nightmare actually, they're a nightmare to fill in

Without the help of the key worker, families had underestimated the amount of benefit they could receive, and they had not known how to word the DLA forms. Some families did not know they were entitled to benefits and the key worker had shown them what they were entitled to. Sometimes families had been receiving the lower rate for years when they started using the key worker service, and the key worker then had re-applied for the higher rate, which they should have been receiving from the start.

There appeared to be differences in how much key workers helped with these three issues of completing DLA forms, ensuring the families were receiving the right benefits, and providing information. For example, in a service where key workers tended to be more proactive, the key worker had taken action to ensure that the family received DLA for a longer period of time than it had been conceded to them:

We had problems with (child)'s Disability and they were only going to give her Disability for two years... and (key worker) said... 'No sorry, that's not

good enough...'. So now (child) got it until the age of 16. So I mean she's sorted that out as well...

By contrast, in a site where key workers tended to be less proactive, the key worker had not looked into providing the family with the ideal DLA rate, although they had said they would do so:

...and they said .. 'Oh he's getting middle rate care allowance, oh he should be on high rate. I'll look in to that'. Well that was last year and they still haven't heard anything.

Housing

The families who were experiencing difficulties with housing and whose key workers had helped them to deal with them far outnumbered the families who were experiencing difficulties and were dealing with them on their own.

Key workers had been involved in helping families obtain all sorts of adaptations to housing, and moving into council housing. Many families had greatly benefited from the key worker's effort, for example one family said that their key worker had pushed for them to obtain a council house within two months of applying for one. Another family had been helped by the key worker in getting work done to level the property, put handrails in and make the back of the house safe for their child.

We had a lot of work done on the property, had to be levelled and handrails put in and things like that, (key worker) co-ordinated all that, got in touch with various people. We weren't aware that, you know, that that could be done... as far as I knew I'd have to pay for that but (key worker) said 'No, no, it should be level for (child)'...

A handful of families reported negative experiences with housing. These were in four services where key workers tended to be less proactive, and complaints included lack of help from key workers in applying for Disabled Facilities Grants and key workers' lack of knowledge of housing issues.

Transport

The families who had been helped by their key workers with difficulties encountered regarding transport far outnumbered those whose key workers had not helped. Key workers had helped families obtain suitable vehicles and obtain blue badges for parking.

Four parents had encountered difficulties and were dealing alone with these, including issues related to school transport, reserved parking outside the family home, funding for a car seat and for transport from school to respite care.

Voluntary agencies

Many key workers had helped the families liaise with voluntary agencies, such as the Family Fund. Families had greatly benefited from computers, bicycles, washing machines, tumble dryers, fridge-freezers, bedding, nappies, driving lessons, fuel, mobility aids, toys, and clothes. Some charities also organised holidays for the children.

Key workers were particularly helpful in informing parents about the charities and what they were entitled to:

The Family Trust Fund she helped with that saying 'This is the number get in touch with them,' you know. 'This is what you can apply for.' Because, you know, I don't know how they work, how, you know, what, this is what you can apply for.

Therapies

Most families were satisfied with the physiotherapy their child received and often families were dealing with their physiotherapists without the intervention of the key worker. Two families had been helped by their key worker to receive specialist physiotherapy (the Peto method) and another key worker had helped the family to receive financial aid to access physiotherapy at the Bobath centre in London. A key worker had helped another family to access physiotherapy and another key worker had contacted the physiotherapist to set an appointment at home.

Five families complained about difficulties they were experiencing with physiotherapy, these included difficulties in accessing physiotherapy, problems in communication with physiotherapists and differences of opinion about discharge from physiotherapy. These families were currently dealing with these particular problems without the help of their key worker, although in two of these cases, key workers had helped families with other situations related to physiotherapy.

Most families were satisfied with the occupational therapy they received. Key workers had referred families to occupational therapists, and had liaised with them.

Speech and language therapy was generally accessed in school. Some families expressed that there was a lack of speech and language therapists locally or nationally. Key workers had helped families to be referred to a speech and language therapist, liaised with them to set up appointments, helped shorten the waiting time for an assessment, and liaised with the speech and language therapist when they wanted to sign the child off and the parent felt the child still needed support.

Equipment

Most families had positive experiences in obtaining equipment. Families would notify their key worker about their need for equipment, or whether their equipment needed replacing or repairing. The key workers' roles included obtaining funding for the equipment and chasing the providers so that the family received the equipment promptly.

A common problem encountered by a few families concerned waiting long periods of time for equipment to arrive. Other times, equipment arrived which was inappropriate or wrongly sized. Sometimes by the time the equipment had arrived the child had outgrown it. Key workers had been involved in obtaining this equipment and 'chasing up' the professionals, but families had nonetheless waited a long time for it to arrive:

Yeah, you know, she'd phone up and say, you know 'Where are those shoes, we've been waiting so many months' or, yeah.

Mental health

Parents identified needs for counselling and/or psychological support for all members of the family: parents, the disabled child, and siblings. The main complaint concerning these services was that waiting lists were too long and there were not enough professionals. Although some key workers had been able to successfully obtain help for families from mental health professionals, for many families it appeared that their key worker was not helping them in accessing these services.

Health

Many families were happy with health services. However, equally many others also expressed frustration with the system. An issue parents spoke about often was waiting for treatment, both in terms of long waiting lists for specialist treatment and waiting in the emergency room or hospitals and surgeries for an appointment. This was problematic particularly to working parents who could not take a day off for medical appointments. Parents also talked about a lack of communication and coordination among medical staff and, although from the same field, different doctors had conflicting advice to give them. Furthermore, some parents felt that doctors from different areas of medicine would not communicate with each other, leaving all the liaising to the parents, who found this frustrating.

Some parents had waited a long time for the child's diagnosis and a few children still did not have one. Waiting for a diagnosis was a very stressful experience for parents, and one described this as a 'limbo' situation. Another parent said that during that period the family sometimes felt like they had lost their child and they

were particularly in need of support during this time. Other issues parents spoke about were: obtaining specialist medical care (particularly getting a brain scan was a problem in one of the areas), perceived mistakes in the diagnosis and treatment of the child, the NHS being short of staff, travelling to a hospital that was far away, and having an unhelpful health visitor. All of these issues were causing the families some distress.

Key workers had helped families with these issues in a number of ways. They had made appointments with doctors and health professionals, helped families to obtain a brain scan, liaised with doctors about the child's health needs, shared information among health professionals, found a paediatrician with experience in disabled children, accompanied the family to doctors' appointments and brought appointments forward:

...we were having to liaise with a lot of different people within the health service who had different roles... So the thing for us was that the key worker very much helped to tighten that up... yeah, so she started actually liaising between the different practitioners who we were having to deal with, would pass information on, would get information and pass it on to another...

Social Services

Some parents expressed that they were receiving good help from social services. However, opinions and perspectives on social services varied within the sites, and approximately an equal number of parents reported some complaints about social services. Parents complained that their social worker had stopped coming, they were not forthcoming with information and help, they were understaffed, and social services had not provided transport and respite.

Key workers had helped in some cases, by contacting the social worker, by informing the family they had a right to a social worker, and by helping the family obtain things their social worker had not helped them to obtain:

I think if it wasn't for (key worker) I probably wouldn't... bother asking them for anything. It's (key worker) who says 'Yeah, it's their place to give you this...'

8.3 Children's views

Nine children and young people were interviewed. In order to speak to children, we first explained to parents what the interviews would cover and asked for their permission to ask the children whether they would be willing to take part. The majority of parents said that their child was too young to take part (32) or that the child's disability meant that they would not be able to understand (22). Two parents said their children did not remember their key workers as it was so long since they had any contact with them, in two cases the parent wanted to protect the child from

meeting another professional (that is, the researcher) and in one case, the child was ill at the time of the interviews.

The interviews started by asking children a little bit about themselves. Children spoke about the things they liked doing most, which were: playing football, pool, on the computer, with the Play Station, horse riding, swimming, taking the dog for a walk, making dinner, going to the cinema, drawing, and watching television. Children also said where they went to school and what school year they were in.

Children were then asked some questions about their key worker. Seven out of the nine children were able to say where they usually saw their key worker. One usually saw them at home, three at school, one at hospital, one at both home and school, and one saw the key worker either at home, at school, or at the key worker's office.

The same seven children were aware of their key worker's role and were able to mention at least one thing the key worker had done. These were: getting the child a respite carer, helping them find a college to attend, talking to their mum and playing with them, finding youth clubs or activities for them, making sure the child was getting on well in school, helping the child to change schools and making sure teachers gave the child more autonomy in school by not following them around. Two children were not really aware of the key worker's role, one of these was in a service where key workers tended to be less proactive and they only saw their key worker approximately twice a year and therefore could not remember what the key worker did.

All children except for one could not think of anything they did not like about their key worker. When asked if there was anything he did not like about his key worker, one child expressed that the key worker spoke mostly to his mother, rather than to him. Children spoke about the characteristics that they liked in their key workers. One child was not sure what he liked about his key worker (perhaps due to limited understanding) and another child had seen the key worker too long ago to remember what he liked. The others replied that: they liked her because she had found someone to take them to the seaside, she helped the young person to decide what to do after leaving school, she was friendly and talked to the child, she helped the child with any problems in school, and she was a kind and helpful person. One child said that he liked his key worker because when she spoke to his mother, he could watch television. Another young person spoke of his key worker's role as his 'guardian angel', in that she took an interest in him and had helped him to find activities to do and to find the right school.

8.4 Summary

This chapter investigated what families with disabled children thought about the key worker service they received and the range of other services available in their area. There appeared to be a wide variation across the areas, both in terms of the quality of key worker and other services. Particularly in one service many families were confused about the key worker role and it was apparent that many key workers were not coordinating care across the range of services.

A significant theme that emerged from families' views on the service was the importance of the key worker being allotted time to carry out their role. Time was an issue that influenced the families' choice of key worker, it emerged as one of the main 'problem areas' within the key worker service, and it was also one of the main areas for improvement of the service. Families underlined how allotted time was essential to carry out what was a time-consuming and difficult role.

Having a clear, written definition of the key worker role was also deemed important and a clearly defined role description would have changed things radically for many families interviewed. For example, they would have been able to detect when the key worker was not carrying out her role and services were not being delivered. Instead, many families felt disappointed or puzzled when their expectations of the key worker had not been met and no information had been provided as to whether they were eligible for help in a certain area or not. Even worse was when families with many unmet needs had been promised a service, but their key worker had visited them only once in more than a year, or the key worker was carrying out only her original role and was not coordinating care at all. Those families had received no written information and were not aware that they were eligible to receive more help.

When services were being coordinated successfully, the family had benefited greatly. The characteristics of the service that families had appreciated most were: the key workers were on the other end of the line, they made sure the family's needs were met, they listened to them, they provided them with information, they took some of their stress away, they were their one point of contact, they coordinated the meetings, and sometimes they helped the family over and above what their job entailed. Key workers were particularly successful when they were able to notice needs existing within the family and took steps to address these needs. For example, a key worker knew that a child's father was struggling with dealing with his son's disability. The key worker had then organised an activity, that both of them could do together, for the father to know he could still enjoy spending time with his child. The key worker had used her knowledge of the family to improve an aspect of their lives and she had been proactive in doing so.

Regarding the quality of services received, it emerged that although some families were happy with the amount and quality of services, others were experiencing a lack of services such as respite, speech and language therapy, and mental health services. It is expected that gaps in services would have repercussions on the child's wellbeing and may be responsible for the low amount of variance accounted for by the path model of child unmet needs (Chapter 5). The MPOC, which comprises the totality of services and professionals that the family interacts with, was the only variable that had a direct effect on child unmet needs. Therefore, it appeared that even if the key worker tried hard to provide the family with the services they needed, the child's needs were not met when there was a shortage of services and professionals in the area.

Chapter 9: Discussion and Conclusions

The topic of key workers for families with disabled children has received considerable emphasis in recent policy and there has been an upsurge in the development of key worker services. Research comparing families who do have with those who do not have key workers has produced positive findings, indicating that overall key workers are beneficial to families (Liabo *et al.*, 2001). However, existing key worker services vary in how they are implemented and how the role of the key worker is defined and interpreted (Townesley *et al.*, 2004) and as yet, we know little about the effectiveness of different models of key worker services. This research therefore set out to investigate the impact on families of different models of service, the specific factors within services that were related to better outcomes, and the costs of the services. The focus was on services that were implemented in a multi-agency context, as previous research had already indicated that such a context was crucial to key working.

This chapter draws together findings from the different phases of the study and goes on to identify the implications of these findings for policy and practice on the development of key worker services. We start by discussing the strengths and limitations of the study to set this in context.

