Policy And Research Unit

# A review of key worker systems for disabled children and the development of information guides for parents, children and professionals

**A report for the Wales Office of Research and Development National Assembly of Wales**

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## SECTION A

### EXECUTIVE SUMMARY

The purpose of this report is to review and summarise literature on key worker systems for disabled children, and make the findings available to as wide an audience as possible, both lay and professional. The justification for the report is that, although the benefits of these systems have been widely acknowledged, fewer than one third of children in the UK have access to a key worker.

While the review summarises all relevant studies, primarily from the UK but also from the USA, it has also been structured to enable core messages to reach as wide an audience as possible. In addition to the following summary and the associated *Spotlight*, the appendices include a Microsoft PowerPoint presentation of the report's main points, draft information sheets for families and professionals and a list of resource material and contacts. A version of the report has also been prepared with summary points in the margin for the busy reader. Key messages are as follows:

- lack of money is identified by families with disabled children as their greatest overall concern. Parents believe, and some evidence supports this belief, that key worker systems can have an impact on this issue.
- where a key worker system is present, the overall quality of life of families with disabled children is improved. Specific outcomes are better relationships with services, better and quicker access to statutory and discretionary benefits, both financial and environmental, and reduced levels of stress. There is no evidence that key worker systems result in variations in quality of medical or para-medical care.
- Despite the acknowledged benefits of key worker systems, the model is available to only one third of families with disabled children.
- Excessive complexity of services, especially in the early years, is regarded as a major problem by over half the parents of disabled children.

- Key worker systems are likely to result in services that are focused on parents' needs, rather than the needs of services.

- While many statutory services are often of high quality, a consistent finding is lack of flexibility and poor co-ordination between agencies.

- Key worker systems contribute to the empowerment of parents; by this we mean that parents will be more effective at exerting control over the professionals that service them, and in having their needs met in their preferred manner.

- While systems may differ in the degree of independence granted to the key worker, which may vary between a fully independent advocate and an agency employed person who also delivers a service, all documented systems appear to be successful at placing the needs of the family higher up the overall agenda.

- There is some evidence that, despite the positive aspects of having an independent role outside service structures, key worker systems that are not embedded in services are unable to exercise the degree of leverage necessary to meet families' needs.

- Key worker systems are highly vulnerable to atrophy if not adequately nurtured; core requirements are a multi-agency steering group and champions at a senior level, availability of administrative support and availability of both individual and joint training.

- Good personal relationships between key workers and parents are reported as an important factor by parents.  The capacity of the key worker to forge sympathetic and supportive relationships with parents is essential to the success of the task, and is reported by parents to have a significant amount of value in itself.

- Key workers themselves, even where difficulties have been encountered in the organisation of the service, report a high degree of satisfaction with the role, and believe that it makes a positive difference to the lives of both children and parents.

## 1. INTRODUCTION

Services to families with disabled children are increasingly delivered through a multi-agency model. It is no longer unusual that professionals from various disciplines work together to deliver the best possible response to disabled children's needs. This model recognises the position of families and parents as being the most crucial resource for care of children. However, despite this, research shows that many services still fail both to empower parents in their role, and help them access the services to which they are entitled [1, 2, 3, 4, 5, 6, 7].

Having a key worker to co-ordinate services has been shown to improve the family's quality of life and to empower parents in their role as carers of their disabled child [8, 9, 10, 11]. In spite of this, the provision of service is scarce and only one family in three with a disabled child is believed to have a key worker [7, 12].

This report identifies the main issues arising from the literature, in terms of:

- managing key worker systems
- the key worker role
- families' needs and requirements for a successful service

It addresses the following questions:

- What is a key worker?
- Why do families want a key worker?
- What lessons can be learned from empirical evaluations of key worker systems?
- What recommendations can be drawn from existing literature?

## 2. METHODOLOGY

Searches were conducted on Datastar, ChildData, CommunityWise and CareData. Assistance was provided, and some hand searching conducted in the British and University of Wales College of Medicine libraries and Barnardo's library. Keywords used were *key worker* (together and with truncation) in combination with *children*, *disability, case co-ordination* and *multi-agency*. The years searched initially were from 1990, but extended to 1985 when it emerged that several key documents from an earlier date were still relevant. In addition, contact was made with a variety of UK sources where relevant work was being conducted, or had recently been completed, notably the Social Policy Research Unit at the University of York, The Hansel Trust, the Institute of Child Health, University College, London and the Leicestershire and Rutland Health Care Trust. The review was guided by an advisory group, whose role, contribution and membership is listed in Appendix 1. The information guides are presented in draft. These will be reviewed, amended and distributed as part of the dissemination process (see Section B). The advice of all these parties, and the generous sharing of associated material, is acknowledged and appreciated by the authors.

A summary of all core studies cited in the report is provided as Appendix 2. These studies share the following features; they are UK based, evaluate a key worker or case co-ordination to families of disabled children and report on impacts.

Main points of the report are summarised in Microsoft PowerPoint format (disk and hard copy) as Appendix 3.

Draft information guides are provided as Appendix 4

Key worker resources are listed as Appendix 5.

## 3. RESULTS

<u>The needs of families and the contribution of key worker and allied systems - the background</u>

There are almost 350,000 children with one or more disabilities in the United Kingdom [13]. Incidence has changed over the past few decades due to the increasing survival of neonates [14, 15]. Most parents feel positive about caring, but this is often at great personal cost, financial disadvantage, and stress on family life [16]. Material, personal and social resources have all been shown to relate strongly to parental well being. Areas where parents would like the most help are information and advice about services, the child's condition and how to help their child; financial and material support with housing and transport, and practical help with breaks from care [17, 18, 19].

Families with disabled children identify money as their biggest unmet need [12]. It costs, on average, three times more to bring up a child with significant impairments than a non-disabled child – up to £100 a week extra.  Parents believe a key worker who could access services and information on their behalf, could help reduce these financial and emotional costs [7, 20].

A range of studies describe the complex framework of services encountered by parents. Beresford [12] found that 60% of parents in her survey had seen 5-9 professionals in the past year and a further 19% had seen 10 or more professionals in the same period.  Less than half the parents said that they had seen a social worker in the previous 12 months, and those parents who were seeing a social worker had mostly seen them fewer than six times.  Only half of parents described their contact with professionals as collaborative, the remainder reported negative relationships.

