

**THE DEVELOPMENT OF CARE
CO-ORDINATION SERVICES
IN SCOTLAND:
A REPORT TO CARE CO-ORDINATION
NETWORK UK**

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SECTION 1: BACKGROUND AND RESEARCH METHODS

The policy context

The modernisation of welfare agenda emphasises the need for flexible and individualised services which are accountable and transparent. This may involve breaking down existing agency boundaries (Perri 6 et al, 2002; Riddell and Tett, 2004) in pursuit of 'holistic governance'. Joined-up working is usually justified in terms of delivering improved services, however, for those whose lives are already extremely challenging, the additional burden of service co-ordination may make parents' lives worse rather than better. The fundamental idea underpinning care co-ordination is that establishing a workable network of services delivered by a range of agencies, including health, education and social work, should not be the sole remit of the parent, who already has the task of nurturing the disabled child along with other family and employment responsibilities. The key worker acts as a source of information and advice to the parent, a link to the other professionals working with the family, as well as someone who can offer both practical and emotional support, leaving the parent with more time to enjoy family life. In addition, key workers are charged with ensuring that inter-agency working is effective, avoiding some of the pitfalls which may occur such as inter-agency disputes over professional boundaries and funding.

The need for tighter inter-agency working underlies recent policy on services for disabled children in Scotland, as elsewhere in the UK (DfES, 2003, 2004). For example, the policy document *For Scotland's Children* (Scottish Executive, 2001) set out the agenda for change and the practical adjustments which were required, such as the sharing of electronic records by health, education, social work and the voluntary sector. This agenda has been further developed in the *Getting It Right for Every Child* initiative, which incorporates a commitment to the development of an Integrated Assessment Framework and a single support plan for disabled children and others with significant additional support needs. Working together is also a central theme of the report of the Children's Sub-Group of the Scottish Government's learning disabilities strategy (Scottish Government, 2006). The report, entitled *Changing Childhoods?*, advocates the extension of the Local Area Co-ordinators scheme, also involving key workers.

New education legislation is based on the principle of joined-up working. The Education (Additional Support for Learning) (Scotland) Act 2004 placed a duty on local authorities to identify and meet children's additional support needs. Children with enduring difficulties arising from one or more complex factors or multiple factors and requiring significant additional support from education and other agencies qualify for a Co-ordinated Support Plan (CSP). This plan specifies the services to be provided by a range of agencies and has statutory status. Health and social work have a duty to assist education in making provision to meet additional support needs. Early evidence suggests that a relatively small proportion of children are deemed to meet the tightly specified criteria for a CSP, however the need for services to be co-ordinated is recognised for all children with additional support needs.

As noted above, key working or care co-ordination has been developed to help disabled children and young people and their families benefit from inter-agency working. However, it is evident from the brief review of policy and legislation above that, whilst the principle of co-ordinated service delivery is endorsed by all agencies, there is a danger of duplication of effort and confusion over terminology. For example, the same family might be eligible for a learning disabilities team key worker and a CSP co-ordinator, who might well be located in different agencies and might not communicate very effectively with each other. CCNUK is a voluntary organisation set up to promote care co-ordination and key working to avoid the dangers of service duplication. Service standards on care co-ordination have been developed by CCNUK which have been endorsed by Westminster and the Welsh Assembly, and recognised by the Scottish Government (see Appendix 1). This research

will up-date earlier work on approaches to care co-ordination in England and Scotland (Greco et al, 2004; 2005), which showed that at that point in time care co-ordination was somewhat better developed in England compared with Scotland. This research demonstrates the extent to which progress has been made in Scotland, but also indicates areas where further development is needed.

Research questions

The overarching research question addressed in this research is the following:

To what extent are key working schemes operating or under development in Scotland and how are they operating in practice?

Sub-questions include the following:

1. How many local authorities are using key workers to support families of disabled children, and how many families have access to this type of assistance?
2. To what extent are the service standards developed by CCNUK being applied in different local contexts?
3. What types of key working are developing in the Scottish context, and which are perceived to be working most effectively?
4. How are parents and children involved in the construction and review of key working arrangements and care plans?
5. To what extent are agreed service standards on care co-ordination being applied in Scotland?
6. How well is care co-ordination articulating with other service co-ordination mechanisms, e.g. Co-ordinated Support Plans introduced under the terms of the Education (Additional Support for Learning) (Scotland) Act 2004?

