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Article:
Sloper, P., Greco, V., Webb, R. et al. (2006) Key worker services for disabled children: the views of staff. Health & Social Care in the Community. pp. 445-452. ISSN: 1365-2524

https://doi.org/10.1111/j.1365-2006.00617.x

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Key worker services for disabled children: the views of staff

Short title: Views of staff in key worker services

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This is the authors' version of the article published as Greco, V., Sloper, P., Webb, R. and Beecham, J. (2006) Key worker services for disabled children: the views of staff, *Health and Social Care in the Community*, 14, 6, 445-52.

The definitive version is available at www.blackwell-synergy.com

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Abstract

Provision of 'key workers' for disabled children and their families, working across health, education, and social services, has been recommended in the Children's National Service Framework. This study investigated the views of staff of key worker services concerning the organisation and management of the services. Interviews were carried out with key workers (N=50), managers (N=7) and members of multi-agency steering groups (N=32) from seven key worker services in England and Wales. A response rate of 62% was obtained. Major themes emerging from the interviews were identified, a coding framework was agreed upon, and data were coded using the qualitative data analysis programme Max QDA. Results showed that although the basic aims of the services were the same, they varied widely in the key workers' understanding of their role, the amount of training and support available to key workers, management and multi-agency involvement. These factors were important in staff's views of the services and inform recommendations for models of service.

Key workers: key workers, care coordination, disability, children, multi-agency working.

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Introduction

Families with disabled children are in contact with many different agencies and professionals. Many families report problems in understanding what services are available and how to access them, understanding the roles of the different agencies and professionals, getting professionals to understand their situation, and delays in receiving services (Sloper, 1999). An answer to these problems, recommended in official reports from the Court Report (1976) onwards, is that families should have one person who acts as their main point of contact, collaborates with professionals from their own and other services and ensures that access to and delivery of services from the different agencies and professionals is co-ordinated. This person has been termed a 'key worker', 'named person' or 'care coordinator. In this paper, the term key worker is used.

Research has shown that less than a third of families with a disabled child has a key worker (Beresford, 1995; Chamba *et al*., 1999) and when this does occur, it is often a professional who takes on the role on their own initiative. Until recently, the development of key working as part of a multi-agency system has been rare. However, with the implementation of the Early Support Programme (Department for Education and Skills/Department of Health, 2004) for families with young disabled children, there has an upsurge of interest in key worker services.

A review of evidence on the effects of having a key worker (Liabo *et al*., 2001) has shown that families with key workers report better relationships with services, reduced stress, improvements in receipt of information and access to services, fewer unmet needs, and more partnership with services. Both key workers and families

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have 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, providing emotional support, and acting as an advocate for the family (Mukherjee *et al.*, 1999; Tait & Dejnega, 2001).

A few studies have investigated views of staff in key worker services. Two studies (Prestler, 1998; Tait & Dejnega, 2001) showed that there was an increase in job satisfaction for those who acted as key workers. Other studies have looked more broadly at professionals' views of the key worker service and their role in it. Appleton *et al*. (1997) reported that key workers felt that they needed more time to dedicate to care coordination and specific training for the role. In an evaluation of two key worker schemes, Mukherjee *et al*. (1999) found that half the key workers saw no differences between the key worker role and their everyday work. Key workers felt that the role produced benefits in multi-agency working and improved relationships with parents. However, difficulties were also encountered: not having enough time for the role, confusion for staff and families about the key worker's role and, in one site, a lack of training and supervision for key workers.

In a recent study exploring the impact of multi-agency working on professionals supporting disabled children (Abbott *et al*., 2005), professionals from six care coordination schemes, four of which provided key workers to families, were interviewed. Results showed that overall, working with families as part of a multi-agency team was felt to be enjoyable and rewarding. Professionals enjoyed better relationships with families and could be more effective in supporting them. Furthermore, they had learned more about each other’s roles and thus felt more able

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to meet families' needs, and they had broadened their own sense of role and identity, although this sometimes raised concerns about erosion of expertise, and some experienced uncertainty about the key worker role. Staff also reported that multi-agency work did not appear to have a detrimental impact on their workload, although there did not seem to be clear guidelines for staff on how much time commitment should be made available to the care coordination service.