9.1 Strengths and limitations of the study

The study employed a multi-method approach and obtained the views on key worker services of a range of different groups of respondents. The quantitative research included both broad survey data on key worker services across the UK and statistical analysis of relationships between service factors and outcomes for families in a subset of services. These quantitative analyses facilitate generalisability of results. Qualitative research explored in depth people's experiences of the services, illuminating and providing more detail about ways in which different types of key worker services impacted on staff and families' experiences and facilitating the interpretation of the processes and mechanisms which produced the statistical relationships. Obtaining data from multiple informants, key workers, managers, parents and children, also allowed a broader exploration of the services, their effects and how these effects were produced. Finally, the triangulation of data from different groups of respondents and different methods, and the fact that these data provided mutual confirmation enhances the validity of the findings (Bryman, 1988).

The findings of the study concur with those of other studies of key worker services for families with disabled children in highlighting positive effects for families and staff, but problems in ensuring ongoing multi-agency commitment, and in understanding of the key worker role, and differences in the way it is carried out in practice. In addition,

the study takes these findings further by exploring different models of key working and identifying aspects of services that lead to better outcomes for families.

Despite these strengths of the study, its limitations must also be acknowledged. The survey of key worker services only produced a snapshot in time and, although the response rate was good for a postal questionnaire, this is not an exhaustive picture of key working and there may have been some schemes that remained uncovered. Similar limitations also apply to the rest of the study. We visited the services during a period of around one year and since our visits many of them have developed and changed further, for example expanding their staff or instituting training where this had not previously happened. Clearly, if we visited these same services again our results may be different. This does not detract from the findings on the importance of some of the aspects of service models, but the cross-sectional nature of the study means that it is difficult to interpret the findings on the effect of length of time a service has been in operation. It may be that the impetus and motivation generated in new services decreases over time but a longitudinal study would be required to explore this more fully.

Another limitation of the study is the low response rates in some of the case study services. These applied to responses to the family survey and for some of the staff interviews. Family survey responses were low in four of the seven services. Although analysis of differences on demographic variables between these sites and the high response rate sites showed no significant differences, it is difficult to predict what effect the response rate may have on the findings. In general, it appeared that the services with low response rates had included 'passive' cases (that is families who were not currently receiving a key worker service) in the mail out of questionnaires. The fact that we received some letters and telephone calls from families in these sites telling us that they could not fill in the questionnaire because they did not have a key worker supports this view. This could call into question the findings on effectiveness of the services, as those families who contacted us were not satisfied with this situation. However, the services which obtained the highest ratings on satisfaction with the service were among those with the higher, and therefore more representative, response rates, and it was not the case that services with low response rates had a narrower range of outcomes. It seems likely that the findings related to effectiveness can stand.

Interviews with steering group members were also difficult to achieve in Service B and only one key worker agreed to be interviewed in Service G. Conversely, in Sites A and C all key workers and nearly all steering group members were interviewed. Clearly a broader perspective on the service was obtained in the latter sites. However, it should also be noted that we found a great deal of consensus between respondents in these latter sites on the services' characteristics, the role of key workers, and other questions. So again it was not the case that those services with higher numbers of staff interviews produced a more diverse range of views.

Although the research aimed to obtain the views of disabled children about the key worker services, in practice we were only able to obtain the views of a minority of children either through questionnaires or face-to-face. The great majority of these children had positive views of their key worker, but we cannot generalise from this finding. The extent to which key workers engaged with children varied widely and it seems likely, as other studies have found (e.g. Morris, 1998b; Noyes, 2000; Rabiee *et al.*, 2001; Stone, 2001; Cavet and Sloper, 2004), that disabled children with complex needs and those who have communication impairments are those whose views are least likely to be accessed by the services. The difficulties of obtaining the views of these children, and the resources needed to do this, should not be underestimated and this is an area where both services and research require further development.

9.2 Key worker services in the UK

The first stage of the research was to find out about the current pattern of multi-agency key worker services. Results of a UK-wide survey, carried out at the start of the project in autumn 2002, identified 30 key worker services. The proportion of areas having key worker services was consistent with findings on research with parents of disabled children, which has reported that less than a third of families have a key worker. However, it was encouraging that 50 areas stated that they were planning to develop care coordination schemes in the next year.

The picture of care co-ordination obtained from this survey was one of considerable diversity. However, there was much emerging from the results that can be recognized as good practice. First, the majority of schemes had all three statutory agencies involved in setting up and overseeing the scheme. This indicated a substantial commitment to promote and support multi-agency working. A second encouraging finding was that, in most cases, parents were involved in setting up and overseeing the schemes. This indicated that the intention to increase user involvement and participation in decision-making was being put into practice (e.g. *The NHS Plan*, Department of Health, 2000; *Shifting the Balance of Power*, Department of Health, 2001). Other encouraging results were that many schemes had open referral, enabling parents and families to refer themselves and their children to services, and that most of the schemes covered all age groups of children.

However, other aspects that have been suggested as good practice were less common. These included involvement of children and young people, joint funding, training for key workers, mechanisms for care planning with the family, and limitations on age range for eligibility. Children and young people were rarely involved in setting up or overseeing the schemes. Disabled children hold and can express views, given the right environment and support (Alderson, 1993), and there

is evidence that children's views are different from adults' and they have valuable and useful ideas. However, involving children requires additional resources and skills (Lightfoot and Sloper, 2003) and disabled children are less actively involved in decision making than non-disabled children (Sinclair and Franklin, 2000). The results of the survey suggest that more effort could be expended in ensuring that children and young people's views are heard.

It was evident that, although agencies were jointly setting up and overseeing the schemes, joint funding from all three statutory agencies was still rare. Few schemes were using the opportunity to pool budgets given by the 'flexibilities' in section 31 of the Health Act 1999. In addition, short-term funding for many of the schemes is a concern. Only half the key worker schemes were able to provide full information on their expenditure or staffing profile. Some of this information deficit was due to the multi-agency working arrangements that relied on agreements about seconded or 'borrowed' staff rather than financial transfers. It is perhaps more concerning that many schemes were not able to report how much time non-dedicated key workers spent on this role or how many children received key worker support from their service.

Appropriate key worker training is suggested as important for a successful service (Mukherjee *et al.*, 1999). The extent of training received by the key workers varied greatly across the sites, and some of the schemes provided no training. Care planning arrangements were also variable. Nine schemes had no initial planning meeting held between the family and the professionals involved in care. Such planning and cooperation is seen as essential in order to avoid duplication and omission of support to children and families and as an important condition for care coordination and multi-agency working (Healey, 1989; Yerbury, 1997). Finally, it was interesting that some schemes only covered a limited age group of children. The fact that all covered the early years is positive, given the evidence on the importance of this stage for family adaptation and accessing services (Department for Education and Skills/Department of Health, 2003). However, other important life stages which are known to be problematic in terms of service coordination, such as transition to secondary school, puberty and transition to adulthood, were not encompassed in some schemes.

9.3 Different models of key worker services in practice

Building on these findings, the next stages of the research set out to tackle some of these limitations by investigating seven services in more detail and also addressing key questions about the impact on families of different models of services. The seven services were chosen to cover a spread of those with designated or non-designated key workers, dedicated funding or not, urban or rural areas, and recently implemented or longstanding.

Interviews with service managers, key workers and steering group members in these areas, and quantitative and qualitative data from parents who received the service showed many positive findings. Overall parental satisfaction with the services was high and, as in earlier studies of key worker services (Liabo *et al.*, 2001; Townsley *et al.*, 2004), positive impacts on a number of areas of parents' lives were seen for a substantial number of families. Many key workers and managers were positive about the service and identified considerable advantages of key workers for families, themselves and staff in other agencies. However, there was considerable variability, both within and between services, in these findings, and it was apparent that the level of key worker contact with families varied, some key worker services were more likely to show positive outcomes than others, and within some of the services some key workers seemed to be more effective than others.

The aim of this research was not specifically to compare the seven services with each other, but to identify important ways in which the seven services varied and further investigate the effects of these variations in the analysis of factors related to outcomes for families. A number of key issues were initially identified from interviews with staff and these were then further explored in the research with families:

- Definition and understanding of the key worker role.
- Type of key worker (designated or non-designated).
- Management of the service.
- Funding of the service.
- Training and support for key workers.
- Time for the key worker to undertake the role.
- Parental involvement in steering the service.

9.4 Factors related to outcomes for families

Four outcome measures were used in the study: parent and child unmet needs, impact of the key worker on parental quality of life, and satisfaction with the key worker service. For each measure, path analysis was used to identify the factors most strongly related to outcome.

Taking the results of the path analyses of all four outcome variables as a whole, there was considerable consistency between analyses of different outcomes and certain general points can be made. First, the extent to which key workers carried out the aspects of key working identified in earlier research as important to families (Mukherjee *et al.*, 1999) was a strong predictor of impact of the service on families, both in terms of the direct impact of the key worker, as measured by impact of the key worker on quality of life and satisfaction with the service, and in terms of the broader impact on unmet need. These aspects of key working comprise provision of emotional support, information about services and the child's condition, advice, identifying and addressing needs of all family members, speaking on behalf of the

family when dealing with services, coordinating care, improving access to services and provision of support in a crisis. For the two outcomes that measured direct key worker impact, carrying out aspects of care was the strongest predictor of outcome, and MPOC scores, which measured processes of care provided by services in general, were not significant once aspects scores were entered into the regression. However, for the two unmet need outcomes, the relationships with MPOC and aspects scores were reversed. MPOC scores, measuring general processes of care, were the strongest predictor and aspects of key working scores impacted on these and consequently on the outcome variable. This relationship is not unexpected as parent and child needs are met by a range of services, not just the key worker. However, the key worker's role in identifying needs, coordinating care and improving access to services, is clearly an important influence. Where key workers carried out this role, parents were more likely to rate services in general as providing coordinated, respectful and supportive care.

Secondly, where respondents rated key workers as having appropriate amounts of contact with the family and did not feel that they needed more contact, levels of satisfaction were likely to be higher and parental unmet need lower. This indicates the importance of key workers having enough time to carry out the role, a factor that was highlighted by key workers themselves as a problem, particularly for non-designated key workers where heavy case loads in their main role impacted on the time they had available for key working.

Thirdly, the provision of regular key worker training, supervision focused on the key worker role, and peer support between key workers strongly influenced the way in which key workers carried out their role, including carrying out the different aspects of key working and having appropriate amounts of contact with families, and thus impacted on outcomes for families. The staff interview data and the analysis of interrelationships between service context variables indicated that in the case study services, having a service manager who was accessible to and provided support for key workers was an important component of the service. In some services, this manager carried out regular training and supervision for key workers and ensured that there was a clear written job description for key workers that covered many of the important aspects of key working. Having some dedicated funding for this manager's time also helped ensure that training and supervision could be part of their role.

The fourth variable to appear in all the path analyses was length of time the service had been in operation. 'Younger' services were associated with better outcomes for families. Why this should be so is unclear, but a number of factors may be operating. In all analyses, the path for this variable was through the extent to which key workers carried out the different aspects of the key worker role. It was clear from the interview data from both key workers and parents that not all key workers saw these different aspects as part of their role. In part, this was a function of provision (or not)

of a clear job description, training and supervision. However, the length of time the service had been in operation had an effect independent of these factors. The fact that research identifying these elements central to key working is relatively recent (e.g. Mukherjee *et al.*, 1999) may have resulted in more emphasis being placed on these when the 'younger' services were set up. In addition, one of the longer established services was experiencing considerable difficulties at the time of our visits and it was doubtful whether all of those identified as key workers for families were carrying out a key worker role at all. This was confirmed by interviews with families, and clearly affected parents' ratings of aspects of key working. Nevertheless, these questions about whether key workers were recognised by families as carrying out a key worker role were not confined to this service and were also apparent in other services, so whilst results will be affected by the problems of this service, it is unlikely that they can be solely accounted for by this one service. It may be that the impetus, motivation and excitement generated by implementing a new service fades over time, and/or staff become jaded and disillusioned if hoped for improvements in services are slow to have effect, or they feel unsupported in their key worker role.

Two service variables that were significantly related to outcome at the bivariate level did not show any significant effects in the path analyses: these were type of key worker and parent involvement in steering groups. In the bivariate analyses, families with designated key workers showed significantly better outcomes on impact on quality of life, satisfaction with the service and parent unmet needs. However, these relationships lost significance in the multivariate analyses when controlled for other service variables, in particular aspects of key working and training, supervision and support. It appears therefore that although, as illustrated in the views of staff and parents, designated key workers have advantages, the disadvantages of non-designated key workers can be overcome if the service is clear about what the key worker role encompasses and provides induction and regular ongoing training for the key worker role, allied with supervision specific to the role and opportunities for key workers to learn and gain support from each other.

Parent involvement in steering groups was also significantly related to impact on quality of life and satisfaction with the service. In the path analyses this lost significance when controlled for aspects of key working and length of time the service had been in operation. This suggests that parent input to the service is valuable, but cannot overcome problems of the key workers not carrying out all relevant aspects of the role. Definition and understanding of the role is central to an effective service and, as noted earlier, this appears to be more likely to have been prioritised in services set up more recently. Clearly, parents can provide valuable input on this but, as some parent members of steering groups commented, there was not always an equal partnership between parents and professionals on the groups when decisions were made, especially when funding and resources were involved.