Research Methods

A questionnaire survey was administered to all thirty two Scottish local authorities. Questionnaires were issued to the person identified by CCNUK as having, or most likely to have, responsibility for disabled children's services in education and social work in each of the authorities. When it was known that health was the lead agency in care co-ordination, then a questionnaire was also sent to the relevant NHS Trust. The aim of the questionnaire was to gain information on the conceptualisation and deployment of key workers, the models of care co-ordination being used and the resources allocated to care co-ordination.

The questionnaire was based on the local authority survey developed by the Social Policy Research Unit at the University of York in collaboration with CCNUK, which was administered in the UK in 2002/03. Some amendments were made to reflect recent policy and practice changes in Scotland (see Appendix 2 for the final questionnaire). Survey data were analysed using the Statistical Package for the Social Sciences (SPSS).

The research began in September 2007, with questionnaires sent out to local authorities in October. Two reminders were then issued and further follow up to non-response was made by phone. Twenty two questionnaires were returned (sixty nine per cent). Thirteen local authorities reported having a formal care co-ordination scheme in place and three authorities were planning to develop a care co-ordination scheme in the near future. In comparison with the previous survey administered in the UK in 2002/03, initial analysis shows that there has been some progress with regard to the development of care co-ordination services in Scotland. The previous study (Greco et al, 2004; 2005) identified only thirty services providing key workers for disabled children and thirty five areas having a care co-ordination scheme in the whole of the UK. Twenty six services were identified in England, five in Scotland and four in Wales with fifty areas planning to develop a care co-

ordination scheme in the following year (2003-04). This study identified thirteen services in Scotland which is a large increase on the figure for 2002/03. Three respondents reported plans to develop a scheme in the near future.

Subsequently, telephone interviews were conducted with three representatives of care co-ordination schemes which were fully operational, and one respondent from a local authority where there was no such scheme. Finally, interviews were conducted with three parents who were care co-ordination services users in order to gain some insight into how the schemes were working out in practice.

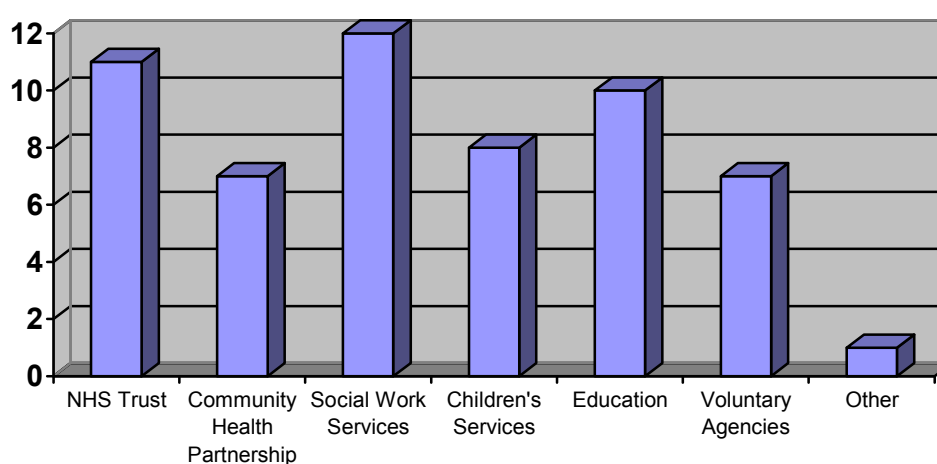
SECTION 2: QUESTIONNAIRE SURVEY FINDINGS

Data from the thirteen questionnaires submitted by local authorities indicating that they had a formal care co-ordination scheme in place were entered into Statistical Package for the Social Sciences (SPSS) and analysed. Frequencies were calculated for the responses to each of the survey questions.

Location of Care Co-ordination Schemes

Five respondents stated that their care co-ordination scheme was operated by a separately identifiable team recognised by management with its own budget. Four respondents reported that care co-ordination was not a discrete activity, but formed part of the activities of a larger team. In general, the schemes mapped onto the local authority areas in which they were based.

Table 1: Which agencies were involved in setting up the scheme?



As seen in Table 1, NHS Trust, Social Work Services, and Education were the main agencies involved in setting up the schemes. Five respondents reported that all of the six agencies mentioned (NHS, Community Health, Social Work, Children's Services, Education and Voluntary) were involved in setting up and overseeing the schemes. The respondent who stated 'Other' reported that parents were also involved in setting up and overseeing the scheme.