Beresford [12] identifies three problem areas characteristic of relationships between parents and professionals:

• discrepancy in opinions as to the child's needs

- confused relationships between parents and professionals

- lack of co-ordinated services

The key worker model is based on the proposition that when agencies and professions work together, they will provide a better and more coherent service for those who depend on them. Accompanying these ideas is the notion of *needs-centred*, rather than *service-centred* assessment and service provision [1]. If a service is needs-centred, an assessment is carried out separately from the decision on which services will be provided [21]. The advantage of this approach is to ensure that the child and the family needs are taken into consideration first and to enable service providers to evaluate what services are actually wanted by families themselves [2].

Statutory framework

In 1976 the Court Committee recommended the establishment of multidisciplinary teams to provide assessment and support functions for disabled young people and their parents [22]. A multi-agency team is a group of practitioners employed by more than one agency, with different professional training (multi-disciplinary), who meet regularly to co-ordinate the work of providing services to one or more clients in a defined area [21]. Services for disabled children have been increasingly organised through multi-disciplinary child development centres.

In a multi-disciplinary environment it is particularly important for families to have a link person to 'guide' them through the organisational complexity that may be a feature of multi-disciplinary and multi-agency work [23]. The Warnock Committee [24] outlined the need for a 'named person', a recommendation further emphasised by the Education Act [25] and the Audit Commission [26]. The 1989 Community Care white paper [27] recommended that services should be flexible, able to respond sensitively to individual needs, and enhance consumer choice and involvement. However, as noted above, dedicated care co-ordination of services remains a reality for only one third of parents with disabled children.

While the statutory guidance for this type of work is unequivocal about what is needed, no UK document describes the practicalities of how such services should be provided [14, 28].

Challenges in multi-disciplinary work

Despite the attention paid in recent years to multi-disciplinary work, and the support of a statutory framework, major flaws remain in the way agencies work together to deliver services to children. A study of 8 local authorities [2] suggested that services have many good points but are inflexible, and that practice is seldom in tune with policies and principles. Little co-ordination was found between agencies and poor co-ordination and joint planning between services (although this was better in multi-disciplinary teams). The work of multi-disciplinary teams was highly sensitive to management practice and pressure for resources, and was affected by weak organisation of communication and responsibilities, a finding replicated in other studies [29, 30, 31].

Goodinge found that services to families with disabled children worked well when specialist workers were involved with the family and when parents were involved in information production and distribution. A more recent study of a multi-agency centre [16] found the resource particularly appreciated by parents because it provided a range of services under the same roof, the building was child friendly and parents felt that professionals were working together to assess their child. It is interesting to note that the researchers did not find the same consensus among professionals, who felt that informal contact was better than formal contact and, as a result, were reluctant to join in planning meetings. While work was made easier because of shared premises, contact with agencies outside the centre remained poor.

The professional challenges of working together are well researched. Members of a multi-disciplinary team will bring with them different cultures, procedures and belief systems into which they have been institutionalised in training and work [14]. A multi-disciplinary team may also relate to various managerial levels, which further complicates accountability.

In order to gain maximum effect from multi-disciplinary work, a clear management structure is needed along with well-developed communication lines between all parties

involved. All members need to agree on the objectives and aims of the team and recognise the importance of the link between assessment, service delivery and service development [32]. Because this may be an unfamiliar model for many team members, training is needed to ensure that professionals understand their mutual responsibilities [29]. When people identify as team members rather than as a collection of different professionals, and give each other mutual support, the team is likely to be successful in its work.

Inter-disciplinary or trans-disciplinary *versus* multi-disciplinary work

Research suggests that a gap exists between professionals' expectations and intentions with respect to multi-disciplinary work and parents' comprehension and experience of complex services [23, 33]. There is still some way to go in bridging this gap [4, 6, 14]. While a multi-disciplinary approach to service provision has laudable aims, a question arises as to whether current service structures are able to ensure that these aims are achieved.

Dale [9] has emphasised the importance of *inter*-disciplinary work as opposed to *multi*-disciplinary work. The inter-disciplinary approach focuses on the interaction between professionals as well as communication between parents and professionals. This encourages professionals to work together to achieve the best possible service for the disabled child. The service plans are therefore developed with all professionals, and one comprehensive plan results for each child.

Carpenter [15] takes this approach a step further and argues for a *trans*-disciplinary approach to services, where professionals are not solely concerned with tasks within their own specific discipline, but also work with their capabilities as empathetic human beings. In order to enhance the lives of the families they support, professionals in this model work to improve both their disciplinary and interpersonal skills base.

Both these authors make a case for increased co-ordination of services, in addition to a change in professional approach and reorganisation. They argue for what has been described [34] as an empowerment model, where services aim to promote parents' sense of control over decisions, and are sensitive to parents' right to opt into the professional

system at a level they choose. The model expects the professional to take on an advocacy role for the disabled child and his/her family. This model of service has been developed in North America over the last decade, where innovative legislation has encouraged individual *family* service plans as opposed to individual plans for the child [31].

What is a key worker?

There is no specific formula as to what a key worker service should look like and how it should be set up [11]. The main idea underpinning the concept is to enable professionals to respond flexibly and adaptively to parents' and children's needs. The organisation of the service should therefore meet these needs, but also respond to the wider organisation of the statutory framework and other services involved. A key worker's main responsibility is that of co-ordination, but not only this. In addition, a decision must be taken as to whether the key worker should be responsible for assessments, service plans, monitoring and reviewing, and for providing information and support to the family. Mukherjee and colleagues [11] identify a conceptual difference in key working and key worker services. While many professionals may find themselves key working on an informal basis, a key worker service would have protocols for the organisation of the work, regular meetings between professionals, and key workers would have a formal 'status' as the family's named worker.  Over the years various forms of key working have been outlined, based on differing ideas as how to best serve the needs of disabled children and their families.

*Case management*

In the Griffith report and subsequent community care white paper of 1989, the model proposed for care co-ordination was *case management,* which included the concept of individual packages of care developed through consultation between clients and providers. The key worker – or case manager - was seen as an integral part of the individual planning system where each client would have their own care plan administered, monitored and reviewed by the case manager in collaboration with other professionals [35]. The case management model focuses on building and strengthening the self-care capacities of the client or the carer, and the main task of the role is to ensure the delivery of a comprehensive assessment. After the assessment, the case manager develops a client

service and support plan which outlines how client needs will be met, and sets the stage for effective monitoring and evaluation of all service delivery and support inputs [36].

Some authors separate the definition of a key worker from that of a case manager by arguing that in case management, the assessment, delivery and review functions can not be accommodated by the same person as they can in a key worker system [37]. Swire [23] views the two roles as one, but prefers the term 'key worker' because case worker refers to the disabled person as a 'case', which may divert the work focus from the fact that families and professionals are partners in providing care to a disabled child.