Finally, the low amounts of variance explained in unmet need scores, particularly those for child unmet need, indicates that other factors outside the key worker services are affecting whether families' needs are met. Clearly, these factors include the other service resources available in the area. As noted earlier, a key worker cannot provide access to a service to meet a need if no such service exists. Unmet needs were likely to be higher for parents of older children. This association was independent of any variables related to the key worker service and suggests that services in general were better at meeting needs of parents with young children. A high level of unmet need was found for help in planning the child's future, a finding consistent with other research (Beresford, 1995).

The amount of variance explained for child unmet need was minimal and suggests that the key worker services may be mainly focusing on supporting parents. Townsley *et al.* (2004), in their study of multi-agency services for disabled children with complex health needs, found that although the services had an impact on families' quality of life, children still experienced many areas of unmet need and there was little evidence of consultation with children about their care or of strong relationships between key workers and children. Our interviews with families support this finding. These indicated that the key workers' contacts were often centred on mothers. To a certain extent this is understandable as the mother was generally the main caretaker, and so possibly the person best able to understand the needs of the family and communicate those to the key worker. However, some key workers made a point of spending time with the child and communicating with the child, but others had little or no contact with the children. The children we talked to and those who completed the children's questionnaire had generally positive experiences of key workers, confirming that when key workers did make this effort to spend time with children, find out about a child's needs and help to meet these, then the service could have positive effects for children and young people as well as their mothers. However, only a minority of children completed questionnaires or were interviewed and mothers' and key workers' accounts suggest that for many other children experiences were more varied.

Finally, we did not find any effects of key worker service variables on parental employment. Given the barriers to employment for parents with disabled children, especially those caused by lack of appropriate child care, this is perhaps not surprising. A key development for the government's child care strategy and multi-agency services is to ensure that high quality options are available for all children, including those who have additional needs (Russell, 2002). If such options are in place, then key workers have a role to play in ensuring that families have information and support to enable them to find the best options for their own situation.

The findings from the quantitative analysis were corroborated and further illuminated by the qualitative data from staff and parents. Key themes from these were: understanding and carrying out the role of the key worker; the key workers' role for

all family members; resources for key working; management of the service; multi-agency working; education and schools; and areas of unmet need. These are discussed below.

9.5 Understanding and carrying out the key worker role

Similarly to Townsley *et al.* (2004), we found that the ways in which the role of the key worker was understood varied between and within the seven services. Data from interviews with parents mirrored information obtained from interviews with staff and quantitative data from the family survey. In two services, key workers were consistently seen by parents as working across agencies, liaising with other professionals and coordinating care. In other services, parents' experiences varied depending on the approach of their particular key worker. Similarly, in the same two services all parents interviewed agreed that key workers had reduced their stress, but in the other services views were variable. Parents' own understanding of what the key workers' role should encompass also varied in five services. A key issue that emerged from this research is therefore the blurred understanding of the role of the key worker, particularly in some services. Two solutions would improve this situation: one is having a clear written job-description for the key worker, which is explained to key workers by the service manager. Likewise, the family needs to be given the clear written information about the role and they need to be taken through it and then left with the leaflet or booklet for further consultation. At certain times, for example after diagnosis, the family may be too overwhelmed to absorb all the information given to them, therefore they need written information and the key worker may need to verbally explain and re-explain their role to the family as much as is necessary.

In addition, training is needed for key workers on the different aspects of the role. Where such training was in place, it was greatly appreciated by key workers and, as shown in the path analyses, was a significant factor in promoting positive outcomes for families. Mukherjee *et al.* (2000) suggested that induction training must take the time to ensure that key workers have a clear understanding of: a) which tasks they are and are not expected to take on for the family, b) what areas they are responsible for, and c) to whom they are responsible. Moreover, induction training should be followed up with regular ongoing training and supervision. Given the importance of the aspects of key working scores in the analysis of factors related to outcomes, it is clear that the definition of the key worker role and training for the role should include all the aspects encompassed within this measure.

The varied aspects of this role, as defined in Section 9.3, point to the importance of the skills and access to knowledge of key workers and their personal qualities. Whilst no one person is likely to have all the knowledge needed for the role, training, identification of sources of information and access to other services are important in

ensuring that key workers can carry out the role. Parents understood that key workers could not be experts in every field but were happy when key workers were able to find out information and get back to them. The personal qualities that parents thought were important for key workers included listening and communication skills, tact and diplomacy, approachability, respect for families' expertise, and persistence.

Key working is a demanding role and key workers also appreciated supervision focusing on the role and peer support in the services where this was provided. Supervision and support, along with training, helped key workers to gain knowledge of other services, aspects of disability with which they might not be familiar, and different ways of working from their normal professional role.

A question that is often posed about key working is: 'is it a different role from that already carried out by professionals such as social workers and health visitors?' Although some key workers we interviewed thought that key working was no different from what they did in their usual professional practice, these tended to be in services with less successful outcomes. In this research, we found that key working took up extra time and involved extra effort for most key workers. Key workers have a 'hybrid' role that requires a broad range of skills and knowledge. The research showed clearly that it is performed best when it is not an add-on role without time and extra provision set out for it. This goes against the opinion that key working is what professionals already do and is just good practice. Key working is also about joining up meetings, promoting communication between professionals, and being a hub of information for services and agencies that are outside of one's own professional remit. This involves a general knowledge of other agencies and professionals that is uncommon for professionals who work within a specialised role.

9.6 The key workers' role for all the family

As noted in Section 9.3, the majority of key workers' contacts appeared to be with mothers. Some key workers made a point of spending time with disabled children and we came across a number of examples of work specifically with children. Nevertheless, both staff and parents highlighted the need for the services to involve children and young people more in review meetings, in decisions about their own care and in decisions about service development. This is consistent with recent policy emphasis on children's participation. Key workers themselves wanted more training and guidance on consulting with disabled children and it is clear that if policy on children's participation is to become a reality for many severely disabled children who have communication impairments, further training is required for practitioners and the time needed to work with these children should also be acknowledged (Rabiee *et al.*, 2001; Morris, 2002).

Despite the fact that many key workers appeared to have little contact with other family members, including fathers and siblings, parents we interviewed appreciated it when key workers took a holistic approach, finding out about the needs of other family members and supporting these needs. Only a minority of interviewees did not feel that their key worker looked at the family as a whole.

9.7 Resources for key working

Protected time for key working was an important issue that came out of this research, both in the interviews with staff and families. Protected time is necessary for the key workers to carry out what can be a very involving and time-consuming task, and time is also needed for key workers to take part in training. Most families were aware that the non-designated key workers had many other families on their 'main job' caseload and, in some cases, they felt that this detracted from their ability to be a key worker. Key workers expressed at times that the key worker role ate into what was their working time with the other job, and some felt that as a result they were not doing justice to either role. There needs to be a specified limit of the number of families a key worker can reasonably take on. For non-designated key workers this must take into account their existing caseload in their main professional role. Figures from this study suggest that non-designated key workers could work with about three families. For designated key workers, caseloads were around 30 families. There should be regular checks that the caseload is appropriate.

Time allotted to key working should be generous, and it should be kept in mind that it is impossible to key work at a certain time each week. There are peaks and troughs in demand and a need for flexibility, so the work will be spaced out across the week. The line manager should be aware of and respect this protected time, for instance in the allocation of new cases. There needs to be information to and involvement of line managers in the key worker service. Non-designated key workers experienced problems when line managers did not understand or recognise the needs of the role.

In addition to time, key worker services need resources for administrative support, training and a manager who has protected time for managing the service. Some dedicated funding is needed for these resources.

Given the importance of protected time, the findings from the earlier survey are somewhat concerning. The absence of full information on expenditure, staff inputs and caseload in more than half the existing key-working teams means that not only is the managing organisation uncertain about the level of service provision and its cost, but also that the service manager has insufficient information to gauge how much service is going to who or to help key workers to protect their time to undertake key working activities.

It is interesting therefore to discover just how much key worker contact have with families varies. The range of contact costs was wide in our sample of 159 families – from £0 to £1540 in the three months prior to questionnaire completion. As is common with costs data there were a few high users but for the majority (110 families) average contact costs were less than £20 per week. Some of this variation could be accounted for by the children's levels of disability and by the way that the key workers undertook this role, but more that three-quarters could not be explained. By combining better information from service managers and provider organisations with research methods based in the principles underlying economic evaluation it may be possible to distil evidence on how best to resource a team and how best to disburse those resources between families to secure good outcomes.

9.8 Management of the service

The role of the service manager appeared to be crucial to the success of the services. In some cases, this manager was a driving force behind the development and implementation of the service and this raises some concerns about the fragility of services should the manager leave. This problem was illustrated in the service that had declined in recent years after the manager left. In the most effective service models, the service manager played a central role in ensuring that key workers had a clear and understood job description, organising training and peer support, supervising key workers, motivating key workers and developing team spirit, and drawing up protocols for and organising assessment and review meetings. In other services, the role of managers was more nebulous and in these cases, key workers were more likely to feel that they lacked support.

Steering groups were also an important aspect of the development and management of services, particularly in trying to ensure multi-agency commitment to and ownership of the service, finding funding, and monitoring the service. Parent representation on these groups was seen as valuable, providing a user perspective and keeping a focus on the needs of families. Most parent members felt that their views were listened to but a few suggested that they had little power, particularly where money was involved. There were no examples of young people's participation. Children and young people's participation in public decision making is growing (Cutler, 2003) and the National Service Framework standards require services to involve children and parents in planning services (Department of Health/Department for Education and Skills, 2004a). Many managers and key workers commented on the need to involve children and young people and this is clearly an area for future development.

Some problems were identified in the services where steering groups had a much wider remit than the key worker service, and in a falling off in attendance in some groups. It seems that the groups were more effective where they were specifically

focused on the key worker service and where continuing representation from all agencies was ensured and members who left the group because of job changes were speedily replaced.

9.9 Multi-agency working

A key role of steering groups was in ensuring multi-agency involvement in the services. In principle, all groups had involvement from all three statutory agencies, although in practice not all representatives attended the group regularly. Key workers themselves collaborated with professionals from many different agencies, including those outside the service, such as housing, leisure and the Benefits Agency. Many examples were provided, by parents and key workers themselves, of key workers liaising with other agencies and professionals. Multi-agency working appeared to be operating relatively well in four services but was more variable in the other three. Problems relating to confidentiality and sharing information had been addressed in some areas by setting up systems whereby parents gave permission to share information, and multi-agency care planning and review meetings were seen by both parents and staff as a central part of multi-agency working. Parents particularly appreciated these opportunities to get people together and share information, but there was variability between and within services in the role taken by key workers in these meetings. Parents were most appreciative when key workers provided support both in preparation for and at the meeting.

Provision of funding for the service was seen as indicative of multi-agency commitment and managers recognised the need to pool resources to improve services. Despite this, pooled budgets were rarely used, and parents provided a number of examples of disputes and delays arising because of lack of joint funding for services such as equipment.

The facilitators of and barriers to multi-agency working that were identified in our interviews were similar to those described in Chapter One that have been identified in other research (for example, Atkinson *et al.*, 2002; Cameron and Lart, 2003; Sloper, 2004). It is clear that further progress is needed in ensuring equal commitment to the key worker services and sharing resources. Service managers played an important part in promoting communication and information sharing and key workers also facilitated contacts between professionals. It is important that these aspects are recognised as part of the roles of service manager and key worker.

In general, differing priorities between agencies were seen as barriers to joint working, and in this respect, as in Townsley *et al.*'s (2004) study, it was felt by some key workers and service managers that education was the agency least committed to the service. It was notable that in all seven areas, the service manager was from a health or social services background and it is possible that they found it easier to

communicate with these agencies. Nevertheless, our research with schools showed that on the ground there were many examples of good practice in relations between key workers and schools.

9.10 Education and schools

An important role of key workers, as viewed by parents, school staff and key workers themselves, was in the selection of an appropriate school for a child, securing a placement in that school and beneficially affecting the educational provision made for that child. The findings demonstrated the potential of key workers to play an important part in assisting schools to meet their responsibilities under the Disability Discrimination Act. However, again practice was variable between services and within some services. There were many examples of key workers improving the quality of children's school experiences, for example, by negotiating adjustments to school buildings and additional resources, securing in-school support, offering suggestions to improve curriculum access and facilitating interaction with peers. Key workers fulfilled an extremely important role as information brokers. They provided parents with information about school procedures, IEPs and the processes involved in drawing up and reviewing statements. They informed teachers of background factors affecting children's attitudes and behaviour and particularly assisted teachers in mainstream schools by explaining the nature and implications of particular conditions and suggesting coping strategies. Particularly valued by both parents and teachers were the ways in which key workers mediated between schools and families to tackle problems, resolve sensitive or contentious issues and diffuse potential confrontations.