Although eight respondents reported that parents with disabled children were involved in setting up the scheme, only five respondents stated that parents were involved in overseeing the scheme. Eleven of the thirteen respondents stated that disabled children and young people had no involvement in setting up and overseeing the scheme whilst four respondents reported no parent or child involvement.

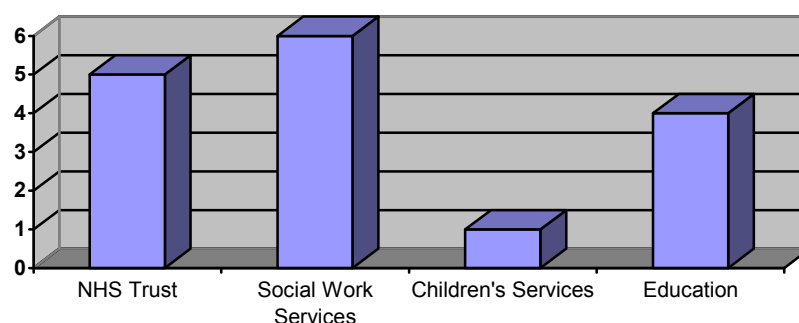
Eleven respondents reported that there was a lead agency within their scheme. Lead agencies identified were as follows: Social Work (n = 4); Health (n = 4); Children's Services (n = 2); Education (n = 1). Two respondents stated that they did not have a lead agency within their scheme.

Starting dates for the schemes ranged from January 1991 to January 2008 with six schemes reporting that they were established in 2004-05.

Table 2 shows that six schemes were funded by Social Work Services, and in two of these cases additional funding was provided by the NHS Trust and Education. Two schemes received money or resources from the NHS Trust and Education. In one case, the only

source of funding was the NHS Trust, and another scheme only received funding from Children's Services. Three of the thirteen respondents did not specify which agencies contributed money or resources to the scheme, suggesting that they may have been unsure. It is worth underlining that, despite the principle of joined-up working, only two schemes appear to have received support from health, education and social work.

Table 2: Which agencies contributed money or resources (staff) to the scheme during the financial year 2006-2007?



The Changing Children's Services Fund was a short-term Scottish Government initiative aimed at providing pump-priming money to start up new types of service provision for a limited period. The understanding was that when this funding stream came to an end, local authorities would have to decide whether to fund these services through their core budget (referred to as mainstream funding). Five respondents specified that they had used funds from the Changing Children's Services fund for support; one respondent had used Changing Children's Services Fund and Sure Start; two respondents had used mainstream funding; and four respondents reported using funds from both the Changing Children's Services Fund and the mainstream budget. Ten respondents reported that an evaluation of the scheme had taken place.

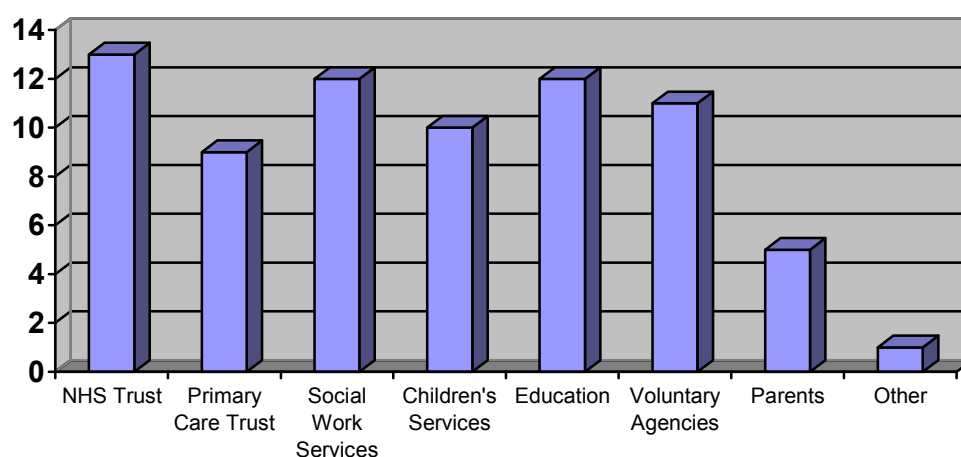
Three respondents reported that they had a separate ring-fenced budget for their care co-ordination scheme. These budgets were £31,327, £30,000 and £67,129 respectively. The schemes which had been resourced from the core budget did not have ring-fenced funding.