*Care management*

*Care management* has been promoted as an alternative approach to case management [21, 30]. In this model, the co-ordinator is not responsible for providing a service, but for deciding with the family what services are needed, helping to arrange services and organising the monitoring of the provision and its effectiveness. Any profession can take on this role, but the person needs to be able to cross service boundaries and negotiate with any agency involved in the child's care.

Ovretveit [21] outlines eight phases of the care management process:

- information about available services and rights to services/resources available
- needs assessment before further assessment
- full needs assessment
- planning how to meet needs
- delivering the resources identified in the plan
- monitoring and adjusting
- formal reviewing
- final closure phase or new assessment

In Ovretveit's model, the care manager assesses and co-ordinates people taking part in the care process. There can be different care managers for each phase, or the same care

manager for most phases. A practitioner may be employed as a care manager and nothing else, or s/he can be care manager for some clients and provide specific services for others. Care managers can be in specialist care teams or in a multi-disciplinary team, and their role is to be responsible for accessing, co-ordinating and liaising with all the services a client needs for their assessment, treatment or care. Some teams may have care managers who are responsible for co-ordinating services outside the team as well as within.

*Key working*

Ovretveit's model closely resembles more recent models of key working as described in Carpenter [15] and by Mukherjee and her colleagues [11]. The focus of these models is on the family and the disabled child, and how to empower them in their relationships with professionals.

Where the case management and care management approaches focus on assessment and care plans in order to ensure a needs-led service, these key worker models emphasise the **family** as the main carers, and the key workers are there to meet the needs as identified by the family, including the monitoring and evaluation of written assessments.

The key worker operates as the integrating link between the family and the various services [38].  An important role of the key worker in these models is that of *advocacy* where the key worker 'stands up' for the family and advocates on their behalf in relation to other service providers. As a professional, the key worker aims to have one foot in each camp, but also needs to act independently from their employing agency. The advocacy role is closely connected to the '*empowerment*' model described by Appleton and Minchom [34] where the service focus is on how to empower parents in their role as carers for their children. Within the empowerment model, the key worker would naturally attempt to strengthen parents' position with respect to services by meeting their needs and providing information about the system.

Mukherjee and colleagues [11] refers to six crucial elements of key working which must be in place in order for the needs of parents and children to be met in a coherent way.

- pro-active, regular contact
- a supportive, open relationship
- a family-centred approach
- working across agencies
- working with families' strengths and ways of coping
- working for the family as opposed to working for an agency

These elements together emphasise the importance of a key worker system being established within a multidisciplinary context, with a family centred, needs-based approach that highlights flexibility and approachability.

The importance of the advocacy role in these models has led some authors to recommend an 'independent' role for the key worker, that is, the key worker may be employed by a voluntary or statutory agency, but is accountable for their actions to the family [8, 10, 11]. It is argued that an independent role will enable the key worker to act as an independent advocate in relation to statutory and other voluntary agencies. To serve the 'empowerment' model, key workers need to be able to set aside agency loyalties. The question is: are they able to do this and still function as agency employees? [39]. Beattie [14] concludes from her interviews with professionals that it is currently unlikely that a professional employed by one agency could be responsible for *overall* service delivery, as this would be incompatible with the present organisational structures and funding arrangements of services.

Dale [9], however, found that the independent role of the workers outside the statutory system was limiting; they had much less power in obtaining certain service resources in the statutory sector, and were sometimes discounted and marginalised. The extra effort to develop and maintain close co-operative contact with health, education and social services was, in this study, seen as very time-consuming, an observation made much earlier by Glendinning [8].

On some occasions, key workers are specialist professionals who are members of multi-agency teams. On others, they are specialist workers whose sole job is to co-ordinate services for parents and children. McGrath [35] found that the advantage of specialist key workers was that the position reduced the tendency for agency bias. This, however, has to be viewed in the context of the demands of teamwork. Some authors have argued that it is difficult for a professional to fulfil both the key worker role and be involved with families in other professional capacities. In fact, the failure of some key worker services has been attributed to this tension [11, 30].

While the literature varies as to whether key workers should be independent from statutory agencies or not, there is a broad consensus on what a key worker service should include, and how it should be set up and managed:

- the key worker should work within a multi-agency setting
- the focus needs to be on the needs of the whole family
- the assessment must be needs -based rather than service- based
- the key worker should work with the family in a way that promotes empowerment

The various studies diverge on a number of issues:

- whether the key worker should be independent from statutory agencies
- whether they should control their own budget
- the scale of involvement and remit in relation to assessment, advocacy, and construction of individual care plans

What is stressed as being important in a key worker role - more than professional background - is a good understanding of childhood disability, experience in the role of counsellor, and the skills and motivation to act as an advocate for the family [40].

The Key Worker studies

While there are many studies examining the needs of families with disabled children, including evaluations of general services and various multi-agency/multi-disciplinary initiatives, there are few studies that have evaluated a key worker model empirically. No systematic review is available on key worker models; however, four key worker projects have been evaluated [9, 10, 11, 41]. A fifth study [14] reviews six small-scale studies from the USA. The main focus of this study is, however, the views of professionals on a multi-agency service co-ordinator for children with disabilities rather than evaluation. Although a protocol for a randomised controlled trial of key worker systems for disabled children has been proposed [40], no trial based on this model has been carried out as yet.

In addition to these key worker studies, there is a range of literature from which some implications may be drawn. Ferlie and colleagues [33] and McGrath [42] included evaluations of key workers in their study of Community Mental Handicap Teams (CMHTs), and make recommendations arising from these findings. Beresford conducted a comprehensive study [12] of 1,100 parents of disabled children, and Sloper and Turner [17] compared families with and without a key worker. Lessons have also been drawn from studies on key worker systems for the mentally ill [43] and the elderly [44].

The main key worker evaluation studies may be summarised as follows:

Glendinning [41] selected 250 families for her study. An overall response rate of 84% yielded 107 families in the experimental group and 103 in the comparison group by the end of the project, with between nineteen and twenty-three families in each of ten local authority areas. The key worker model examined was intended to overcome the problems arising from the fragmentation of services for disabled children and their families, and to alleviate isolation and lack of support. The key workers in this study were employed part-time on the project, and their work was solely concerned with 'key working'. They had no professional contact with the families except in their role as key workers.

Dale [9] reports on the KIDS Family Centre and their 'named worker' support service for parents of children. The service aimed to provide support, counselling, guidance and advice to parents and the whole family through regular, long-term contact. The main functions were an advisory and networking service, and assistance for the family and the child in dealing with problems and challenges around disability and special needs. The key workers in this study were employed by the Centre and were already members of staff, which meant that they had other responsibilities besides being a key worker.