Unless school staff were involved in the setting up of a key worker service, they tended to learn about it in an ad hoc manner or when a key worker made contact in response to parental concerns. These kinds of initial contacts could put schools on the defensive and render key workers as reactive rather than proactive. Examples of key workers contacting and/or visiting schools immediately they were allocated to a child and explaining their role, demonstrated that such an approach led to a more immediately productive relationship and facilitated any subsequent interventions, if and, when problems arose. The escalating amounts of information being sent to schools in recent years means that if information on key working is periodically circulated to schools it may not be read. However, brief information on the service given by key workers to the teachers with whom they will be communicating during an introductory school visit could prove helpful.

School staff were generally very positive about the benefits of key working for the child and family and the school. From their perspective, designated and non-designated key workers were equally effective. The personality and skills of a key worker, their familiarity with, and confidence in, working with schools and the

importance they attached to this aspect of their role were viewed as more important than their status. The teachers interviewed who were non-designated key workers carried out the role in relation to children at their school. While they viewed their detailed knowledge of the children through daily contact as greatly assisting them in carrying out the role, lack of time and flexibility during the school day were cited as major constraints.

9.11 Unmet needs

Levels of unmet need in many aspects of services were lower than have been found in earlier research (e.g. Beresford, 1995; Sloper and Turner, 1992). This was particularly the case for services that are within the direct control of key workers, including having someone to talk to about the child, someone to show what services are available and help getting information. However, over a third of parents had unmet needs for breaks from care and time for their partner, learning ways to help the child and to develop the child's communication, help planning for the child's future, and help in school holidays. Levels of child unmet need were high in almost all categories and over half the respondents identified unmet needs for their children for help with learning independence skills, communication, developing learning abilities, and social skills.

The path analyses indicated that the quality of key worker services, although not the quantity of support as summarised by contact costs, did impact on unmet needs. The data from interviews with parents supported this indicating that when key workers were more proactive in looking at and addressing needs, problems were more likely to be dealt with. However, the amount of variance explained in path analyses of unmet needs was low, especially for children's needs. It is likely that other factors besides the key worker services, particularly the resources available in the area and the quality of other services, had considerable impacts on meeting children's and parents' needs. There is a need for further research that assesses the extent of the impact of key worker services within the context of other services used. We know from this study that key workers encountered problems when services were not available to meet the needs they identified and parents felt that provision of services was patchy. Interviews with parents highlighted waiting lists and lack of provision, and consequently unmet needs for breaks from care, counselling and mental health services, housing adaptations, provision of equipment, speech and language therapy, and activities and opportunities for social contacts for children.

Whilst good key worker services can help to maximise families' access to the resources that are available in their area, they cannot provide services that do not exist. It is important that key worker services carry out comprehensive assessments of the needs of children and their parents, and that data from such assessments inform the development of services at a multi-agency level in local areas. Children's

Trusts in England and Local Children and Young People's Framework Partnerships in Wales should collect and use these data.

9.12 Implications for future research

As noted earlier, this was a cross-sectional study and further exploration of the findings about length of time services have been operation would be useful, using longitudinal designs.

The study highlights the importance of training and supervision for key workers and provides some information on the training and supervision some of the services provided. More detailed investigation of training needs and programmes and arrangements for supervision would further inform service developments.

A question that is often asked is which professionals should be key workers. A range of professionals undertook the role in the study services and we were not able to ascertain any patterns that might suggest that some professions are more appropriate than others, apart from noting the difficulties teacher key workers experienced in the time constraints associated with teaching timetables, and the difficulties one service experienced with having a social worker as a non-designated key worker. More detailed work to investigate the experiences and outcomes of key workers from different professional backgrounds would help to answer these questions, but it should be noted that such research should be able to control for the effects of training, supervision, how time is allocated for key working in the service, and type of key worker, as it was these aspects rather than the professional backgrounds of key workers per se that seemed to have greater effects on the way key workers carried out their role.

Although the services in this study were all set up and managed in collaboration between all three statutory agencies, pooled budgets were not being used. With the policy push for more integrated services and greater use of pooled budgets and joint commissioning, research on the ways in which this is implemented and the impact on the services families with disabled children receive is needed. It was also apparent that multi-agency working with other services outside the key worker scheme was often not in place. Another research area is how key workers are perceived by, and assist with the work of, (or generate more work) for other agencies, including Housing, the Benefits Agency, voluntary bodies, and Parent Partnerships. This research was only able to obtain a view of key worker services at one point in time. Although we asked about the impact of key workers on other the work of other professionals, we were not able to obtain the views of the whole range of other professionals on this, to compare experiences of other professionals for families who did or did not have key workers, and to track this over time. Further research on this

would help to answer questions over whether, in the long run, key workers do prevent duplication and save time for other professionals.

The findings from the education dimension of the project, suggest that there is a need for more detailed research on how key workers impact on the way mainstream schools are coping with the inclusion of disabled pupils and how this compares with pupils who do not have key workers.

Better information on the costs of key working services is required as this study indicates a wide variation. Understanding what influences costs – both at the service and the user level – will provide a better evidence base for the development of the service. Our findings also suggest that more research is needed into the place and impact of key workers within the full array of supports used by families with disabled children. It is likely that the contact costs are only a small part of the total cost of disabled children's care packages but key workers have been shown to be a pivotal service in these families' lives. We cannot tell from this study the extent to which key working supplements, complements or substitutes for other supports, or the extent to which key workers link families into more services, more appropriate services, or into different services. Each of these possibilities may have an impact on the costs of supporting families and their outcomes. With costs per annum of around £1,820, key working may prove to be a cost-effective way of providing support and a comparison of costs and outcomes for families who receive and do not receive a key worker service is required.

Finally, further research is needed on disabled children's experiences of key workers. Such research should include observational methods and more in-depth work to explore children's contacts with their key workers.

9.13 Summary of recommendations for policy and practice

The findings of this study have a number of messages for policy and practice on the development of key worker services for disabled children and their families. In general, the findings of the research were positive, substantial numbers of parents were satisfied with the service and key workers had many positive impacts on families' lives. Key workers' collaborative work with other agencies and professionals and with schools facilitated access to appropriate support for children and their families, and families particularly appreciated key workers taking a holistic approach to family needs. The Children's National Service Framework specifically recommends that local services should ensure that families caring for a child with high levels of need have a key worker and that key worker services are provided in line with guidance in *Together from the Start* (Department of Health/Department for Education and Skills, 2003) and the *New Standards for Key Working* (Care Coordination Network, 2004). Similarly the Early Support Programme is using such

guidance to inform the implementation of key worker services in the early years. Our findings endorse this advice and emphasise the importance of those aspects of the service models that were related to better outcomes for families.

For those setting up and managing key worker services, we would suggest the following recommendations:

Management of the service

Multi-agency commitment to the service is required and this should be reflected in the contribution of funding and resources and in a multi-agency steering group that oversees the service. This group should involve senior managers from each agency. If any members leave the group they should be quickly replaced by an equivalent person from their agency so that momentum and commitment is not lost. As highlighted in both *Together from the Start* (Department of Health/Department for Education and Skills, 2003) and the Children's National Service Framework (Department of Health/Department for Education and Skills, 2004a, 2004b), the involvement of parents in this group helps to focus on the needs of families, but it is important that parents' views are a central part of discussions around the design and ongoing development of the service and that they do not feel that their views are marginalised. Part of the role of the group should be to facilitate information sharing, and to agree ways in which the service will gain families' consent for information relating to them to be shared between professionals and agencies.

At a minimum, funding is required to cover the time of a dedicated service manager and some administrative support. Such funding should be agreed on an ongoing basis. Short term funding can increase the fragility of the services. Information on the full service expenditure and use of dedicated key working time should be held by the service manager to help them use the team's resources in the most appropriate manner.

The service manager's role should include inducting key workers, organising regular training and opportunities for key workers to meet together, ensuring that key workers are provided with supervision specific to their role, organising joint care planning and review meetings, and drawing up information about the service and publicising the service to families, and other agencies and professionals. If non-designated key workers are employed an important part of the role of the manager and of the steering group members is ensuring that line managers in agencies from which key workers are drawn understand the role of the key worker and are committed to the key worker service. The time commitments of the role should be recognised and agreed between the service and the agencies that provide key workers.

The role of the key worker

A definition of the role of key worker should be drawn up and incorporated in a job description. The service manager should spend time going through this definition so that every key worker understands the role. Information for families should also make clear what is and is not within the key workers' role and similarly, key workers should spend time explaining this to families. Families should have written information about the role to refer back to. Other services in the locality, including schools, should receive information about the key workers' role, and key workers and service managers should be proactive in ensuring that relevant professionals know about, and understand the remit of, the service.

Our findings on the crucial effect on family outcomes of whether key workers carried out the majority of aspects of key working, indicate that the key worker role should include:

- Providing information and advice to families about services and support available, both locally and nationally, and how to access these.
- Providing information specific to the child's condition where needed.
- Coordinating care and working across agencies, including supporting families with regard to care planning and review meetings.
- Improving access to services.
- Identifying and addressing the needs of all family members.
- Speaking on behalf of the family when dealing with services.
- Providing emotional support.
- Providing help and support in a crisis.

In order to carry out this role, key workers need training and supervision, and sufficient time to work with the family and with other agencies. They should be proactive in contacting the family.

Key worker training and supervision

Key workers require induction and ongoing training specific to their role. Interviews with staff and families suggested that this should cover:

- Information about the work of all agencies relevant to disabled children and their families, and if possible the provision of key contacts in these agencies.
- Information about common disabling conditions and about where to find further information.
- Information about relevant legislation.
- Information about sources of financial support for families and eligibility criteria.
- The personal skills needed by key workers – communication, listening and negotiating skills; communicating with disabled children; time management.

- Disability awareness and understanding of what life is like for families with disabled children.

Parents and disabled young people can play an important role in training key workers.

Key working is a demanding role and supervision and guidance specific to the role helps workers to meet these demands. In addition, regular opportunities for key workers to meet each other are important aspects of learning and support.

Type of key worker

Designated key workers were found to have some advantages over non-designated key workers, in terms of contributions to outcomes for families, ease of management and development of team spirit. However, our results suggested that the potential disadvantages of non-designated key workers could be overcome by provision of training, supervision and peer support. Nevertheless, the appointment of designated key workers should not be ruled out solely on cost grounds. Our analysis of costs indicated that estimated average costs per family per year for services with designated key workers were £1,380 to £2,300 and those for services with non-designated key workers were £1,565 to £2,935 (see Table 6.1). The more detailed analysis of associations between characteristics of the seven case study services and costs per family over three months did not find any significant association between type of key worker and costs.

Working with disabled children and other family members

It is important that key working is not only a service for parents, particularly mothers, all family members should be seen as recipients of the service. Key workers need training to support them in working with disabled children and young people, particularly those who have cognitive and/or communication impairments. In addition, time is needed for key workers to ensure this work can take place. Children and young people's participation in decisions about developing the service should also be promoted, again this will need time, resources and support for children.

Care planning

Multi-agency care planning and review meetings should be part of the service. These provide a valuable means by which actions of different agencies and professionals can be agreed in collaboration with parents and, hopefully, young people. Such meetings are also an important part of information sharing. Key workers should support families to prepare for and take part in these meetings. Whenever possible, meetings should be combined with other reviews, such as statementing reviews, so that families are not required to attend multiple meetings.

Meeting children's and families' needs

Key worker services cannot meet all needs and they are dependent on the resources and other services available in their local area. However, holistic assessment of needs should be part of the overall multi-agency service and key workers can play a useful role in recording unmet need. Data on unmet need should be collated and inform future service development.

Quality and costs of services

Finally, the study shows that quality and costs are linked. Higher costs – summarising more intensive contact – were associated with greater satisfaction with the service and, although less strongly, with a greater impact on parental quality of life. Higher costs were also associated with providing more aspects of care. However, key workers carrying out more aspects of the role with families was more strongly associated with both satisfaction and quality of life.

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Appendix 1

CCNUK Survey

KEY WORKING /CARE COORDINATION: INFORMATION ABOUT LOCAL SCHEMES

Name of person completing this questionnaire _____
Job Title _____
Organisation _____
Address _____
Telephone number _____ Email _____

SECTION A: CARE COORDINATION SCHEMES

For the purpose of this questionnaire we will define care coordination as a service or scheme involving two or more agencies that provides disabled children and their families with a system whereby services from different agencies are coordinated. Care coordination encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels, and a named care coordinator or key worker for the child and family. This is someone whom the family can approach for advice about any problem related to the disabled child. The named person has responsibility for working with professionals from their own and other services.

A1. In your local area, do you have a care coordination or key worker scheme for disabled children and families?

- ☐ Yes
☐ No

IF **NO**, please go to **question D on page 10**

IF **YES**, please could you answer **all questions in Sections A, B, and C.**

A2. Is your care coordination scheme:

- ☐ A separately identifiable team recognised by management, with its own budget
☐ Part of another team
☐ Other, please describe.....
.....

A3. What geographical areas does the scheme cover?

.....

A4. Which agencies were involved in setting up the scheme? (please tick all that apply)

- ☐ NHS Trust
- ☐ Primary Care Trust or Group
- ☐ Social Services
- ☐ Education
- ☐ Voluntary Agencies
- ☐ Other (please describe)

A5. Were any parents with disabled children involved in planning the scheme?