Four respondents stated that the scheme was based in Social Work Services, three were based in NHS Trust, two in Education and one in Children's Services. Three respondents reported that the schemes were jointly 'owned', being split between Children's Services and Social Work Services or between the NHS Trust and Social Work Services.

Families using care co-ordination: eligibility and referral

The number of families being supported by the schemes varied greatly according to the size of the local authority. The smallest scheme, in a rural area, supported twelve families whereas schemes in urban areas typically dealt with more than 150 families. Five of the schemes only covered the 0-5 age range. Two schemes covered 0-15 years and six covered the complete age range from 0-16+ years. Most respondents stated that all children with a diagnosed complex disability that required the involvement of two or more services were eligible for the scheme.

Table 3: Who refers families to the scheme?



Twelve schemes used an open referral system. As Table 3 shows, many respondents stated that they took referrals from a range of agencies as well as other sources. On average, respondents took referrals from six agencies although one respondent reported that they only took referrals from the NHS Trust. The respondent who stated 'Other' reported that anyone can refer a child for assessment.

Nine of the thirteen respondents stated that nothing in particular had been done to make the scheme accessible to ethnic minority groups. Three respondents reported that they offered interpreting services and one respondent stated that they followed their local authority's equal opportunities policy.

Care Co-ordination Schemes: Operational issues

Ten respondents stated that they held initial planning meetings where services were arranged whilst three respondents stated that they did not hold initial planning meetings. Twelve reported that regular review meetings were held between the family and all professionals involved. Of these twelve, nine respondents held monitoring meetings on a six monthly basis and one respondent was still to determine how frequently the meetings would take place. Two respondents reported that the regularity of the meetings varies according to the parents' needs.

All thirteen of the respondents stated that one person was allocated to each family to act as a key worker. Two respondents used the term 'Social Worker' instead of 'Key Worker' and two referred to the Lead Person/Professional. Other terms used were: Key point of contact; Children with disability worker; and Co-ordinator. Two respondents had designated key workers and ten respondents stated that the key workers worked with a few families as part of a larger caseload with one respondent failing to answer.

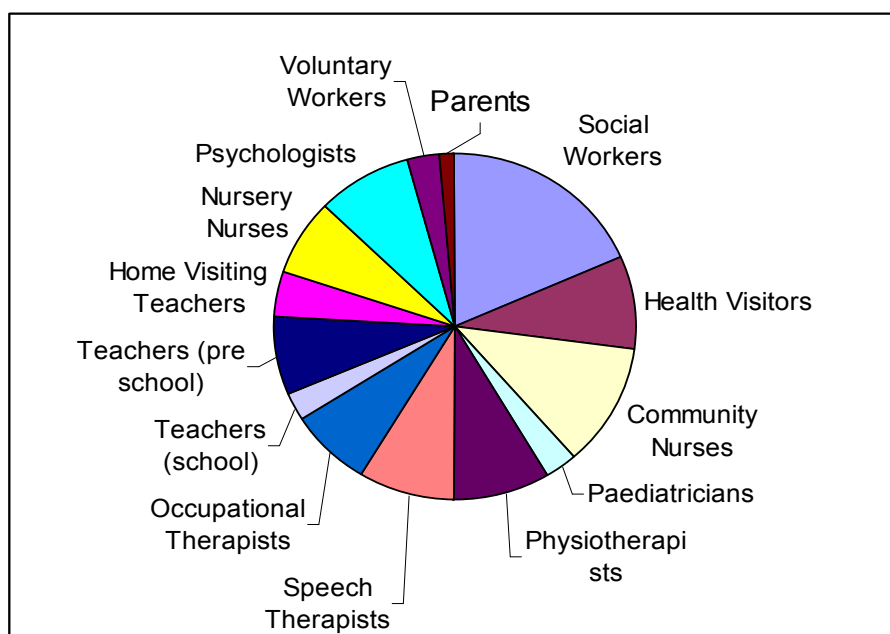
Six respondents reported that they had vacant posts with the majority reporting vacancies for clerical/administrative positions. Two respondents stated that they had vacancies for social care workers. Four respondents reported that there was a waiting list for key workers whilst seven reported no waiting list. Two respondents did not reply to this question. One respondent stated that there were twenty one families on a waiting list for key workers, and one respondent reported thirty seven families on the list. The remaining eleven respondents did not specify a number. The amount of time a family waited to have a key worker allocated varied depending on the urgency of the case.