The aim of the study reported here was to investigate the views of staff from seven key worker services which differed in their management and operation. This was part of a larger project evaluating key worker services, involving parents, children and staff in the services, and exploring the effectiveness of different models of service (Greco *et al*., 2005).

Methods

Selection of key worker schemes

Seven key worker services were selected from 30 that were identified from a national survey (Greco & Sloper, 2004). The rationale for selection of the seven services was to represent variation in terms of models of service and types of locality covered. Results of the survey indicated that an important difference between services was the type of key workers employed, with non-designated key workers (who key work for a few families on top of their ordinary role) being the most common (21 services), and five services employing designated (full-time) key workers and three using both types of workers. Thus, services were selected to reflect these different models: four used only non-designated key workers, two used only designated key workers, and one used both. In addition, funding situations varied from ongoing multi-agency

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funding to no dedicated funding; two services were longstanding and five were more recently set up. Four of the catchment areas were predominantly rural, two were predominantly urban, and one encompassed both urban and rural areas. Four of the services were in England and three in Wales. The study aimed to investigate the selected services as cases viewed from the perspectives of key workers, service managers, and members of the steering group.

Procedure

The study was approved by a Multi-Centre Research Ethics Committee. Packages, each containing a cover letter, information sheet, response form and postage-paid return envelope, were sent to managers of the services, who distributed these to key workers and all members of steering groups. The project aimed to interview all managers, up to 10 key workers and up to 8 members of steering groups in each service. Where services included a large number of key workers, managers were asked to send packages to 20 key workers from a variety of professional backgrounds. Where services included large steering groups (over ten), packages were sent to ten members, selected to cover a variety of backgrounds, including parents. If willing to take part, recipients provided contact details on the response form, and were contacted by researchers to arrange an interview. Interviews lasted approximately one hour and, with participants' consent, were tape-recorded. Informed consent was obtained before the interview commenced.

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Interview schedules

The interview schedules set out a list of questions and possible prompts to guide interviewers but were used flexibly in order to respond to the issues raised by the interviewees.

Key workers were asked questions about: their professional background, typical day, training and supervision received, and problems encountered.

Interviews with steering group members included questions about their role on the steering group; procedures for steering group meetings; multi-agency involvement; involvement of parents and children in setting up and overseeing the service; and funding for the service.

Interviews with service managers covered: their professional background and role in the service; history of the service; multi-agency involvement; parent and child involvement in the service; and funding of the service. All interviewees were asked about the role of key workers, advantages and disadvantages of the service and suggested improvements.

Data analysis

The interviews were analysed following established qualitative analysis procedures (Taylor & Bogdan, 1984). This involved three researchers each reading a set of transcripts to identify major themes emerging from the interviews. A coding framework was agreed and themes were coded, employing the qualitative analysis programme Max QDA. Data were analysed with the aim of identifying characteristics

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and views of the different models of services and then comparing these. Initially, a report on the interviews for each service was produced, and these were checked by another researcher and sent to the service manager in the appropriate site for further checking. These reports were then drawn together, identifying differences and similarities between views in the different services for a full report on the study (Greco *et al*., 2005).

Results

Sample

One hundred and fifty-five packages were handed out to service managers. Ninety-six responses were received. This represents a response rate of 62%. However, in two services, it was not clear whether all packs were distributed to staff. In addition, eight respondents were not included as they exceeded the number of interviews planned for their services. In one interview, the tape was faulty and could not be transcribed. Eighty-seven interviews, between six and 16 per site, were analysed (see Table 1).

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Table 1: Interviews conducted with staff

Service	*No. of interviews with key workers*	*No. of interviews with steering group members*	*No. of interviews with service managers*[a]	*Total*
Service A	9 (9)[b]	5 (5)[b]	1	15
Service B	6 (6)	1 (3)	1	8
Service C	4 (5)	9 (10)	1	14
Service D	9 (40)	5 (8)	1	13
Service E	10 (c.80)	4 (8)	1	15
Service F	11(c.60)	4 (16)	1	16
Service G	1(c.20)	4 (4)	1[c]	6

[a] In all sites except E, there was one service manager.

[b] ( ) = no. of key workers/steering group members in service

[c] Joint interview with service manager and administrator who carried out much of the day to day running of the service.