- ☐ YES
- ☐ NO

A6. Were any disabled children and young people involved in planning the scheme?

- ☐ YES
- ☐ NO

A7. Which agencies are involved in overseeing the scheme, e.g through membership of a steering group? (please tick all that apply)

- ☐ NHS Trust
- ☐ Primary Care Trust or Group
- ☐ Social Services
- ☐ Education
- ☐ Voluntary Agencies
- ☐ Other (please describe).....

A8. Are any parents with disabled children involved in overseeing the scheme?

- ☐ YES
- ☐ NO

A9. Are any disabled children and young people involved in overseeing the scheme?

- ☐ YES
- ☐ NO

A10. Is there a lead agency?

- ☐ YES
- ☐ NO

IF YES, which agency is this?

A11. When did the scheme start?monthyear

A12. Is the scheme a pilot project or a mainstream part of service provision?

☐ PILOT For how many years do you have funding agreed?.....

☐ MAINSTREAM For how many more years do you have funding agreed?

If appropriate, please describe your funding situation.....

.....

.....

A13. Has anything in particular been done to make the scheme accessible to families from minority ethnic groups?

☐ YES

☐ NO

If YES, please describe

.....

A14. Has there been any evaluation of the scheme?

☐ YES

☐ NO

IF YES, we would be grateful for any details you could send us (e.g. evaluation reports)

The next questions are about how the scheme is funded. Please provide as much detail as you are able to. If you are able to send us a recent copy of your income and expenditure accounts, that would be very helpful.

A15. Which agencies contributed money or resources (staff) to the scheme during the financial year 2001-2002?

Agency	Currently provide finance? (Y/N)	Proportion of scheme's finance (%)	No. wte* staff from this agency
NHS Trust			
Primary Care Trust or Group			
Social Services Department			
Education			
Voluntary Agencies			
Other (please describe)			

* whole-time equivalent

A16. Have any of the Health Act 1999 Partnership Arrangements (England)/Flexibility Funding provisions (Wales) been used in the scheme?
(Please tick all that apply)

- ☐ Pooled fund
☐ Lead commissioning

IF YES which agency is the lead commissioner

- ☐ Integrated provision

A17. Has Quality Protects (England)/Children First (Wales)/Changing Children's Services Funds (Scotland) funding been used to support the scheme?

- ☐ YES
☐ NO

A18. Could you tell us about your expenditure in the last financial year (2001-2002)? *If you are not able to complete the information in the table below, it would be helpful if you could give us the name and contact details of someone in your finance department whom we could approach:*

.....

Category	Expenditure 2001-2002	Any comments?
Care staff (salaries/on costs)		
Manager (salaries/on costs)		
Clerical/domestics (salaries/on costs)		
Other service costs (e.g. staff/user travel, subsistence, office expenses)		
Building costs (e.g. power, cleaning, maintenance)		
Rent/capital charges		
Overheads costs/charges for managing agency		
Charges made to the scheme for services (describe)		
Other costs (describe)		

SECTION B: THE CHILDREN AND FAMILIES

B1. What age groups does the scheme cover? Please tick all that apply

- ☐ 0-5 years
- ☐ 6-11 years
- ☐ 12-15 years
- ☐ 16+years

B2. What are the eligibility criteria for children and families?

.....

B3. How many families are currently being supported by the scheme?

B4. Who refers families to the scheme? (Please tick all that apply)

- ☐ Education
- ☐ Health
- ☐ Social services
- ☐ Voluntary agencies
- ☐ Open referral
- ☐ Other, please describe.....

SECTION C: THE COORDINATION SYSTEM/PROCESS

C1. Once a referral has been accepted, are initial planning meetings held between the family and all professionals involved in their care?

- ☐ YES
- ☐ NO

IF YES, please provide brief details

.....

.....

C2. Are regular review meetings held between the family and all professionals involved in their care?

- ☐ YES
- ☐ NO

IF YES, how frequently?

C3. Do families have one person as a key worker (or similar)?

- ☐ YES
- ☐ NO

If NO, please go to question C 18.

- C4. Which professionals working within this scheme are key workers? If possible, please enter the number of whole-time equivalent (w.t.e) posts you have in your scheme for each professional group (e.g. two full time posts would be entered as 2.0, a half-time post would be 0.5) or the total hours per week spent on key working in each professional group.**

Staff Category	Key workers: w.t.e OR hours per week spent on key working
Social workers	
Health Visitors	
Community nurses	
Paediatricians	
Physiotherapists	
Speech therapists	
Occupational therapists	
Teachers	
Nursery nurses	
GPs	
Psychologists	
Workers with voluntary agencies	
Other (please describe)	
TOTAL	

- C5. How many key workers currently work on the scheme?**
- C6. Are they dedicated key workers or do they key work with a few families as part of a larger caseload? (Please tick as appropriate)**
- ☐ Dedicated key workers – How many key workers?
(Please answer question C7)
- ☐ Part of larger case load – How many key workers?
(Please answer question C8)
- C7. Dedicated key workers: How many families, on average, does each full time equivalent worker key work with at any one time?**
- C8. Part of larger case load: How many families, on average, does each worker key work with at any one time?**
- On average, what proportion of their time do they spend on key worker activities?
.....
- C9. How many posts do you have vacant within your scheme?.....**

C10. Is there a waiting list of families requiring key workers?

- ☐ YES
☐ NO

If YES, how many families are on the list?

How long on average does a family wait to get a key worker?

C11. How are the key workers supervised?.....

.....
.....

C12. Is any special training provided for key workers on appointment?

- ☐ YES
☐ NO

If YES, please provide a brief description

.....
.....

C13. Is ongoing training provided for key workers?

- ☐ YES
☐ NO

If YES, please provide a brief description

.....
.....

C14. What does the role of the key worker cover? (Please send a job description or describe below)

.....
.....
.....
.....
.....

C15. How are key workers and families matched?.....

.....

C16. Do families have a choice as to who is their key worker?

- ☐ YES
☐ NO

C17. Do key workers regularly visit families at home?

- ☐ YES
☐ NO

C18. Does the scheme have a coordinator/manager who oversees the day-to-day running of it?

- ☐ YES
☐ NO

If YES, who employs the coordinator/manager?

How much time does the coordinator/manager spend on this role – as proportion of w.t.e?

C19. Where is the scheme based?

- ☐ Community health facility
☐ Hospital
☐ Social services
☐ School
☐ Other, please describe.....
.....

If available, please could you send any written information about the scheme when you return this questionnaire **(e.g. annual reports, publicity material or user information)**.

D. If no care coordination scheme at present - are you planning to develop such a scheme within the next year?

- ☐ YES
☐ NO

Please add any additional information or comments below or opposite.

.....
.....
.....
.....
.....
.....

Have you heard of Care Coordination Network UK (CCNUK)?

- ☐ YES
☐ NO

Would you like to receive information about CCNUK?

- ☐ YES
☐ NO

We will send you feedback on the results of this survey. If you do **not** wish to receive this please tick here

☐

In the future, we will be carrying out further research on care-coordination and may wish to contact you again. If you do **not** want us to contact you, please tick here

☐

PUBLICATION

We plan to produce a summary report on the results of this survey. This will report general trends. Data will be anonymised and individual schemes will not be identified. In addition, CCNUK would like to produce a directory of schemes that will be available to members of the Network. We would check details in the directory with each scheme before publication. In principle, would you be prepared to discuss with us inclusion of details of this scheme in the directory?

☐

YES, I would be prepared to discuss inclusion of details of this scheme in the CCNUK directory.

☐

NO, I would not wish details of this scheme to be included in the directory.

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Please return the questionnaire in the envelope provided.

Please remember to enclose any written documentation about your scheme.

All responses will be treated in confidence.

Appendix 2

Information pack for staff interviews

Cover letter to staff

VG/

Address

E-mail: vg3@york.ac.uk

Date

- Dear Member of Staff -

Enclosed please find an information sheet concerning a research study on '*Evaluating key worker services for disabled children*'. The study is based at the Social Policy Research Unit at the University of York and is funded by the Department of Health, the Department for Education and Skills, HM Treasury Evidence Based Policy Fund and the Welsh Assembly.

We would like to know if you would be willing to participate in this research project, which is fully described in the information sheet. By agreeing to help, we would be able to draw upon your expertise and knowledge of the key work service in your area. The aim of the research is to provide information that can help to improve care co-ordination in services for disabled children.

Yours sincerely

Veronica Greco
Research Fellow

Enc

EVALUATING KEY WORKER SERVICES FOR DISABLED CHILDREN AND THEIR FAMILIES

Information Sheet for Staff

The purpose of this leaflet is to outline the above study and explain what will happen if you decide to take part.

What is the project about?

It is well documented that parents with disabled children express the need for a single point of contact with services by means of an effective, trusted person who will ensure that they receive the help they need. This person is often called a *key worker* or care coordinator. Findings show that families with key workers have better relationships with services, less isolation and feelings of burden, more information about services, and fewer unmet needs. However, as yet, there is little information on different models of key worker services in practice, including models of multi-agency partnerships to support such services. Neither is there any research on the effectiveness of different models.

The aims of the study are to:

- Compare the implementation and operation of different models of key worker services in practice
- Assess outcomes for children and families of different models of key worker services
- Investigate costs and sources of funding of different models of key worker services
- Identify the features of the service that contribute to improved care
- Inform standards of good practice in models of key worker services

Who is doing the study and how is it funded?

The study is based at the University of York (in the Social Policy Research Unit) and is being conducted by Veronica Greco, Tricia Sloper, Jennifer Beecham, Rosemary Webb and Sheila Sudworth. It is jointly funded by the Department of Health, Department for Education and Skills, HM Treasury Evidence Based Policy Fund, and the Welsh Assembly.

Why do you want me to help?

The project seeks to explore the ideas and experiences of professionals, children, and parents concerning key worker services. In a first stage, we are interested in the views of staff, such as managers, coordinators, and key workers, on a wide range of aspects pertaining to key worker services. In a second stage, we are interested in the views of families and children on the key worker services they receive. By agreeing to help, we would be able to draw upon your expertise and knowledge of the key worker service in your area.

What would I have to do?

If you agree to participate, we will arrange a date to meet you for an interview at a place of your choice. In the interview, we will ask for your views on a variety of issues concerning key worker services, such as: what agencies are involved in delivering the service; difficulties and successes encountered; funding and costs of the services; the definition of the key worker role; which practitioners become key workers; who manages them, and what training and supervision they receive; recommendations for good practice in key worker services. We would like to tape record the interviews and we will ask you about this before we start. If you would prefer not to be tape recorded, we will take notes. Your information will be very valuable in providing us with an accurate description of key worker services.

In the second stage of the study, with the permission of service managers, families using the key worker service will be sent a questionnaire covering topics such as: parents' perceptions of the extent to which services are meeting the family's needs, the impact of the service on family stress and on other aspects of family life. Families' responses will be kept anonymous. We will subsequently ask a sub-sample of the parents who respond to the questionnaire if they and their children are willing to be interviewed for further information on the key worker service they receive.

Do I have to take part?

You do not have to take part. If you decide not to take part, you do not have to give a reason. If you do decide to take part and later change your mind, you can withdraw at any time.

What will happen to the information?

All information will be treated in confidence. No names or identifying information will be used in any reports of the study.

The information from staff, children and parents will be collated together in a report documenting their views on key worker services. Key issues will be identified and recommendations made, especially around producing national standards of good practice in key worker services for disabled children and their families. When completed, you will receive a summary of the report. The report will also be sent to the government departments that funded the research.

What do I do next?

If you are willing for a member of the research team to contact you about taking part in an interview, please complete the enclosed form and send it to us in the envelope provided.

Further Information

If you are interested and you would like further information on the study, please contact Veronica Greco (vg3@york.ac.uk) or Tricia Sloper (ps26@york.ac.uk) at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD. Or telephone Veronica Greco: Tel: 01904 433608.

**EVALUATING KEY WORKER SERVICES FOR
DISABLED CHILDREN AND THEIR FAMILIES**

Staff Response Form

I am interested in taking part in an interview for the 'Evaluating key worker services for disabled children and their families' project. I would like the researchers to contact me to find out more and, if I decide to participate, arrange a date to be interviewed.

Name.....

Job title

Address

..... Post code.....

The best times to contact me are:

Please tick boxes for times that suit you and number(s) to contact you at those times

Mornings ☐ Tel. No.

Afternoons ☐ Tel. No.

Evenings ☐ Tel. No.

Please add any other details, e.g. days of the week or specific times that are best for you:

.....

I agree to researchers contacting me to tell me more about the project

Signature

Please return this form, and your completed availability form, to the researchers using the envelope provided. You do not need to use a stamp.
Thank You.

Veronica Greco, Tricia Sloper
Social Policy Research Unit, University of York, Heslington, York YO10 5DD
Telephone: 01904 433608 Fax: 01904 433618

EVALUATING KEY WORKER SERVICES FOR DISABLED CHILDREN AND THEIR FAMILIES

Consent Form For Staff

I have read the project information leaflet and understand the purpose of the project and what is involved.