Appleton and colleagues [10] studied 21 families who joined the care co-ordination project. The objectives for the care co-ordinators were to provide a structured assessment which would focus on the family's (as well as the child's) needs, a care plan (incorporating a school transition plan), continuity of service for parents throughout the period of transition to nursery school, and the co-ordination of case reviews. Key workers in this study were recruited on a voluntary basis from professionals connected to a multi-agency team for children with disabilities. The key workers were therefore employed by various statutory agencies and had other professional responsibilities besides being a key worker.

Mukherjee and colleagues [11] evaluated and compared two pilot projects in local authorities where professionals took on the role of key worker for 27 volunteering families, working in a multi-agency context. Twenty-four of the families participated in the evaluation. The aim of the key worker service was for site A to "provide a key worker service for a small sample of families who are struggling with the complexities of their situation and test out the concept in the local authority" and for site B to "provide an identified person who will co-ordinate and/or facilitate the health and social care, and education for each disabled child in the pilot group". The focus of site A was more on co-ordination on services, while site B emphasised the assessment process as a main task of the key worker. The key workers in the two sites were recruited from statutory agencies (and one voluntary agency) and the workers had other professional responsibilities besides being key workers.

Summary of recommendations of the key worker studies

**How does the key worker model serve families' needs?**

Research shows that parents would like a key worker because they believe that the resulting close relationship will lead to a particular appreciation of their specific needs, so that the key worker will be in a better position to negotiate for any special requirements [33]. Parents also expect a key worker service to ensure quicker solutions to problems, improved access to information and provide easier availability of services with less risk of parents and their child being passed back and forth between agencies. However, each family will differ in terms of needs and will therefore value different aspects of the key worker service, which is both an indicator of the organisational context in which the key worker operates, and a reminder of the importance of a flexible and adaptable service to parents' needs [8, 9, 11].

When the key workers had been successful in their work, parents in all the evaluated projects felt that the service had been able to meet their needs in a more comprehensive and helpful way than previous services without a key worker. The interpersonal aspect of the relationship was particularly appreciated along with regular, pro-active and family-centred contact. Parents felt that their concerns were being listened to, and that issues and problems were sorted out more easily through the co-ordination provided.

It is clear that 'someone to talk to', along with the co-ordinating and facilitating role of the key worker were the aspects of the service most valued by parents in all studies. Mukherjee *et al.* [11] found that this was also the area where key workers put in most effort. In the same study, the key workers were least involved in written assessments and the level of support provided - as perceived by parents - was higher in the family than in the organisational contexts.

Glendinning [8] found that the key workers had little impact on medical or paramedical care, but compared with the control group, the parents in the key worker project experienced significant improvements in the practical day to day care such as receipt of

toilet and bedding aids, alterations to bathrooms, and items of laundry equipment. There was also progress in terms of housing; either improvements in their current home or by their being helped to move to more suitable accommodation. Compared with the control group, the families with a key worker scored higher on parental well-being factors, notably in terms of health, relationship, freedom to go out, more holidays and satisfaction with respite care.

The same study also found that slightly more claims for supplementary benefits and single payments were made by families during the project period, and such claims were also more likely to be successful. The overall impact of these changes was that, by the end of the project, there had been a significant decrease in the proportion of parents who said they had worries about money and financial matters.

The overall message from all these studies is that when key workers are able to provide regular pro-active support and information to parents in a personal fashion, and with a view to the whole family, parents will have a positive experience of the service. Indeed, in a post study interview with parents, Glendinning [8] found that 89% of the respondents would rather have this service than exchange it with the equivalent amount of cash. Sixty nine per cent thought that other parents would also make the same choice if given the option.

Although evidence is limited with respect to the direct impacts of key worker systems on the well-being of the child, it is clear from these studies that when the service works, the family and the child benefit in terms of practical day to day care, information about opportunities to improve their situation and through emotional support. It was also noted that parents became more confident and competent as a result of receiving the service, which made them feel more positive about themselves both as carers and with life in general [9]. When the key worker is unable to provide these services, the satisfaction about the service will decrease. However, Mukherjee and colleagues [11] found that even when the service was unsuccessful parents wanted the key worker as an integral part of the service.

In Beresford's survey [12] parents with a key worker were more likely to report a positive relationship with professionals, but they did not necessarily experience fewer problems with services than parents without a key worker.  The author concluded that the effectiveness of a key worker in reducing the number of service related problems is dependent on interagency co-operation, the services required by the parent or child being available and, to some extent, the particular needs of the child.

These studies indicate that the most important function of the key worker, from a parent's perspective, is the support it can provide *them* in caring for their disabled child and in easing their anxiety about services and the information 'out there'. When considering that these are areas where parents identify the most needs [17], the key worker studies indicate that this dimension of the model is highly successful.

**What were the main reasons for the key worker services' success?**

The successful aspects of the key worker models evaluated were closely related to the 'empowerment' model as described earlier in Appleton and colleagues study [10]. The key workers were successful when they provided the families with the kind of regular support they valued and had previously lacked.  The emphasis is thus less on the more 'professional' aspect of the service, in terms of written assessments and care plans, and more on the quality of the personal relationships.

The studies agree largely on the inputs that are important for a key worker service to succeed in meeting the needs of the parents and fulfilling the role of co-ordinator and 'single door' contact person. All the studies found that the key worker needs to have regular and pro-active contact with the family and provide regular information and support to solve problems. Because of the demands of the role and its location within a multi-disciplinary framework, the provision of regular training and evaluation is emphasised, particularly in terms of clarifying the role and tasks expected from it.

Flexible and well-resourced administrative support appears necessary to secure a smoother transition to a co-ordinated service. A committed steering group helps in the

development a key worker model, especially when representatives from all the relevant agencies are present. A steering group can help ensure that the communication to all parties involved has the support of management and all agencies are committed to the project. Management itself needs to ensure that responsibilities are clear and that the remit of the key worker role is made explicit to all parties involved. It is an advantage if key workers are drawn from different professions and that the interpersonal aspect of the role is taken into consideration when appointing key workers [10, 11].

Experience from the mental health sector indicates that the way the key worker fulfils the role may depend on their professional background. Martin and colleagues [43] found that the number of people and range of skills a client encountered was related to the disciplinary background of the key worker. This finding is not, however, replicated in any of the evaluations of key worker services to disabled children reviewed here.