The role and professional background of the key worker

Ten respondents reported that key workers were supervised regularly within their own workplace directly by their individual line managers. Two respondents stated that there was no formal supervision of key workers whilst one respondent did not answer this question.

Ten of the thirteen respondents reported that key workers were provided with special training on appointment. Four respondents reported that this training was provided through the Special Needs Information Point (SNIP), a voluntary organisation supporting families of disabled children, and two stated that key workers underwent formal training in care co-ordination. Four respondents reported that key workers were provided with in-house training but not specifically in key-working. In three cases, no special training was provided for key workers on appointment.

Table 4: Which professionals working within this scheme act as key workers? (Currently or in the past)



Seven of the thirteen schemes provided ongoing training for key workers which included updated training in relation to individual key worker's learning needs. Six respondents stated that they did not currently provide on going training, and in two of these cases this appeared to be linked to the absence of a manager or co-ordinator. Where ongoing training was provided, this was arranged or delivered by a manager or co-ordinator with time explicitly allocated to this role.

Table 4 shows that a range of professionals act as key workers with the exception of GPs. The most frequently cited professionals were social workers and community nurses. There were several similarities between the respondents' descriptions of the role of the key worker. The majority of respondents reported that the key worker was a named point of contact for families with the job of ensuring the smooth running of the co-ordination scheme. They were also charged with organising and chairing regular meetings and developing a relationship with the family and all professionals involved.

Matching key workers and families

Ten respondents reported that families had a choice in deciding who to have as their key worker, although they were told that their preferred key-worker might not always be

available. Three respondents stated that families did not have a choice. Three respondents reported that attempts were made to match the needs of the child and the skills of the key worker. All thirteen of the respondents reported that the key workers regularly visited families at home.

Eleven respondents reported that they had a coordinator/manager overseeing the day-to-day running of the scheme whilst two respondents said that such a management role did not exist. These coordinators/managers were employed by the Local Authority (n = 3); Local NHS (n = 3); Local Authority and NHS (n = 2); and Social Work Department (n = 3). The amount of time the coordinator/manager spent on their role varied greatly between the respondents, ranging from thirty seven hours per week (70% of the individual's time) to four hours per week.

Links with Other Planning Mechanisms including Co-ordinated Support Plans

Seven respondents were aware of how many children in their local authority area had a Co-ordinated Support Plan (CSP) whilst six were unsure. These numbers ranged from 20 to 135 depending on the size of the local authority area. Eight respondents claimed that more children had a Record of Needs (RoN) in their area than had a CSP. Only one respondent thought that fewer children had a RoN and four respondents did not know.

Four respondents reported that children who have a CSP always have a key worker, five stated they sometimes have a key worker, one stated they rarely have a key worker and three respondents did not know. One respondent reported that children involved in a care co-ordination scheme always have a CSP, nine reported that this is sometimes the case and two reported that this was rarely the case. One respondent failed to answer. Ten respondents stated that key workers are generally involved in compiling CSPs, one stated that they were not and two did not know.

Eleven respondents reported that there are other relevant planning mechanisms operating in their local authority. Among those thought most important were: Child Protection Case Conferences; Integrated Assessment Framework; Special Needs Service; and Integrated Support Plans.

Additional comments regarding CSPs

Two respondents reported that they thought CSPs were an unnecessary piece of additional paperwork which did not holistically gather the views or assessments of children's needs. It was felt that children who have complex needs already have a high level of structure surrounding them.

Awareness of CCNUK

Eleven respondents stated that they were aware of CCNUK with two reporting that they were unaware. Nine respondents were aware of the CCNUK Key Worker Standards (see Appendix 1) and six schemes were currently using them. Of the thirteen respondents who reported having a scheme in place, ten agreed to participate in a telephone interview. Only one of those who responded and did not have a scheme in place agreed to participate in a telephone interview.

Section 2: Summary of Key Points

- The local NHS Trust, social work services and education services were the main agencies involved in setting up the care co-ordination schemes. Parents were also involved in setting up the schemes but did not tend to be involved in their monitoring. There was very little child involvement in either setting up or reviewing activities.