I understand that the project is strictly confidential and I will not be named in the project reports.

I understand that participation in the project is voluntary and that I can withdraw from the project at any time without giving a reason.

I am willing to take part in the project
(Please tick)

Yes ☐ No ☐

I agree to my interview being tape recorded

Yes ☐ No ☐

Name

Signature

Date

Signature of researcher

Date

Appendix 3

Information pack for parent questionnaires

VG/

Address

E-mail: vg3@york.ac.uk

Date

- Dear Parent -

Enclosed please find an information sheet concerning a research study on *Evaluating key worker services for disabled children*. The study is based at the Social Policy Research Unit at the University of York and is funded by the Department of Health, the Department for Education and Skills, HM Treasury Evidence Based Policy Fund and the Welsh Assembly.

We would like to know if you would be willing to participate in this research project, by filling in the enclosed questionnaire. By participating in this project you will help to inform service providers about your experience of key worker services. The aim of the research is to provide information that can help to improve care coordination in services for disabled children.

Yours sincerely

Veronica Greco

Enc

EVALUATING KEY WORKER SERVICES FOR DISABLED CHILDREN AND THEIR FAMILIES

Information Leaflet For Parents/Guardians

This leaflet tells you about the research project we are running, why you have been sent a questionnaire and what will happen to the information if you decide to complete the questionnaire.

Who is doing the study?

The study is based at the Social Policy Research Unit at the University of York and is being conducted by Veronica Greco, Tricia Sloper, Jennifer Beecham, Rosemary Webb and Sheila Sudworth. The study is funded by the Department of Health, the Department for Education and Skills, HM Treasury Evidence Based Policy Fund and the Welsh Assembly.

The aim of the project

The aim of the study is to find out more about *whether the services provided to disabled children and their families are meeting their needs, and how services can be improved*. Particularly, we are interested in evaluating the *key worker service* you receive. A key worker or care co-ordinator is a person who should be contacting you regularly to co-ordinate the care your child receives and to make sure you are getting the services you need.

This project has three main aims:

- To compare different types of key worker services in the UK, and find out how these services affect children and families.
- To describe the views of children and parents concerning the key worker service they receive and find out which aspects of the service contribute to better care.
- To develop recommendations about how key worker services should best be provided.

Why am I being asked to take part in the project?

We are trying to find out what you and other people like you feel about the services on offer to you and your family and the effect they have on the family. It is important that we hear the ideas of as many families who receive key worker services as possible. Your service provider has agreed to help us by passing this information sheet and questionnaire on to anyone receiving the service who might be interested in completing the questionnaire.

By participating in this project you will help to inform service providers about your experience of key worker services. By doing this, we hope that in the future, disabled children will get better help.

Do I have to fill in the questionnaire?

No, you do not have to fill in the questionnaire. *If you decide not to take part, that's OK.* You do not have to give a reason. If you want to take part but do not want to answer some of the questions, just leave them out. Whether or not you decide to take part will not affect any services that you or your child receive.

What does the questionnaire ask?

The questionnaire covers topics such as: the kind of key worker service you are receiving, if your key worker is meeting your family's needs, and the impact of the service on family stress and other aspects of family life. The aim of the questionnaire is to give us a complete idea of how your key worker service works and if it is meeting your family's needs. It will take about 40 minutes to fill in.

At a later date, we may contact some of you to ask you whether you would be interested in meeting one of us to tell us more about how services could better meet your needs. The questionnaire asks whether you would be willing for us to contact you again. However, if you complete the questionnaire, it does not mean you need to have any further contact with us.

We realise that the key worker service supports both parents and children. We would like to find out children and young people's views of the service, so we have enclosed two questionnaires: a blue one for parents and a yellow one, with a brief information sheet, for children and young people. If your child is willing and able to complete the questionnaire, we would be very grateful for his or her response.

What will happen to the information?

All the information you give us is confidential. Your name will be removed from the questionnaire and substituted with a number, so as to keep the information anonymous. All names will be kept separately from questionnaires. We will not disclose to anyone that you are taking part.

When we have completed the research, we will produce a report of what parents, young people and staff have told us. The report will include recommendations about the best way to meet the needs of disabled children and young people and their families.

You will be sent a summary of the report. The report will also be sent to those who funded the research. We hope they will use our report to plan future help for children, young people and their families.

What happens next?

If you feel that you would like to take part in the research, please fill in the questionnaire and return it, with your child's questionnaire if appropriate, in the envelope provided. You do not need to use a stamp. If you have any questions about filling in the questionnaire, please contact us at the address and phone number below.

If you have any questions about the project, please contact Veronica Greco or Tricia Sloper at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD. Telephone 01904 433608. Email vg3@york.ac.uk (Veronica) or ps26@york.ac.uk (Tricia).

Thank you for reading this leaflet!

EVALUATING KEY WORKER SERVICES FOR DISABLED CHILDREN AND THEIR FAMILIES

Questionnaire for Parents*

*If you do not wish to fill in the questionnaire and do not want to any further contact about the research, please could you fill in your name, tick the box below and return the blank questionnaire in the envelope provided.

1. Your name _____

2. Child's name _____

3. Child's age _____

4. Child's gender (please tick) Male ☐ Female ☐

5. Family address _____

6. Telephone number _____

☐ I do not wish to fill in the questionnaire and do not want any further involvement with the research.

--	--	--	--

7. **Are you...?** Child's mother ☐ Child's father ☐
 Other (please state) _____

8. **Is your child either fostered or adopted?**

Yes ☐ No ☐

9. **If yes, which of these?**

Fostered ☐ Adopted ☐

10. **Are you...?**

Married or living as married ☐ Separated or divorced ☐
 Single ☐ Widowed ☐

If married or living as married, please fill in the following section about your partner. If not, please move on to *Section B*.

SECTION A: YOUR PARTNER

11. **Partner's age** _____

12. **Is your partner living at home?** Yes ☐ No ☐

13. **Is your partner employed?** Yes ☐ No ☐

14. **If yes, full time or part time?** Full time ☐ Part time ☐

SECTION B: ABOUT YOURSELF

15. Your age _____

16. Which best describes your origin?

White ☐

Indian ☐

Black-Caribbean ☐

Pakistani ☐

Black-African ☐

Bangladeshi ☐

Chinese ☐

Other (please state) _____

17. Are you employed? Yes ☐ No ☐

18. If yes, full time or part time? Full time ☐ Part time ☐

19. Including your disabled child, how many children do you have?

20. How old are your other children (if any)? _____

SECTION C: YOUR CHILD'S DISABILITY

21. How old was your child when you found out he/she had a disability?

Before birth ☐ At birth ☐ Years Months

22. Please describe the diagnosis you have been given for your child's condition

23. What kind of school is your disabled child currently attending?

Child too young to go to school ☐

Special school ☐

Nursery ☐

Special needs nursery ☐

Residential school ☐

Ordinary/mainstream school ☐

Special unit in ordinary/mainstream school ☐

24. Does your child have a statement of special educational needs?

Yes ☐

No ☐

25. Does your child's disability mean he/she has difficulties in any of the following areas?

	Not at all	Moderately so	Very much so
a. Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26. Do you receive any of the following disability benefits?

Disability Living allowance (DLA)

- | | | |
|-------------------|--|--------------------------|
| a) Care needs | Lower rate (currently £ 15.15 per week) | <input type="checkbox"/> |
| | Medium rate (currently £ 38.30 per week) | <input type="checkbox"/> |
| | High rate (currently £ 57.20 per week) | <input type="checkbox"/> |
| b) Mobility needs | Lower rate (currently £ 15.15 per week) | <input type="checkbox"/> |
| | Higher rate (currently £ 39.95 per week) | <input type="checkbox"/> |

SECTION D: YOUR NEEDS

27. How long have you had a key worker?

Years

Months

28. Over the past six months, how much help have you had for each of these needs? (Please tick one box for each line)

		Getting enough help	Need help	Help not needed
1)	Getting a break from caring for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2)	Spending more time with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3)	Having more time with my other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4)	Help with managing my child's behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5)	Help getting my child to sleep better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6)	Learning the best ways of helping my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7)	Having someone to talk about my child with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8)	Help with the housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9)	Help with the day to day care of my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10)	Having someone who will show us which services are available to us	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11)	Meeting other parents of disabled children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12)	Help with planning for my child's future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13)	Having more money in order to care for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14)	Help with my child during the school holidays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15)	Having someone to look after my child so I can go to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16)	Help with improving my child's mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17)	Help to develop my child's communication skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18)	Help with improving housing for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19)	Help with transport problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20)	Help getting the information we need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21)	Help planning my child's schooling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22)	More time to spend with my child (e.g. to play, relax, have fun etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23)	Help obtaining aids and equipment for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24)	Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. Finally, we would like you to describe the greatest need you have at the moment and how you would like this to be met

Please tick the box that best shows how much help YOUR CHILD needs.

30. My child needs help...

		Getting enough help	Need help	Help not needed
1.	To learn skills which will help him/her be more independent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Finding someone to talk to about being disabled	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Moving about independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	With communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	With developing his/her physical abilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Getting support for developing his/her learning abilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Getting treatments to cure or improve his/her condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Meeting non-disabled children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Meeting other disabled children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	With behaviour problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	With social/relationship skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION E: THE SERVICES YOU RECEIVE

31. Overall, how satisfied are you with the key worker service you receive?

Very satisfied ☐ Satisfied ☐ Not satisfied ☐ Not at all satisfied ☐

32. Overall, how much does your key worker service provide you with the following?

		Not at all	Some	Very much
a.	Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	Information about your child's condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	Information about services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	Advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	Identifying the needs of all family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	Addressing the needs of all family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g.	Speaking on behalf of the family when dealing with services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h.	Coordinating care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i.	Improving access to services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j.	Help/support in a crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k.	Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION F: RELATIONSHIPS WITH STAFF

33. In general, do you think having a key worker positively affects the way you are treated by services?

Never ☐

Sometimes ☐

Often ☐

Always ☐

34. Which is the aspect of your key worker service you value MOST?

35. Which is the aspect of your key worker service you value LEAST?

SECTION G: YOUR QUALITY OF LIFE

36. In the past six months, has having a key worker had an impact on the following areas of your life:

	Positive impact	Negative impact	No impact
1) My physical health or well-being (e.g. sleep, rest, exercise)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) My emotional/mental health (e.g. stress, anxiety, depression)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Time to myself (e.g. work, studies, interests)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) My relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) My financial or material circumstances (e.g. income, housing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) My feeling of control over my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) My peace of mind (being less worried)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION H: STRESS

Have your contacts with services affected the amount of stress you have experienced in caring for your child in the past six months? (please tick **ONLY** one)

37. My contact with services has...

- ☐ Considerably reduced my stress
- ☐ Somewhat reduced my stress
- ☐ Not had any effect on my stress
- ☐ Somewhat increased my stress
- ☐ Considerably increased my stress

SECTION I: PROCESSES OF CARE

We would like to measure the experiences of parents who have a child with a disability. In particular, we wish to know your views of: the care you and your child have been receiving over the past **6 months**. We would like you to indicate how much the event or situation described happens (or doesn't happen) to you. You are asked to answer each question on a scale from 1 (Never) to 4 (Always).

1=Never 2=Sometimes 3=Often 4=Always N/A=Not applicable

Please also circle "Yes" or "No" to say whether your key worker has helped with this.