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, a few parents acted as key workers for themselves, supported by the service manager. Service managers had professional backgrounds in health or social services. Members of the steering groups included parents as well as representatives from all three statutory agencies and voluntary agencies, the majority at managerial level.

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Aims of the services

The basic aims of the services were similar across all seven services. These were: identifying the needs of the child; providing key workers as a main point of contact for the child and family; drawing up and reviewing a multi-agency care plan; working with other professionals; providing information to families; and providing support for families and helping them to access services.

Understanding of the key worker's role

In four services, interviews with all staff showed clear agreement about what the key worker role 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 the other three services different key workers interpreted their role in different ways. Many key workers felt that the role was not clear to them or they did not see any difference between the key worker role and what they had always done. Some key workers expressed uncertainty about how families and other professionals understood the role.

> …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 understanding the role, considerable discrepancies were found in key workers' accounts of their work with families. Some

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were clearly undertaking the role defined in earlier research (Mukherjee *et al*., 1999; Tait & Dejnega, 2001) but others saw their role as more limited. Some did not feel that they should be proactive in contacting families or that liaising with other professionals on behalf of the family was part of their role. The following contrasting accounts from workers in the same service illustrate this diversity in understanding:

> 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-date …..and 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'm not checking up on other professionals and their involvement in families, that's not my role.

Training

Three services had induction and regular ongoing training for key workers. Two currently had no initial or ongoing training, although one of these had training sessions in earlier years and plans were being made to reintroduce them. In another service, some induction training was provided, consisting of one workshop when the service first started; in the seventh service, each new key worker met the service manager who explained the aims and nature of the service and what was expected of them. This service manager also ran occasional sessions to explore key working in more detail.

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In services with regular training, a wide range of topics was covered, including: law relating to children, disability rights legislation, child protection, direct work, life story work, charging policy, presentation skills, housing grants and benefits, Disability Living Allowance, Motability, direct payments, statementing, 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 often identified issues on which they required training and they spoke very positively about the training 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; others expressed a need for training.

Supervision

The three services with regular training also had regular supervision specific to key working. This was provided by the service managers between fortnightly and six-weekly and was highly valued by the key workers.

> It's excellent, you know. So...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

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> 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.

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 that related specifically to their key worker role.

Regular supervision was provided in services with between five and nine key workers. In the larger services (40-80 key workers) the managers' contact with key workers was more erratic. In some services, supervision was limited to the possibility of telephoning the manager when a crisis occurred.

Peer support

In the three services that had key worker-specific training and supervision, there were also regular opportunities for peer support. Members of two designated key worker teams shared accommodation with each other, and one service with non-designated key workers arranged regular training and group support meetings. Key workers in these services particularly valued opportunities to meet and share information and support. Key workers said having a diversity of professional backgrounds in the team was an asset in providing a range of expertise. However this synergy was possible only when key workers were given the opportunity to meet each other regularly.

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> 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…

Caseloads and contact with families

There was considerable variation in caseload size. Designated key workers commonly worked with 20 to 40 families. In four of the services, non-designated key workers worked with between one and five families in addition to their usual role and caseload. In the other service, workers spent a greater proportion of their time on the key worker part of their role and caseloads ranged from two to 25 families.

Key workers emphasised that the amount of time they spent on the key worker role varied according to families' levels of need at the time. Both designated and non-designated key workers could struggle to cope if more than one family had a crisis at the same time. Key workers found it difficult to estimate how much time they spent in direct contact with families. Those who did make an estimate suggested that 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 remainder.

Funding

Service managers and members of the steering group expressed that lack of funding and resources were key barriers to a successful multi-agency service. In areas

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experiencing the most difficulties, there was no dedicated multi-agency funding for the service. Managers and steering group members saw this 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, problems could still arise over which agency should fund resources or equipment needed by families. This was frustrating for key workers who felt that these problems still needed to be sorted out at strategic levels.

Where funding was committed from the three statutory agencies, inequities in funding and the separation of funding streams, rather than pooled budgets, were seen as barriers to good collaboration.

Role of the service manager

All services but one had a service manager who was responsible for the key worker service. 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

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related roles, however, it did not appear that these detracted from their management of the key worker service. 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 key workers valued this.