- As well as being the main agencies involved in setting up the schemes, health services and social work services were also reported as the lead agencies within the care co-ordination schemes. Most key workers were employed by health or social services, with a small number employed by education.
- The starting dates for the schemes ranged from January 1991 to January 2008 with the most popular year for starting schemes being 2004-05. The Changing Children's Services Fund was the main funding source used by care co-ordination schemes.
- The majority of the schemes had nothing particular in place to make them accessible to ethnic minority groups. Three respondents offered interpreting services.
- The number of families supported by the schemes varied according to the size and population density of the local authority area. The schemes also supported different age groups which would also contribute to these differences.
- In general, open referral systems were used and referrals were accepted from six different agencies. Initial planning meetings were held by all but three schemes and most of these held regular review meetings on a six-monthly basis.
- All of the respondents stated that one person acted as a family's key worker but it was also reported that different terms were used to describe the key worker.
- Half of the respondents reported that their scheme had vacant posts and the majority of these were in administrative and clerical positions. The majority of respondents stated that they did not have a waiting list for key workers.
- Key workers were generally reported to be supervised directly by their line managers. Ten respondents stated that the key workers received special training on appointment whilst three reported that no special training was given. Ongoing training was provided by seven schemes whilst six reported no ongoing training. Most schemes providing on-going training had a manager with time dedicated to this role.
- It was reported that a range of professionals acted as key workers with social workers and community nurses as the most frequently cited. The description of the role of the key worker used by different schemes was broadly similar.
- Families were mostly given a choice as to who they would prefer to be their key worker but they were always reminded that they might not always get their first choice. All of the respondents stated that key workers made regular home visits.
- The majority of the respondents reported that they had a co-ordinator or manager overseeing the running of the scheme with the majority of these employed by the local authority or the NHS Trust.
- Almost half of the respondents were unaware of the number of children in their area who had CSPs. Less than half of the respondents stated that children involved in care co-ordination had a CSP. Where the children were reported to have a CSP, key workers were generally involved. There appears, therefore, to be room for improvement in the articulation of CSPs and care co-ordination schemes,

particularly in the light of the goal of having a single service planning mechanism by 2010.

- The respondents were mostly aware of CCNUK and of the CCNUK Key Worker Standards with half of the respondents reporting that they were currently using them.

SECTION 3: FINDINGS FROM PRACTITIONER INTERVIEWS

To gather a more detailed picture of the way in which key working services in Scotland operate, interviews were conducted with three interviewees from local authorities which had an established key working system. One interview was also carried out with a respondent from a local authority which did not have a formal care co-ordination scheme in place.

Area profiles

Scheme A covered a large, mainly urban area with considerable cultural density with a total population of just less than 500,000. The service was set up in the mid 2000s as an initial three-year pilot project jointly funded by health, social work and education.

Scheme B covered a large semi-rural area with a population of just over 350,000. A third of the area's population lived in its three main towns. The area's key working scheme had been in place since 2004 once funding became available. The lead agency for this scheme was education.

Scheme C was the largest of the four schemes. It was located within a mainly rural area with a population of around 150,000. The scheme had been running for almost a decade and was set up by the area's health service.

Area D was largely suburban with a population of around 323,000. There was no formal care co-ordination scheme in place and its current social work service had been in place for about 10 years.

Key working services in each local authority/health board

Respondents from Schemes A, B and C stated that they did not see the key working service as a new way of operating but rather as a way of formalising good practice and making sure that every family is able to gain access to the same level of service.

A lot of people are carrying out very similar roles with families, what we're trying to do is encourage them to make that more formal relationship with the families they work with based around core documents, core policies... (Scheme A).

Respondents from Schemes A, B and C all spoke of their commitment to a child- and family-centred approach. To achieve this, a single point of contact with a familiar individual was essential. The key worker was also an important intermediary between professionals, who otherwise might fail to communicate effectively with each other. One respondent commented:

There were times when you could be working with a family and there would be other professionals that you didn't even know were around (Scheme B).

Key workers were able to ensure that unnecessary meetings were avoided, thus reducing time-wasting and stress:

There were pleas from families about repetition, about repeating their story 20 times (Scheme C).