38. To what extent do the people who work with your child...

1)	Suggest services that fit in with your family's needs and lifestyle? Yes/No	1	2	3	4	N/A
2)	Fully explain treatment choices to you? Yes/No	1	2	3	4	N/A
3)	Offer you positive feedback or encouragement? Yes/No	1	2	3	4	N/A
4)	Explain things to your child in a way that he/she understands? Yes/No	1	2	3	4	N/A
5)	Take the time to get to know you and your child when staff changes occur in your services? Yes/No	1	2	3	4	N/A

6)	Discuss with you everyone's expectations for your child so that all agree on what is best? Yes/No	1	2	3	4	N/A
7)	Make sure that your child's skills are known to all persons working with your child? Yes/No	1	2	3	4	N/A
8)	Tell you about options for treatment or services for your child (e.g. equipment, teaching, therapy)? Yes/No	1	2	3	4	N/A
9)	Accept you and your family as you are, without judging you? Yes/No	1	2	3	4	N/A
10)	Provide ideas to help you work with the services available to you? Yes/No	1	2	3	4	N/A
11)	Recognize the demands of caring for a child with special needs? Yes/No	1	2	3	4	N/A
12)	Trust you as the "expert" on your child? Yes/No	1	2	3	4	N/A
13)	Look at the needs of your "whole" child (e.g. at mental, emotional, and social needs) instead of just at physical needs? Yes/No	1	2	3	4	N/A
14)	Show sensitivity to your family's feelings (or worries) about having a child with special needs? Yes/No	1	2	3	4	N/A
15)	Be aware of worries you may have by offering information even before you ask? Yes/No	1	2	3	4	N/A
16)	Make sure you have a chance during visits to say what is important to you? Yes/No	1	2	3	4	N/A
17)	Let you choose when to receive information and the type of information you want? Yes/No	1	2	3	4	N/A
18)	Remember personal details about your child or family when speaking with you? Yes/No	1	2	3	4	N/A
19)	Tell you about the reasons for treatment or equipment? Yes/No	1	2	3	4	N/A
20)	Follow up at the next appointment on any concerns you discussed at the previous one? Yes/No	1	2	3	4	N/A
21)	Make sure that at least one team member is someone who works with you and your family over a long period of time? Yes/No	1	2	3	4	N/A
22)	Provide opportunities for you to make decisions about treatment? Yes/No	1	2	3	4	N/A
23)	Answer your questions completely? Yes/No	1	2	3	4	N/A

24)	Explain what they are doing when you are watching your child in therapy? Yes/No	1	2	3	4	N/A
25)	Recognize that your family has the final say when making decisions about your child's treatment? Yes/No	1	2	3	4	N/A
26)	Tell you about the results from assessments? Yes/No	1	2	3	4	N/A
27)	Provide you with written information about what your child is doing in therapy and teaching programmes? Yes/No	1	2	3	4	N/A
28)	Ask for your opinion when discussing equipment or services? Yes/No	1	2	3	4	N/A
29)	Provide a caring atmosphere rather than just give you information? Yes/No	1	2	3	4	N/A
30)	Tell you the details about your child's services, such as the reasons for them, the type of therapies and the length of time? Yes/No	1	2	3	4	N/A
31)	Treat you as an individual rather than as a "typical" parent of a child with a disability? Yes/No	1	2	3	4	N/A
32)	Develop both short-term and long-term goals for your child? Yes/No	1	2	3	4	N/A
33)	Treat you as an "equal" rather than as just the parent of a patient? Yes/No	1	2	3	4	N/A
34)	Plan together so they are all working in the same direction? Yes/No	1	2	3	4	N/A
35)	Make sure you have opportunities to explain what you think are important treatment goals for your child? Yes/No	1	2	3	4	N/A
36)	Make you feel like a partner in your child's care? Yes/No	1	2	3	4	N/A
37)	Make sure you are informed ahead of time about any changes in your child's care? Yes/No	1	2	3	4	N/A
38)	Help you to feel competent as a parent? Yes/No	1	2	3	4	N/A
39)	Provide you with written information about your child's progress? Yes/No	1	2	3	4	N/A
40)	Seem aware of your child's changing needs as he/she grows? Yes/No	1	2	3	4	N/A
41)	Provide enough time to talk so you don't feel rushed? Yes/No	1	2	3	4	N/A

42)	Treat you and your family as people rather than as a “case”? Yes/No	1	2	3	4	N/A
43)	Listen to what you have to say about your child’s needs for equipment, services, etc.? Yes/No	1	2	3	4	N/A
44)	Make themselves available to you as a resource (e.g. emotional support, help, information etc)? Yes/No	1	2	3	4	N/A
45)	Give you information about your child that doesn’t differ from person to person? Yes/No	1	2	3	4	N/A
46)	Have information available to you in various forms, such as a booklet, kit, video, etc.? Yes/No	1	2	3	4	N/A
47)	Have support staff (e.g. office staff) that are polite and courteous to you and your family? Yes/No	1	2	3	4	N/A
48)	Promote family-to-family gatherings for sharing information, social events, or shared experiences? Yes/No	1	2	3	4	N/A
49)	Provide opportunities for special guests to speak to groups of parents on topics of interest? Yes/No	1	2	3	4	N/A
50)	Provide support to help you cope with the impact of childhood disability? Yes/No	1	2	3	4	N/A
51)	Notify you about the reasons for upcoming case conferences, meetings etc. about your child? Yes/No	1	2	3	4	N/A
52)	Have information available about your child’s disability (e.g. its causes, progression, future outlook?) Yes/No	1	2	3	4	N/A
53)	Provide advice on how to get information or contact other parents? Yes/No	1	2	3	4	N/A
54)	Provide opportunities for the whole family to obtain information? Yes/No	1	2	3	4	N/A
55)	Have general information available about different concerns (e.g. financial costs, genetic counselling)? Yes/No	1	2	3	4	N/A

SECTION J: CONTACTS WITH SERVICES

39. In the last 3 months, how often have you seen your key worker? (Please fill in the approximate number of times) _____

40. Typically, how long do these visits last? _____

41. Would you like to see your key worker:

More often ☐ About the same ☐ Less often ☐

42. In the last 3 months, how often have you spoken to your key worker over the phone? (Please fill in the approximate number of times) _____

43. Typically, how long do these contacts last? _____

44. Would you like to talk to your key worker

More often ☐

About the same ☐

Less often ☐

45. Regarding contact with your key worker (please tick **ONLY ONE**):

My key worker usually makes contact with me regularly ☐

My key worker usually leaves it up to me to contact them ☐

46. Have you or your child have seen the following professionals in the last 3 months? (*please tick all those seen*)

GP ☐

Portage/home liaison teacher ☐

Social Worker ☐

Physiotherapist ☐

Psychologist ☐

Community nurse ☐

Psychiatrist ☐

Health visitor ☐

Voluntary worker ☐

Hospital doctor ☐

Speech and language therapist ☐

Community paediatrician ☐

Occupational therapist ☐

Other..... ☐

47. If your child is in mainstream school, please tick whether you or your child have seen the following professionals in the last 3 months (*please tick all those seen*)

Behavioural support assistant in school ☐

Learning support assistant in school ☐

Classroom support assistant ☐

SECTION K: EMPLOYMENT

48. Do you work as an employee or are you self-employed?

- a) Employee ☐
b) Self-employed with employees ☐
c) Self-employed/freelance without employees ☐
d) Not currently employed ☐ (please go to question 51)

49. How many people work for your employer?

- a) 1 to 24 ☐
b) 25 or more ☐

50. Do you supervise any other employees?

Yes ☐ No ☐

**51. Please tick the box that best describes the sort of work that you do
(Please tick ONE box only)**

☐ **Modern professional occupations**
Such as: teacher – nurse – physiotherapist – social worker –
welfare officer – artist – musician – police officer – software designer

☐ **Clerical and intermediate occupations**
Such as: secretary – personal assistant – clerical worker –
office clerk – call centre agent – nursing auxiliary – nursery nurse

☐ **Senior managers or administrators**
Such as: finance manager – chief executive

☐ **Technical and craft occupations**
Such as: motor mechanic – fitter – inspector – plumber –
printer – tool maker – electrician – gardener – train driver

☐ **Semi-routine manual and service occupations**
Such as: postal worker – machine operative – security guard – caretaker –
farm worker – catering assistant – receptionist – sales assistant

- ☐ **Routine manual and service occupations**
Such as: driver – cleaner – porter – packer – sewing machinist – messenger – labourer – waiter/waitress – bar staff
- ☐ **Middle or junior managers**
Such as: office manager – retail manager – bank manager – restaurant manager – warehouse manager – publican
- ☐ **Traditional professional occupations**
Such as: accountant – solicitor – medical practitioner – scientist – civil/mechanical engineer

52. Has having a disabled child affected your employment?

- ☐ No
- ☐ I had to leave work to care for child
- ☐ I have not been able to return to work
- ☐ I have not progressed as far in my job
- ☐ I cannot work as many hours as I like

Regarding your partner...

53. Does partner work as an employee or self-employed?

- a) Employee ☐
- b) Self-employed with employees ☐
- c) Self-employed/freelance without employees ☐
- d) Not currently employed ☐ *Please go to question 56*

54. How many people work for your partner's employer?

- a) 1 to 24 ☐
- b) 25 or more ☐

55. Does your partner supervise any other employees?

- Yes ☐ No ☐

56. Please tick the box that best describes the sort of work that your partner does
(Please tick ONE box only)

- ☐ **Modern professional occupations**
Such as: teacher – nurse – physiotherapist – social worker – welfare officer – artist – musician – police officer – software designer
- ☐ **Clerical and intermediate occupations**
Such as: secretary – personal assistant – clerical worker – office clerk – call centre agent – nursing auxiliary – nursery nurse
- ☐ **Senior managers or administrators**
Such as: finance manager – chief executive
- ☐ **Technical and craft occupations**
Such as: motor mechanic – fitter – inspector – plumber – printer – tool maker – electrician – gardener – train driver
- ☐ **Semi-routine manual and service occupations**
Such as: postal worker – machine operative – security guard – caretaker – Farm worker – catering assistant – receptionist – sales assistant
- ☐ **Routine manual and service occupations**
Such as: driver – cleaner – porter – packer – sewing machinist – messenger – labourer – waiter/waitress – bar staff
- ☐ **Middle or junior managers**
Such as: office manager – retail manager – bank manager – restaurant manager – warehouse manager – publican
- ☐ **Traditional professional occupations**
Such as: accountant – solicitor – medical practitioner – scientist – civil/mechanical engineer

57. Has having a disabled child affected your partner's employment?

- ☐ No
- ☐ Had to leave work to care for child
- ☐ Has not been able to return to work
- ☐ Has not progressed as far in his/her job
- ☐ Cannot work as many hours as he/she likes

58. Do you have any specific comments on the key worker's role in relation to the different services your family receives from: Education, Social Services, and Health?

59. Any other comments

Please attach separate sheet if you would like to write more comments

We will be inviting some parents and disabled children (or young people) to take part in interviews about key worker services. We would be grateful if you could indicate below whether you and/or your child would be willing to consider this.

NB. This does not commit you to being interviewed. We will send you more information at a later date.

☐ **Yes, I would like to receive more information**

☐ **No, I do not want to receive more information**

Thank you for taking the time to fill in this questionnaire!

Appendix 4

Information pack for children's questionnaire

VG/

Address

E-mail: vg3@york.ac.uk

Date

- Dear Child/Young person -

Enclosed please find an information sheet concerning a research study on *Evaluating key worker services for disabled children*. The study is based at the Social Policy Research Unit at the University of York and is funded by the Department of Health, the Department for Education and Skills, HM Treasury Evidence Based Policy Fund and the Welsh Assembly.

We would like to know if you would be willing to participate in this research project, by filling in the enclosed questionnaire. By participating in this research, you would help us find out what you and other people like you think about the services you receive. The aim of the research is to provide information that can help to improve care co-ordination in services for disabled children and young people.

Yours sincerely

Veronica Greco

Enc

EVALUATING KEY WORKER SERVICES FOR DISABLED CHILDREN AND THEIR FAMILIES

Information Sheet For Children and Young People

Why have I been sent this questionnaire?

This leaflet is designed to tell you about this research project and explain why we have sent you a questionnaire. Please read this leaflet and discuss it with your family, if you wish.

Who is doing the study?

The study is based at the University of York (in the Social Policy Research Unit) and is being carried out by Veronica Greco, Tricia Sloper, Jennifer Beecham, Rosemary Webb and Sheila Sudworth. The study is funded by the Department of Health, the Department for Education and Skills, HM Treasury Evidence Based Policy Fund and the Welsh Assembly.

What is the study about?

The aim of the study is to find out more about the needs of disabled children and young people and about the services they receive. We are interested in knowing whether you have a key worker and what you think about your key worker service. A key worker is someone who may be visiting you regularly to make sure you are getting the services you need. We are trying to find out about the best ways of providing key worker services. We would like to hear your point of view about these things.

What do I have to do?

We would like you to fill in a questionnaire about what you think about your key worker service. The questionnaire is very short and we hope it is easy to complete.

Why me and my family?

We are trying to find out what you and other people like you think about the services you get. It is important that we hear the ideas of as many disabled children and young people and their families as possible. Your key worker service has agreed to help us by passing this letter on to anyone who might be interested in filling in the questionnaire.

Do I have to fill in the questionnaire?

No, you don't have to fill in the questionnaire. *If you decide not to that's OK.* You do not need to give us a reason if you don't want to take part. If your parents or guardians want to take part, they still can without involving you. If you want to take part but do not want to answer some of the questions just leave them out. Whether you fill in the questionnaire or not will not affect any treatment or care you or your family receive.

We would also like to know if you would want to be contacted so that one of us could come to visit you and ask you some questions about your key worker service, and any needs you may have that aren't being met. If you want to fill in the questionnaire, but don't want us to contact you again about coming to talk to you, that's OK. You can tell us this at the end of the questionnaire.

Will you tell anyone else what I say?

If you fill in a questionnaire, only members of the research team will know your answers. Your name will NOT be mentioned to others or published in the reports of our work.

How will the information I provide be used?

We will examine the information from all the young people and families and staff who took part in the study and write a report on what we found. This will include recommendations about the best way to meet the needs of disabled children and young people and their families. We will send you a summary of this report. The report will also be sent to those who funded the research. We hope that the report will be used in planning help for young people in the future.

What happens next?

If you feel you would like to take part in the project, please fill in the **yellow questionnaire** and return it in the envelope provided. You do not need to use a stamp. If you have any questions or trouble filling out this questionnaire please call Veronica or Tricia on (01904 433608) and we will help you.