In one service with 40 non-designated key workers, the manager's role included organising planning and review meetings for 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 it was not possible to provide regular supervision for such a large number of key workers.

Service managers in the two remaining services had somewhat different roles. Both had a role in overseeing the service but 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 contact the service manager. In the other case, one manager was responsible for the implementation of four key worker teams in four areas of the county. Each team 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 team 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 in non-designated key worker services with large numbers of key workers it was less likely that the service manager could

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provide support or supervision and organise training.

Roles of the steering groups

In the initial stages of developing the services, multi-agency steering groups had been instrumental in defining criteria and finding funding for the service. Most continued to have a role in monitoring the service, reviewing and developing policies and practices, and finding funding for new developments or expansion of the service. A number of members 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.

All groups met regularly, varying between quarterly and once every two weeks. However, in two areas there were concerns about poor attendance. Replacing agency representatives who had left their agencies was identified as problematic in both areas. In one area, poor attendance was also attributed to the fact that the service was well established so people did not feel the need to prioritise the meetings. In the other, there were concerns about lack of representation from some agencies which meant that decisions could not be made, and it was felt that there was a need for involvement from higher levels of management so that decisions could be acted upon. In two areas, the groups' responsibilities were much wider than the key worker service and the service was only a small part of the agenda.

Parent and child involvement

Five steering groups had between two and eight parent members per group, one steering group had links with a parent forum, and one steering group currently had no

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parent members but was planning to have parent representation. Nine parents were interviewed in their capacity as steering group members. In all services, parents were seen as an important force in keeping the group 'grounded', focussing on things that affect families most, and providing a user perspective on the service. 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. None of the groups had children or young people involved, although in one scheme young people had been involved when initially planning the service. In one scheme, children were too young to be involved in consultation. In the others, the high level of expertise and the considerable amount of time and effort required to involve disabled children and young people in consultation meant that this had not yet taken place. However, four groups were currently looking at ways for this to happen.

Constraints and problems of the key worker role

A consistent theme among non-designated key workers was having insufficient time to devote to the role. Many did not have dedicated key working time, and some felt they were not doing justice to either role. Other constraints were engendered by gaps in the provision of services in the areas and lack of resources. Problems in making contact with other professionals, both to pass on and to obtain information, were common. Some key workers felt that it was difficult to get other professionals to understand their role and liaise with them.

Where key workers did not have regular supervision in their key worker role, lack of support was at times problematic. Lack of relevant information and knowledge was a problem for key workers in services where training and supervision were lacking, and

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confusion about the role of the key worker was cited as a problem in three areas.

Type of key worker: designated or non-designated

Views on the advantages and disadvantages of designated and non-designated key workers are summarised in Table 2.

Table 2: Advantages and disadvantages of different types of key workers

Designated key workers	Non-designated key workers
Advantages: • Easier to supervise and manage • More time for key working • Greater availability for families • Greater knowledge and awareness of services • Clearer job specification • Greater team spirit • Higher motivation • Independence of statutory agencies, able to advocate for families	Advantages: • Variety in roles for individual workers • Variety of knowledge and perspectives brought to the scheme by workers from different agencies, learning from each other • Key worker knowledge and skills informing everyday work
Disadvantages: • Hybrid profession • Possibility of losing skills	Disadvantages: • Not having protected time for key worker role • Conflict of priorities between different roles, key worker role

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	taking second place • Not being 'an expert in everything' • Not using key worker skills all the time • Uncertainty about role • Little contact with other key workers • Juggling two roles • Failure to know difference between two roles

The disadvantages identified for designated key workers were seen as a risk of the role but had not been experienced by the key workers interviewed. Some of the disadvantages identified for non-designated workers may be overcome by better management of the services, for example, by having a clear job description, training and supervision, and agreements on protected time for key working with line managers.

Advantages, disadvantages and suggested improvements to the service

Key workers identified a number of advantages for themselves: opportunities to build good relationships with families; being able to 'make a difference' for families; learning new skills and increased knowledge about children and families and other services; and developing effective frameworks for information exchange with other agencies and professionals.

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Perceived advantages for families 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 their story to different professionals. Respondents felt that this resulted in greater consistency and continuity of care and thus stress was alleviated.

Advantages of the service for other professionals also 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.

Most of the disadvantages mentioned for key workers themselves concerned non-designated key workers (see above). 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.