Because of the small number of studies relevant to this review, and the fact that all the studies reached positive conclusions (apart from one of the sites visited by Mukherjee and colleagues [11]), it is difficult to reach a conclusion on the most successful way of organising a key worker system. This study did find that in the "successful" key worker site, professionals were asked by their line manager to join the project, while in the "unsuccessful" site the key workers volunteered. The steering group in the former site came from all relevant agencies (education, health and social services), while the latter site had a steering group only from social services and health. Most important, perhaps, is the observation that the supervision and training provided to the successful key workers was more comprehensive than in the more 'unsuccessful' site.

The studies reviewed had mixed arrangements as to whether the key worker had additional responsibilities [9, 10, 11] or if their main task was that of co-ordination and support to the families [8]. One argument for dedicated key workers is that when the key worker is also the professional most involved with the child, the perspective on the child's needs is of that particular discipline and might therefore be too narrow. Also, when the key worker is also the service provider the family can be hesitant to complain about the service or ask for changes [30]. Moreover, the time pressure experienced by workers in this situation (as identified in the above studies) would indicate that specialist key workers could have more

time to concentrate on the families, rather than being torn between two possibly conflicting responsibilities -the family and the agency.

Common for all the successful key workers was that they received regular supervision and at least some training at the beginning of the project. Support from other professionals and management was also essential in providing the key workers with the confidence and emotional resources needed to meet families' requirements.

**What were the main concerns of the key workers in the studies?**

Problems were identified around the confusion of who is responsible for co-ordinating people external to the core team [9, 21]. Key workers in all studies had concerns about how the service was organised and the supervision and support they received from management and other professions. Some found that the amount of travel limited actual work time, which further strengthened the pressure experienced from the role [8].

Another common finding was lack of resources to deal with the needs of the family, which caused considerable frustration when needs assessments were agreed with families, as few of the resources recommended could actually be put in place. This issue is related to the question of whether the key worker should have budgetary responsibilities and/or be connected to a statutory service. It has been argued that budget control will enable the worker to be more flexible in terms of responding to the clients' needs. One study of key workers for the frail elderly [44] found that this arrangement also made the role more cost effective because the co-ordinators were able to make more appropriate priorities in terms of service provision, and were thus more effective in providing the services.

The importance of clarity about the key worker role has already been emphasised. Confusion about the remit and the management structure within the team and for the key worker was found to delay an effective service and create frustration, and sometimes tension, among both professionals and parents [11, 43]. The importance of management commitment to the service cannot be over-emphasised and is also crucial if the key worker

is to be provided with the necessary support from other professional sources to fulfil the role.

Lack of appropriate training and supervision renders the key worker service vulnerable to breakdown, as does no provision for leave of absences. Mukherjee and colleagues [11] and Ferlie and colleagues [33] experienced difficulties in persuading staff to take part in the project, and associated this problem with the amount of information, training and support staff are provided with before and when taking on the role.

Two of the projects evaluated were time-limited, which was seen as negative both by parents and professionals [8, 11]. Some key workers ended up in situations where they felt torn between their professional role and their role as key workers acting as advocates for the family.

Key workers may experience difficulties in collaborating with other professionals [33], which could be related to Beattie's [14] observation that, from a professional perspective, the co-ordinator role is irrelevant in that it carries no status for the professionals. It is also threatening because it may be perceived to blur distinctions between disciplines. Concern was expressed that co-ordinators, because of low role status and poor communication with colleagues, might personally have to fill gaps in service provision. Consequently, the key worker role can result not only in higher levels of flexibility, but also in role confusion, isolation, stress and burnout. In addition to this, philosophical differences between service co-ordinators and other professionals may result in inter-professional conflicts.

The key worker evaluations make the same observation as Cigno and Gore [16] in their study of Child Development Centres.  They noted that, while most parents were satisfied with the service, the service providers themselves experienced difficulties in terms of training and supervision, clarity of the role, finding time for the role and gaining resources to implement services.  This indicates that a major problem in organising and delivering more key worker services to families is that the organisational obstacles are perceived by agencies to be of a higher order of magnitude than the perceived benefits of the model.

<u>The American experience</u>

While this review has deliberately focused on UK literature, similarly positive findings in terms of client gains have arisen from studies of care co-ordination in the USA. Beattie reviewed [14] several American studies [45, 46, 47, 48] and found improvements in family outcomes similar to those described above.  She concluded that the service of a co-ordinator resulted in better help and access to services. Her review also reports that the co-ordinator increased parents' access to equipment, family involvement, satisfaction and a more comprehensive provision of services.  Other US studies provide corroborating data. US federal law requires a service co-ordination function in individualised service programmes for the families of children with special needs; in relation to the early years, this dimension was reported by a nationwide poll to be the single most important issue raised by parents [49].  Illback and Neill [50], in a study of service co-ordination for children with mental health problems, concluded that the model received strong positive feedback from most practitioners, clinicians, families and local agencies.  In terms of cost effectiveness, Jackson and colleagues [51] found that unit costs of service co-ordinator input varied according to the complexity of the diagnosis, but concluded that co-ordination of services for families would provide for greater efficiency in the use of health resources and an improvement in families' ability to access services and support their children. However, while these studies complement and UK literature, their main methodological approach is based on measures of parent satisfaction with the quality or perceived outcomes of the service.   As with the UK literature,  controlled trials which compare different service options remain a rarity.

## 4.    DISCUSSION

The main aim of the key worker model is to provide a co-ordinated, needs-led approach to families with the objective of empowering parents in their relationship with services and professionals. To fulfil this aim, a key worker system needs to be organised within an inter-disciplinary framework where professionals share information and work together to promote collectively the welfare of the family.  A range of issues arise from the literature reviewed, which may broadly be clustered into issues for key workers, and issues for managers.

Issues for key workers

The ability of a professional to provide a key worker service is dependent on two core factors:

• the extent to which multi-agency working is in place, with a commitment to promote and support key workers
• the availability and ongoing delivery of training and supervision for key workers

The experience of key workers in working with other agencies may be difficult, but have the capacity to be overwhelmingly positive [52]. A clear majority of key workers interviewed felt that they had made a difference for the better to the life of the child.

Sufficient time needs to be allocated for the task, along with training in promoting parental empowerment, delivering and reviewing care plans, listening and counselling skills and assessment.  The importance of full care service co-ordination earlier in the child's life is also emphasised. The lack of a team leader will make it difficult to provide regular, supportive supervision [10, 11, 52].

The main studies in this review all emphasised the personal relationship between the key worker and the family as one of the main reasons for the success of the projects. Professionals taking on this role need to consider the implications of a personal, but professional relationship and the challenges in terms of boundaries this can present. If the purpose and remit of the role is made explicit, much confusion and misunderstanding may be avoided.