The Area D respondent felt that there was a need to raise the profile and level of service to families with disabled children but worried that if there was one person on a team with specialised knowledge then they might encounter a situation when, if that person was off sick or on holiday, the other members of the team would not feel as if they could deal with families with disabled children. The respondent felt it was important that all members of

the team acknowledged that it should be part-and-parcel of their day-to-day work as a social worker. Despite expressing a desire to re-structure their children and families group in order to look at developing more community-based support, Area D was not familiar with key working services and was not aware of any plans to develop key working services in that area.

The referral system

The systems for referral used in the local authorities were each slightly different from the next. The respondents from Schemes B and C stated that once a child is referred to the scheme, that referral then goes to a central co-ordinator. The respondent for Scheme C stated that the referral form then goes to a secretary who is responsible for obtaining the family's consent and setting up the initial planning meeting. In Scheme B, the referral came to the co-ordinator who then sent the referral to the local child development centre, which then co-ordinated the initial planning meeting. All three of the established services (Schemes A, B and C) acknowledged that although referrals were accepted from a range of sources, they would not take on a referral without the family's consent. In Scheme C, having one referral form was felt to be important. This was sent to the chair of the meeting and was not copied multiple times, whereas in Scheme B a copy of the referral form was sent to the local child development centre and to the educational home visiting service so that they knew about the child and could make contact with the family. Schemes A, B and C all stated that there were several professionals involved in the planning stage all of whom were expected to be present at the initial planning meeting.

The family was seen by all four of the respondents as a central part of the initial planning.

It's quite interesting because all the reports that come in for example may give an indication that this child requires more physiotherapy or whatever, and yet when the family start talking it's quite clear it's respite they're looking for. Therefore it's vital that we get the parents' view (Scheme C).

Within Area D, a general assessment form was used to draw up a plan which involved accessing the services such as residential respite or overnight care. This then went to a local screening group before the head of the team made the final decision.

The initial planning meeting

In Schemes A, B and C, the initial planning meeting was regarded as the stage when the key worker was identified.

There will be a meeting held and we'll look at the assessments that have been going on, formulate a family support plan for the family with their involvement and identify a key worker (Scheme B).

The respondents stated that the family always had a say in the appointment of their key worker, who was very often someone with whom the family had built up a level of familiarity and trust.

Often families say that they've actually asked somebody already or they're actually thinking about someone else (Scheme C).

However, despite best efforts it was not always possible for the family to get their first choice. The respondent from Scheme C felt that more could be done to ensure the family's involvement in choosing the key worker, whilst in Scheme A it was acknowledged that they did not get a report from the families, and this was a shortcoming.

It's all very well having a consultant's view of a child, or a therapist's view of a child but, we need to have the family's view of the child (Scheme A).

In each scheme, the lead agency was generally the one which had taken the lead in the original setting-up phase. Schemes A and B were jointly managed by health, social work and education, whilst in Scheme C, health was the lead agency, and it was reported that in the early stages there had been some difficulties between the different agencies:

Health took on the major initiative; this did not go down well with our education colleagues ... We've managed to iron that out for the most part (Scheme C).

This conflict was resolved by focusing on children from birth to five-years-old rather than birth to eighteen, which was the previous arrangement. This prevented conflict with education, which took over when the child started school and the Co-ordinated Support Plan (CSP) became the major planning instrument. This also streamlined the care co-ordination scheme by avoiding unnecessary duplication for families.

The key working schemes had been in existence for different amounts of time. Schemes A and B had been running for three years and Scheme C had been in existence since 1999. Funding was a major problem for the implementation of the schemes. The Changing Children's Service Fund had been used to fund Scheme B. The respondent from Scheme C stated that they were initially seconded for two days a week in 1999 and were still technically on secondment. Although Scheme A had been in existence for three years, it was an initial pilot scheme and its future fate had yet to be decided.

In Area D, specialist workers had been in teams for about ten years and they had been involved in activities for disabled children for about fourteen years.

The number of families requiring support

The number of families using key workers varied according to the referral criteria and the size of the local authority. In Scheme C, around sixty-five children had named key workers, but this did not include all disabled children in the area since some were deemed not to require help from the child locality team or their families did not wish to engage in the scheme. Around 162 families had a key worker in Scheme B, and all families with a disabled child were offered a key worker at their initial planning meeting. Very few families chose not to use a key worker. The interviewee from Scheme A stated that they had around 427 families who had participated in the care co-ordination programme over the initial three year pilot, although they acknowledged that these figures might not be entirely accurate.