Improvements needed in some services were already valued features of other services. These include:

- Clear description of the role of the key worker
- Administrative support
- Regular training and supervision for key workers
- Register of information about services for key workers and families
- Opportunities for key workers to exchange information and experiences
- Dedicated multi-agency funding

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- A manager who can devote time to supervising the service.

There were some improvements that 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 they could spend on their key worker role and reductions in case loads in their main jobs to allow this. 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 wanted guidance on consulting with disabled children and young people.

Discussion

The research is timely given the recent emphasis on providing key workers for families with disabled children in the Early Support Programme (Department for Education and Skills/Department of Health, 2004), the Children's National Service Framework (Department of Health/Department for Education and Skills, 2004) and *Improving the Life Chances of Disabled People* (Cabinet Office, 2005).

Findings show similarities with Abbott *et al's*. (2005) study on the impact of multi-agency working on professionals. For example, Abbott *et al*. showed that clear guidelines on the nature of the key worker role were often not available and having peer support with key workers from other professional backgrounds was helpful. However, that study found that key workers did not report a detrimental impact on their ability to manage their workload. On the contrary, staff in this study found key working required extra time and effort, and lack of time to perform this role was a constraint.

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The findings of the study must be viewed in the context. The study is limited to a snapshot in time and some of the services will already have changed by expanding their staff or instituting training. The services in this study were focused on disabled children with complex needs and we are not able to comment on issues concerning key working for other groups of children. In addition, interviewees were self-selecting and interviews with steering group members were difficult to achieve in one service and in another only one key worker agreed to be interviewed. Potentially a more varied perspective might have been obtained in services where a higher proportion of staff was interviewed. However, overall there was a wide range of views within and between staff in the different services.

The study showed that although the basic aims of the services were very similar, the processes used to achieve those aims were different. Many staff were positive about the advantages of the services for families and for themselves. However, there were some crucial differences between services affecting how well they were viewed and the problems encountered by staff. Services varied in the understanding of the key workers' role, the amount of training key workers received, whether they received supervision or not, their opportunities to meet other key workers, level and stability of funding, and the roles of the service manager and steering group.

Based on these findings, a number of recommendations can be made. Having a clear, written job description for key workers helps to clarify the key worker role for key workers themselves and other professionals. Key workers also need to have a clear understanding of their role in order to explain it to parents, so that families know what to expect of the service. Interviews with parents in the larger research study

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showed that in services where there was confusion among key workers about the role, parents were equally confused and different parents had very different experiences of the same service (Greco *et al*., 2005).

Key working crosses the boundaries of different agencies and disciplines. The key worker is the main point of contact for families, and needs to have a broad knowledge of disability, other agencies' and professionals' roles, what services are available locally and nationally, and where to find information. The role can also be very demanding, and support structures need to be in place for key workers. These include specific and ongoing training focused on the key worker role; supervision specific to the role; opportunities for contact with other key workers; and agreement on time for key workers to undertake the role. The findings suggested that the service manager plays a central part in leading and developing the service and supporting key workers, and needs sufficient time for running the service.

Staff in services with no dedicated funding spoke of the problems of lack of ownership of the service and it is clear that dedicated funding, at least for a manager and a training budget, is crucial. Steering groups could provide strong multi-agency backing for the service and facilitate collaboration. However, managers on these groups should be senior enough to make decisions, and able to prioritise steering group meetings. Efforts must be made to ensure that parent representatives on the steering group have a say in decision-making and do not feel powerless when decisions are made.

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The findings indicate that staff in services where the above factors were in place were most positive about the service. Where they were not in place, they were identified as improvements needed in the service. Professionals interviewed in this research generally felt that, as indicated in earlier research (Liabo *et al*., 2001), key working was a way of providing a better and more effective service. However, with the recent growth in key worker services (Care Coordination Network UK, 2005) it is important to consider how such services can best be provided.

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Acknowledgements

The study was funded by the Department of Health, Department for Education and Skills, HM Treasury, and Welsh Assembly Government. The views expressed here are those of the authors and not necessarily those of the funders. We would like to thank all the staff who gave their time to participate in interviews, Sheila Sudworth who carried out some of the interviews, and the project advisory group who provided valuable ideas and support throughout the project.