Issues for management

Various sources [10, 11, 33, 42] recognise the importance of full management commitment and allocation of resources.  This can be summarised as follows:

- some degree of joint working between agencies
- secure funding
- committed agencies
- steering groups rooted within the organisations
- information available to stakeholders
- a clear model of the service and job description

For a key worker system to run efficiently and effectively, management in all agencies must be involved, with direct participation in steering groups, championing and promoting the service and driving the project forward. Funding needs to be secured to enable key workers to respond to needs assessments and implement improvements identified.

The importance of clear information and communication between parents and the key worker, and the key worker and the team, cannot be over-emphasised.  Detailed action plans at an individual and agency level are crucial in making key worker systems work, and these will include all the above mentioned aspects of communication and commitment from managers [10, 11, 33, 42]. Time must be spent in clarifying roles, and teams need the right mix of skills and a good working plan and to recognise the different levels of skills and experience present in the team [21].

The literature emphasises the importance of an agreed understanding between management and key workers, and key workers and families, of what the role will provide [11, 42]. This aspect of key working is particularly challenging in terms of joint working because the various professions involved will focus on different models of care [33]. Because of the particular emotional and practical relationship required of the worker towards the family, it is suggested that the personal characteristics of key workers, particularly with respect to empathy, are considered in the appointment process [11].

Commitment from all agencies to multi-agency work is emphasised as important. Mukherjee *et al.* [11] recommend time out for people from different agencies to help the service to come together, get to know each other, and work together as a group, a process that they suggest is helped by the use of external facilitators.

There may be a lack of understanding in some agencies regarding disability issues. To ensure effective multi-agency working, training is essential [2]. Emphasis should be put on training for teams in negotiating with managers, financial information systems, liaising with other agencies and monitoring procedures [11, 42]. One study [53] has measured the competence of the pre-school consultant (the Swedish version of a key worker) before and after an extensive training programme by looking at the impact on the consultants, the child, the parents and other care givers, concluding that the training impacted on the consultants' knowledge, methods of working and conception of role. Goodinge [2] found that where multidisciplinary training did occur there seemed to be benefits, not only in the increase of knowledge and skills, but also in inter-disciplinary understanding of roles and organisational structures.

With respect to practical arrangements, it is reported that a flexible and well-resourced administrator together with a full-time inter-agency development officer/co-ordinator post will contribute to a smooth and seamless service [10, 11]. As child and family needs may change over time, teams need to have mechanisms for changing the key worker where indicated by the changing situations of families [30].

## 5.    CONCLUSIONS

This review indicates that the available evidence overwhelmingly agrees that the key worker approach has the capacity to improve services significantly to disabled children and their families. All the main studies in the field found that parents' experiences of key workers were positive, in terms of empowering parents in their role as carers, enabling services provided to be more relevant and in reducing levels of stress.   The absence of well-controlled studies however, makes confident assertions about the specific benefits of key worker models as opposed to other systems of organising services for families of disabled children difficult to make.   The overwhelming focus of the literature on benefits accruing to parents, as opposed to children, compounds this deficit, as we cannot assume with any confidence that the needs of children will be in all cases congruent with the needs of their parents.   The need for such information is not simply the routine plea for more research.   The more robust the evidence that specific outcomes are more likely to arise where key worker systems are in place - for example, increased income for families, housing adaptations, lower levels of depression, improved functioning of the disabled child, access to the family's choice of educational and social settings - the more likely that agencies will come under pressure to overcome the undoubtedly challenging organisational barriers that exist, and parents will be more confident - and justified - in demanding that such arrangements be made.

Key worker systems are, however, largely dependent on the organisational framework within which they are set up, and key workers themselves are largely dependent on training, resources and support to fulfil the role satisfactorily for both themselves and parents.   The relatively low coverage of key worker systems, despite their acknowledged effectiveness, is an indication of the magnitude of the organisational difficulties that may be encountered.

Although the findings of research on the effectiveness of key worker services are positive, it is apparent that this is not the only characteristic of services that needs to be addressed to improve the circumstances of families of disabled children. Issues of co-ordination and parent-professional relationships remain [32]. The key worker model can, however, with

professional commitment and dedication, provide a major step in the right direction in the relationship between parents and professionals, and in the situation of families with a disabled child.

## 6.    REFERENCES

1.  Dunst, C., Trivette, C., Starnes, A. L., Hamby, D. W. and Gordon, N. (1993) *Building and Evaluating Family Support Initiatives: A national study of programs for persons with developmental disabilities*, Paul H. Brookes Publishing Co: Baltimore, Maryland
2.  Goodinge, S. (1998) *Removing Barriers for Daisabled Children: Inspection of Services to Disabled Children and Their Families*, Department of Health
3.  Middleton, L. (1998) Consumer satisfaction with services for disabled children, *Journal of Interprofessional care*, 12, 2, pp. 223-231
4.  Case, S. (2000) Refocusing on the Parent: what are the social issues of concern for parents of disabled children?, *Disability and Society*, 15, 4, June, pp 271-29
5.  Knox, M. (2000) Family Control: The Views of Families Who have a Child with an Intellectual Disability, *Journal of Applied Research in Intellectual Disabilities*, 13, pp. 17-28
6.  Murray, P. (2000) Disabled Children, Parents and Professionals: partnership on whose terms?, *Disability and Society*, 15, 4, June 2000, pp. 683-698
7.  Rickford, F. (2000) The forgotten families, *Community Care*, 6 – 12 July
8.  Glendinning, C. (1984) The Resource Worker Project: Evaluating a Specialist Social Work Service for Severely Disabled Children and their Families, *British Journal of Social Work*, 14, pp 103-115
9.  Dale, N. (1996) *Working with Families of Children with Special Needs: partnership and practice,* Routledge, London
10. Appleton, P., Boll, V., Everett, J. M., Kelly, A. M., Meredith, K. H. and Payne, T. G. (1997) Beyond child development centres: care co-ordination for children with disabilities. *Child: care, health and development*, 23, pp. 29-40
11. Mukherjee, S., Beresford, B. and Sloper, P. (1999) *Unlocking key working. An analysis and evaluation of key worker services for families with disabled children*, Bristol: Policy Press and the Joseph Rowntree Foundation
12. Beresford, B. (1995) *Expert Opinions: A national survey of parents caring for a severely disabled child*, The Policy Press, Bristol
13. Department of Health, 2000  www.open.gov.uk/eor/children/htm
14. Beattie, A. (2000) *Service Co-ordination: Professionals' views on the role of a multi-agency service co-ordination for children with disabilities*, Handsel Trust:Birmingham
15. Carpenter, B. (2000) Meeting the needs of families of children with disabilities, *British Journal of Special Education*, 27, 3, September, pp. 135-144
16. Cigno, K. and Gore, J. (1999) a seamless service: meeting the needs of children with disabilities through a multi-agency approach, *Child and Familly social Work*, 4, 4, October 1999, pp. 325-335
17. Sloper, P. and Turner, S. (1992) Service needs of families of children with severe physical disability, *Child: care, health and development*, 18, 5, pp. 259-282
18. Cowen, A. (1994) *Taking Care*, York: Joseph Rowntree Foundation for the Family Fund
19. Sloper, P. (1999) Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25, 2, pp 85 – 99
20. Dobson, B. and Middleton, S. (1998) *Paying to Care: the cost of childhood disability*, Joseph Rowntree Foundation, York Publishing Services: York
21. Ovretveit, J. (1993) *Co-ordinating Community Care: multidisciplinary teams and care management*, Open University Press, Buckingham