If you have any questions about the project, please contact Veronica Greco or Tricia Sloper at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD.

Telephone 01904 433608.

Email vg3@york.ac.uk (Veronica) or ps26@york.ac.uk (Tricia).

Thanks for reading this leaflet!

EVALUATING KEY WORKER SERVICES FOR DISABLED CHILDREN

CHILDREN'S AND YOUNG PEOPLE'S QUESTIONNAIRE




Your name

Your age



Please tick YES or NO to tell us what
you think about your key worker.

Please tick YES or NO to tell us what you think about your key worker.



My key worker makes my life easier
☐ ☐
Yes No

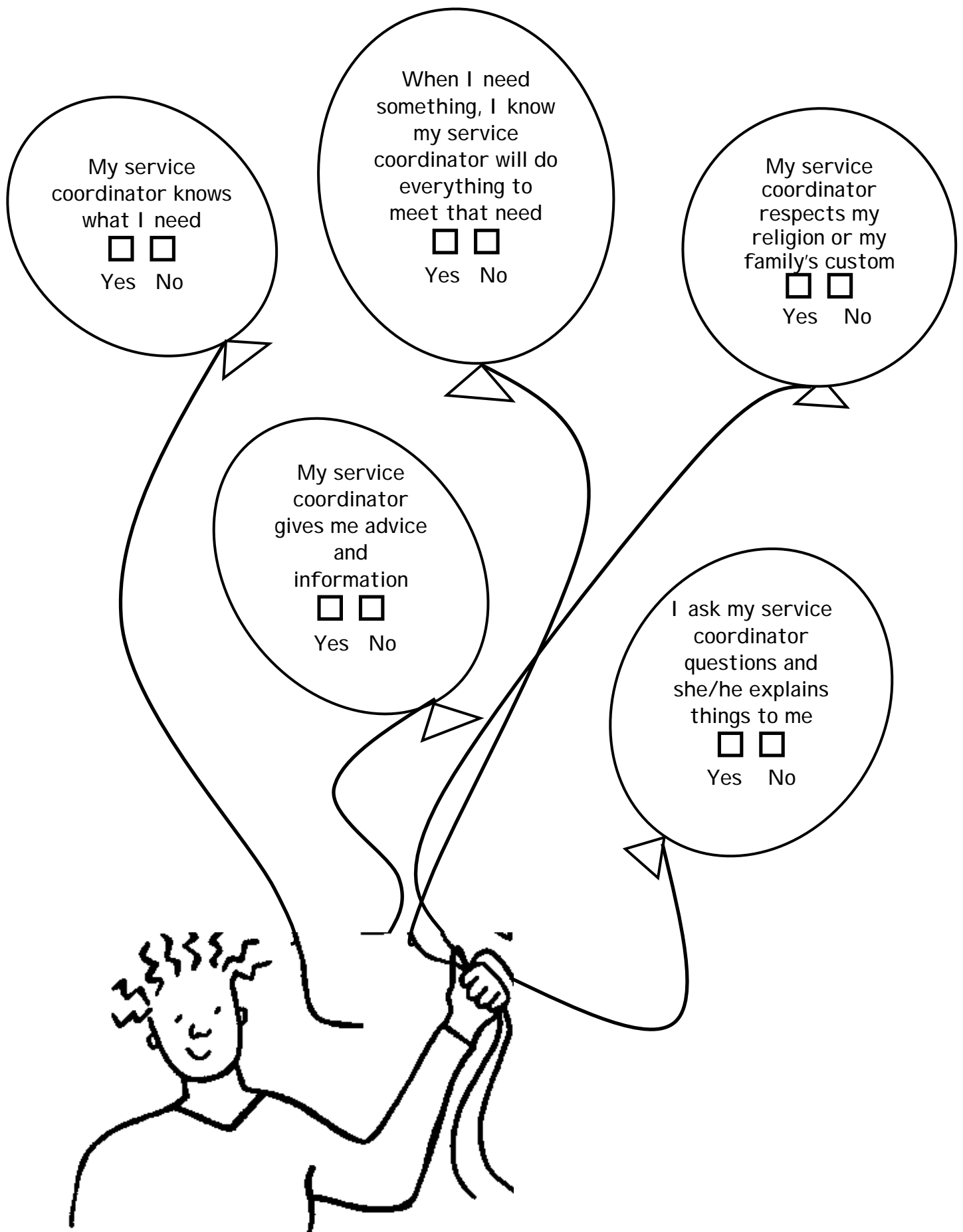
My key worker helps me to become more independent and do things for myself
☐ ☐
Yes No

My key worker understands about my illness or disability
☐ ☐
Yes No

My key worker knows how to help and look after me
☐ ☐
Yes No

My key worker asks me for my ideas and listens to what I have to say
☐ ☐
Yes No

Please tick YES or NO to tell us what you think about your service coordinator.



My service coordinator knows what I need
☐ ☐
Yes No

When I need something, I know my service coordinator will do everything to meet that need
☐ ☐
Yes No

My service coordinator respects my religion or my family's custom
☐ ☐
Yes No

My service coordinator gives me advice and information
☐ ☐
Yes No

I ask my service coordinator questions and she/he explains things to me
☐ ☐
Yes No

We will be inviting some children and young people to take part in interviews about their key worker service. If you think you might like to do this, we will send you more information about it. Please could you tick below to tell us whether you would like more information or not.

- ☐ Yes, I would like more information
- ☐ No, I do not want any further contact with the research.

Appendix 5

Information sheet and list of topics for parent interviews

EVALUATING KEY WORKER SERVICES FOR DISABLED CHILDREN AND THEIR FAMILIES

Information Sheet For Parents/Guardians

Thank you for completing the questionnaire we sent you. This leaflet is to remind you of the nature of the research project and to ask you if you would like to participate in the final phase of the study.

The aim of the project

The aim of the study is to find out more about *whether the services provided to disabled children and their families are meeting their needs, and how services can be improved*. Particularly, we are interested in evaluating the *key worker service* you receive. A key worker or care co-ordinator is a person who should be contacting you regularly to co-ordinate the care your child receives and to make sure you are getting the services you need.

This project has three main aims:

- To compare different types of key worker services in the UK, and find out how these services affect children and families.
- To describe the views of children and parents concerning the key worker service they receive and find out which aspects of the service contribute to better care.
- To develop recommendations about how key worker services should best be provided.

Who is doing the study?

The study is based at the Social Policy Research Unit at the University of York and is being conducted by Veronica Greco, Tricia Sloper, Jennifer Beecham, Rosemary Webb and Judith Cavet. The study is funded by the Department of Health, the Department for Education and Skills, HM Treasury Evidence Based Policy Fund and the Welsh Assembly.

What will I be asked to do?

You indicated on the questionnaire that you would be willing for us to contact you about participating in a final phase of our study. This would involve one of us coming to visit you at your home, or any other place you choose, at a date and time that would best suit you. We would like to interview you about whether your key worker service has been helpful and how it could be improved. We also would like to discuss any needs you may have that are not being met by the services you are receiving at the moment. The aim of the interview is to collect information on parents' views of their key worker service and anything they think could be done to improve services they receive. We expect that the interview will take about one to one and a half hours. We would like to tape record the

interviews and we will ask you about this before we start. If you would prefer not to be tape recorded, we will take notes.

If your child is interested in taking part, we will also ask him or her to talk to us. This could be when we visit you or at another time. More information about this is provided in the enclosed information sheets for children and young people. If you would like to take part but your child does not wish to, or vice versa, that is OK.

Why should I take part in the project?

By participating in this project you will help to inform service providers about your experience of key worker services. By doing this, we hope that in the future, disabled children will get better help.

Do I have to take part?

If you decide not to take part, that's OK. If you do decide to take part and later change your mind, you can withdraw at any time. You do not have to give a reason. Whether or not you decide to take part will not affect any treatment or care that you or your child receive.

What will happen to the information?

All the information you give us is confidential. We will not discuss what you have told us with anyone and we will not disclose to anyone that you are taking part. Reports from the research will not identify anyone who has taken part.

When we have completed the research, we will produce a report of what parents, young people and staff have told us. The report will include recommendations about the best way for key worker services to meet the needs of disabled children and young people and their families.

You will be sent a summary of the report. The report will also be sent to those who funded the research. We hope they will use our report to plan future help for children, young people and their families.

What happens next?

If you feel you *might* like to take part in this phase of the project, please post the enclosed *response form* to us in the envelope provided. You do not need to use a stamp. We will then get in touch with you to tell you more about the project. If you then decide to take part, we will arrange a date to come to visit you.

If you would like to get in touch with us, please feel free to contact Veronica Greco (email: vg3@york.ac.uk) or Tricia Sloper (email: ps26@york.ac.uk) at the Social Policy Research Unit, University of York, York YO10 5DD, tel. 01904 321950.

Thank you for reading this leaflet!

Topic guide: these are *some* of the topics we will ask you about.

- How would you describe your key worker's role?
- Was this role described to you before you started to receive the service?
- How would you describe your family's relationship with your key worker?
- Is it easy to speak to him/her when you need him/her?
- Was the key worker assigned to you or did you have a choice?
- If you did choose, why did you choose this person?
- What is the key worker's professional background?
- Can he/she help you in areas outside his/her field? E.g. work across agencies?
- Is your key worker able to meet the needs of you and your family?
- If not, what needs are not met?
- What do you think your key worker could do better to meet those needs?
- Does the key worker liaise with the school on your behalf?
- Can you give any examples where the key worker has assisted your child to participate more fully in any aspects of school life?
- Does your key worker coordinate services for you?
- Has having a key worker reduced the number of professionals you interact with or not?
- How does your key worker get on with your child?
- Does the key worker look at the needs of the whole family?
- Do you feel you have learned something from the key worker system so that you could do what your key worker does?
- What kind of paperwork do you have to fill in?
- Does your key worker help you with this?
- How do you think the service could be improved?

Appendix 6

Service A

Led by a voluntary organisation, this service has one full-time designated key worker and eight part-time non-designated workers from other agencies amounting 1.0 whole-time-equivalent person. The service supports around 60 families. Costs estimated using specific budget information from voluntary organisation that manages the key worker service and nationally applicable unit costs data for the key workers (which include overheads; Netten and Curtis, 2003). Total cost is £80,600 per annum. Four key workers estimated around 50 per cent of their time was taken up with visiting families (including travel) and the remainder was taken up by follow-up work. One key worker estimated 40 per cent of their time was spent on visits, another estimated a third of her time, and one estimated 25 per cent of the time.

Service B

With the manager employed by the NHS Trust, the project is joint-funded through a transfer of main grant resources to the health sector. Good budget and expenditure information was provided. Around 170 families are supported by approximately 6,600 hours of key working time at a total cost of £273,800. Travel is quite time-consuming in this very rural area. One key worker suggested a third of her time each for travelling, contact and administrative work. Another suggested that the administrative work took twice as long as visiting the families.

Service C

Based within mainstream social services, the service supports 92 families with a 0.5 wte manager and 2.7 wte designated key workers (one each from health, education and a voluntary organisation). A partial budget for the social services element was provided which excluded any direct or indirect overhead costs. All costs therefore have been estimated using the nationally applicable unit costs data, which include overheads (Netten and Curtis, 2003). Total cost is estimated at £144,000. Two key workers estimated that they spent 50 and 60 per cent of their time on visiting families.

Service D

Managed by a multi-agency Steering group and a full-time manager, around 40 non-designated key workers currently work on this service amounting to just over 3,000 key working hours. Costs have been estimated using the budget for the service's direct managements and nationally applicable unit costs data for the part-time 'donated' key workers, which include overheads for their home organisation (Netten and Curtis, 2003). Total costs for the service are estimated at £115,000.

Service E

The manager for the whole of this local authority's key-working service was interviewed but was unable to provide sufficient or disaggregated information on costs, inputs (staffing, etc.) or outputs (caseload, etc) to estimate a unit cost for the local areas participating on Phase 2 of the research. However, in the earlier CCNUK survey, the manager for another local area in the same authority was able to provide staffing and caseload information for their team so we have used the unit costs for that team for the Phase 2 data. Costs were estimated using the data on whole-time-equivalent staffing provided by the manager and estimates of staff costs from Netten and Curtis (2003). This approach assumes that arrangements for the teams are similar throughout the county, but we were unable to verify this fully.

Service F

The service has non-designated key workers with a manager and part-time administrator working from the PCT base. Sixty members of staff from health, social services, and the education department each provide about 2.5 hours key-working time per week to support around 70 families. The total cost of the service using nationally applicable unit costs data for the key-workers (which include overheads; Netten and Curtis, 2003) is estimated to be £197,00.

Service G

In this service we know how many of each type of professional were working as key-workers but do not have data on either the proportion of time each person spent on key-working activities or salaries. The average cost per hour for all of these types of inputs was estimated using nationally applicable data on unit costs per hour for each professional weighted by the number of staff in each professional group (Netten and Curtis, 2003).

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