22. Department of Health (1976) *Fit for the future: Report of the Committee on Child Health Services*, London, HMSO
23. Swire, G. (1992) 'Case Management and Key Working' in Thompson, T. *Standards and Mental Handicap: keys to competence*, Balliere Tindall
24. Warnock, H. (1978) *Special Education Needs: Report of the Committee of Enquiry into the Education of Handicapped Children and Young People*, London: HMSO
25. Department for Education and Employment (1993) *Education Act*, London, HMSO
26. Audit Commission (1994) *Seen But Not Heard: Co-ordinating Community Child Health and Social Services for Children in Need.* HMSO, London
27. Department of Health (1989) *Caring for People. Community Care in the Next Decade and Beyond*, London, HMSO
28. Davidson, L. (1999) Evaluating child disability programmes: the role of commissioners. *Child: care, health and development*, 25, 129-139
29. Holt, G. and Oliver, B. (1989) Reducing stress in community mental handicap teams, *Mental Handicap,* 17, 1, March, pp.4-5
30. Hall, D. and Hill, P. (1996) Services for disabled children, *The child with a disability*, Blackwell Science, pp 116-130
31. McConachie, H.R. (1999) Conceptual frameworks in evaluation of multidisciplinary services for children with disabilities, *Child: Care, Health and Development*, 25, 2, pp. 101-113
32. Beresford, B., Sloper, P., Baldwin, S. and Newman, T. (1996) *What works in services for families with a disabled child?*, Barnardo's: Barkingside
33. Ferlie, E., Pahl, J. and Quine, L. (1984) Professional Collaboration in Services for Mentally Handicapped People, *Journal of Social Policy*, 13, 2, pp 185-202
34. Appleton, P. and Minchom, P. (1991) Models of parent partnership and child development centres, *Child: care, health and development*, 17, 2, pp. 27-38
35. McGrath, M. (1991) *Multidisciplinary Teamwork – Community Mental Handicap Teams,* Aldershot, Avebury
36. McGrath, M. and Grant, G. (1992) 'Supporting "needs-led" services: Implications for planning and management systems*, Journal of Social Policy*, 21, 1, pp. 71-97
37. Moxley, D. P. (1989) *The Practice of Case Management*. Sage, London
38. Limbrick, P. (1997) Keyworking: a parent support, in Limbrick, P. *Who Supports the Parents? Five Year Review for Parents, Professionals and Funders*, Todmorden, W. Yorkshire: One Hundred Hours
39. Cormany, E.E. (1993) Family centered service coordination: a four tiered model, *Infants and Young Children*, 6, 2, pp. 12-9
40. Junqueira, H.S. (2000) *Care coordination for diabled children: A protocol for a randomized controlled trial of the key worker model*, MSc Community Paediatrics, Institute of Child Health, University College London
41. Glendinning, C. (1986) *A Single Door: social work with families of disabled children*, Allen and Unwin, London
42. McGrath, M. (1993) Whatever Happened to Teamwork? Reflections on CMHTs, *British Journal of Social Work*, 23, pp 15 - 29
43. Martin, C. J. (1999) Developing community mental health services: an evaluation of Glasgow's mental health resource centres, *Health and Social Care in the community*, 7, 1, pp 51-60
44. Dant, T. and Gearing, B. (1990) Keyworkers for Elderly People in the Community: Case Managers and Care co-ordinators, *Journal of Social Policy*, 19, 3, pp 331-360

45. Jackson, B., Finkler, D. and Robinson, C. (1992) A Case Management System for Infants with Chronic Illnesses and Developmental Disabilities, *Children's Health Care*, 21, 4, pp. 224 - 232

46. Marcenko, M. and Smith, L. (1992) The Impact of a Family-Centred Case Management Approach, *Social Work in Health Care*, 17, 1, pp. 87 – 100

47. Koren, P., Paulson, R., Kinney, R., Yatchmenoff, D., Gordon, L. and DeChillo, N. (1997) Service Coordination in Children's Mental Health: An Empirical Study From the Caregiver's Perspective, *Journal of Emotional and Behavioural Disorders*, 5, 3, pp. 162 – 172

48. Presler, B. (1998) Care Coordination for Children with Special Health care Needs, *Orthopaedic Nursing*, March / April Supplement, pp. 45 – 51

49. Cormany, E. (1993) Family-centred service coordination: A four-tier model, *Infants and Young Children*, 6, 2, pp. 12 – 19

50. Illback, R. and Neill, T. (1995) Service Coordination in Mental Health Systems for Children, Youth and Families: Progress, Problems, Prospects, *The Journal of Mental Health Administration*, 22, 1, pp. 17 – 28

51. Jackson, B., Finkler, D. and Robinson, C. (1995) A Cost Analysis of a Case Management System for Infants with Chronic Illnesses and Developmental Disabilities, *Journal of Paediatric Nursing*, 10, 5, pp. 304 – 310

52. Stone, B. (1998) Child Neglect: Practitioners' Perspectives, *Child Abuse Review,* 7: 87 – 96

53. Granlund, M. and Bjorck-Akesson, E. (1996) In service training of pre-school consultants in family-oriented intervention – training process and outcome, *The British Journal of Developmental Disabilities*, 42, 1, pp 1-23

*SECTION B*

**7.     DISSEMINATION**

A wide variety of mechanisms for disseminating the study findings and information guides are planned. In addition to the current report format, short summaries of the findings will be prepared under the WORD Spotlight and NCB Children's Highlights series. Dissemination plans include the production of papers for publication in professional and popular journals, distribution of summaries and guides directly to local and national organisations for carers and professionals, and to statutory authorities, and electronically through a variety of relevant websites, together with a conference presentation.  Specific details are as follows:

Papers will be prepared for submission to: Community Care; Childcare, Health and Development; Professional Care of Mother and Child journals and Llais. A letter for publication will be submitted to the British Medical Journal.

Summary findings and copies of the information guides will be distributed in hard copy to:

The Association of Directors of Social Services; Welsh Health Authorities; Welsh Education Authorities; the Care Co-Ordination Centre; Disability Wales; the All Wales Forum; NCVA; WCVA; NCVCCO; the Carers Association; SCOPE; voluntary organisations for specific impairments and public libraries;

And via the websites of:

The Health and Social Care Research Support Unit for South-East Wales; Barnardo's; ESRC; the Evidence-based Project Group at Southampton University; Welsh Office of Research and Development; Cardiff and the Vale Parents Federation; WCVA and Welsh Health Authorities.

The study findings will also be presented at a conference on Children's Services planned for later this year by the Health and Social Care Research Support Unit for South-east Wales.

## 8.    STAFF DEVELOPMENT

Although the study has not resulted in the gaining of academic qualifications or in any career changes among the project team, it has contributed to the gaining of valuable experience. In particular, Kristin Liabo and Jo Stephens, two junior members of Barnardo's research staff have participated actively in the study from inception to completion. With guidance and supervision, Kristin took lead responsibility in reviewing and summarising the literature, while Jo took lead responsibility for producing the PowerPoint version, and writing and designing the information guides. Both gained experience of networking and liaising with senior professionals in related disciplines from statutory and voluntary agencies, and both gained further experience in employing computer-based techniques. Participation in the study will also contribute directly to their CVs through joint authorship of this report and subsequent publications.

## Appendix 1: Advisory Group members

Dr Liz Penny, Consultant Community Paediatrician, Cardiff and District Community NHS Trust

Mr Mike Davies, Operational Manager, Children's Services, Cardiff County Council

Mrs Hasina Kaderbhai, Field Officer, Cardiff and the Vale Parents Federation

Mrs Carys Davies, Special Needs Health Visitor, Riverside Health Centre, Cardiff and District Community NHS Trust

Mr Sam Carson, Senior Educational Psychologist, Pupil Support Service, Education Department, Cardiff

Mrs Betsan Dunn, Principal Clinical Psychologist, Child and Adolescent Children's Centre, University of Wales College of Medicine

Mrs Pippa Mundy, Clinical Psychologist, Children's Intensive Support Service, Bro Morgannwg NHS Trust

Advisory group members were selected for their expertise, experience and contacts across a wide range of local agencies concerned specifically with issues associated with disabled children and their families.  Members were closely involved in the project from its inception, advising on ways of taking the process forward, suggesting sources of information, commenting on the format of both the report and the guides, and discussing the various drafts produced.  Meetings for the full group occurred on four occasions during the six month project period, and two members of the group attended a relevant conference in the Midlands to gather additional information for the study.  The role of the group is continuing beyond the study period, as they are key contacts for the piloting of the information guides through their respective agencies, and will be closely involved in the production and dissemination of the final products.

## Appendix 2: Summary of key worker evaluation studies

| Focus and findings of main studies included | |
|---|---|
| **Study**<br>**'A single door: social work with the families of disabled children'**<br>(Glendinning 1986)<br><br>**Participants**<br><br>250 families with one or more disabled children (84% response rate yielded 107 families in the experimental group and 103 in the control group) | **Purpose**<br>Evaluation of a project designed to overcome problems with fragmented services for disabled children and their families and to ease their feeling of isolation and lack of support<br><br>*Findings*<br>Parents who were receiving a key worker service experienced significant improvements in the practical day to day care, housing, parental well being and help with financial matters.<br><br>Most appreciated by the parents was having somebody to talk to, the information, advice and practical help received and the reliability of regular visits by the key worker. |
| **Study**<br>**'Working with Families of Children with Special Needs: partnership and practice'**<br>(Dale1996)<br><br>*Participants*<br>Families using the KIDS Family Centre and their 'named worker' support service | Purpose<br>Report from a family centre and it's key working service to parents. The aim of the service was 'to provide support, counselling, guidance and advice to parents and the whole family through regular, long-term contact'.<br><br>**Findings**<br>Most appreciated with the service was the emotional support, care and concern and the availability and approachability of the staff. The key workers' support was able to empower the parents to become more confident and competent in their caring of their child. |

| | |
|---|---|
| *Study*<br>**'Beyond child development centres: care co-ordination for children with disabilities'**<br>(Appleton et al 1997)<br><br>**Participants**<br>21 families with one or more disabled children | *Purpose*<br>Evaluation of a pilot service designed to provide a structured assessment focusing on the family's needs, a care plan, continuity of service for parents throughout the period of transition to nursery school, and the co-ordination of case reviews.<br><br>*Findings*<br>The empowerment element of the project was evident on two levels<br>- They were able to respond to parental concerns about local co-ordination of services at the transition to school stage<br>- There was an empowerment basis to the training of the care co-ordinators in listening skills, and assessment and care planning. |
| *Study*<br>**'Unlocking key working. An analysis and evaluation of key worker services for families with disabled children'**<br>(Mukherjee et al 1999)<br><br>*Participants*<br>27 families with one or more disabled children | **Purpose**<br>Evaluation of two key worker projects. Site A aimed to "provide a key worker service for a small sample of families who are struggling with the complexities of their situation and test out the concept in the local authority" and site B to "provide an identified person who will co-ordinate and/or facilitate the health and social care, and education for each disabled child in the pilot group".<br><br>**Findings**<br>Successful keyworking incorporates 'the six elements of keyworking':<br>- Pro-active, regular contact;<br>- a supportive, open relationship;<br>- a family-centred approach;<br>- working across agencies;<br>- working with families' strengths and ways of coping<br>- working for the family as opposed to working for an agency<br><br>For a professional to provide a key worker service there needs to be commitment and support to multi-agency working and initial and ongoing training and supervision of key workers. |

**Appendix 3:  Resources**

Two recently published resource packs both provide very useful information on the development and maintenance of key worker and care co-ordination services.

**Hansel Trust (2000) Care Co-ordination & Keyworking Resource Pack**

Available from The Hansel Trust, 83 Silver Street, Kings Health, Birmingham B14 7QT. Tel: 0121 441 1580.  Email handsel@LineOne.net

**Mukherjee, S; Sloper, P; Beresford, B. and Lund, P. (2000) A Resource Pack: Developing a Key Worker Service for Families with a Disabled Child, York: Social Policy Research Unit, York University.**

Available from:  Publications Office, Social Policy Research Unit, University of York, Heslington, York YO10 5DD.  Tel: 01904 433618.  Email: spruinfo@york.ac.uk