Area D, where there was no care co-ordination scheme in place, stated that around 300 families used residential 'respite' services and holiday play schemes, and therefore might be eligible for care-co-ordination.

Identifying a key worker

As previously stated, key workers were generally identified at the initial planning meeting. In general, in line with the CCNUK Key Worker Standards, which set out clear guidelines for key working, families were offered a key worker if the child had complex disabilities requiring the involvement of two or more professionals above the universal services. Respondents from Schemes B and C stated that all of the families who attended the initial planning meetings were offered care co-ordination, but whether a key worker was appointed depended on their individual circumstances and attitudes.

We open that negotiation with them early. Some families want to think about it for a while and manage, some families are really just so in a state of anxiety etc that it's of

huge benefit and they want it right away. Some families feel so empowered from the support from the team that they prefer to do their own key working if you like (Scheme C).

In Scheme C, whether the families accepted a key worker was very much open to negotiation. By way of contrast, in Scheme B it was almost assumed that if a child had several professionals involved with them then there was a need for inter-professional co-ordination. Although the family was given the option of opting out of the co-ordinated meetings and dealing with the professionals on an individual basis, the use of regular review meetings ensured that a degree of co-ordination still occurred.

Of the three schemes, it was only in Scheme A that requests for a key worker were sometimes turned down and such decisions were based on the CCNUK Key Worker Standards. The respondent from Scheme A was the only one to indicate that the demand for key workers exceeded supply. Respondents from Schemes B and C stated that although the demand did not exceed supply at the time of interview, there was potential in the future for key worker services to be under greater pressure.

I think that those who are co-ordinators need support and training....it hasn't exceeded supply at the moment because what we have is a willingness, but if you have a really problematic family it can be quite an emotional strain and a task to become a co-ordinator. It's not just an easy option (Scheme C).

The key worker role was seen by respondents from Schemes B and C as something that should be integral to the roles of those who were already working with the families. However, the lack of additional funding could place a strain on what was expected of people especially if they were working with a few families. Schemes B and C also stated that they attempted to deal with this by trying to make sure that the key worker was responsible for no more than three families in their locality.

The needs of families

The main problems encountered by families with a disabled child were associated with the stresses and strains of dealing with a multitude of professionals. The respondent from Scheme C acknowledged that maintaining service continuity was very difficult:

Staff will leave the predominately female profession, get married, get pregnant and they only come back part time so you get families frustrated at the lack of consistency in the service they receive (Scheme C).

Families who had built up a level of trust with professionals could be left feeling isolated when the professional left the area or moved on to a new position. Respondents also mentioned that financial problems were a source of strain for families. Finding the right housing could also be a problem, as some children needed a variety of equipment to help with mobility issues.

Respondents all agreed that families needed different things from key workers as all relationships were completely different and everything had to be negotiated on an individual basis.

In the beginning there's a lot for key workers to do because they're building a relationship with families, they're building relationships with the other professionals, they are trying to make links with all the different agencies (Scheme B).

Some families were happy with the level of support from the key worker and this filled them with the confidence they needed to do a lot of the phone calls themselves. By way of

contrast, other families wanted the key worker to do as much as they could for them because they did not feel able to manage these tasks by themselves. Some families were seeking someone to manage services on their behalf, for example co-ordinating hospital appointments. Other families needed to have breaks and alternative childcare arrangements organised on their behalf. The respondent in Scheme C stated that key workers needed to be far more knowledgeable than they were in the past because families have much greater access to information through the internet. Children were also presenting with very different conditions than in previous years as advances in medical technology allowed many pre-term babies to survive, many of whom had significant and complex impairments. Some key workers felt that they were unable to meet all of the needs which families might have:

Some of them (key workers) don't have a particular resource or might not be asking the right questions around benefits where other professionals would so there's a bit of an inconsistency about the service you get at the moment (Scheme A).

The respondents believed that on the occasions that key working had not been successful; this had been largely due to a lack of understanding of the key worker's role on the part of the family:

For the most part we've had 85 per cent of our families fed back to say it was a lifeline. For the 15 per cent for whom it hasn't worked out maybe they haven't understood. So from that point of view it doesn't always work but it works in more cases than it fails (Scheme C).

This clearly highlights the need for clarity with regard to what can and cannot be provided through key working services. However, there are also clearly dangers in blaming parents where key working services fail to work effectively. The possibility that the role of the key worker has not been properly explained or understood, either by the key worker or the parent, needs to be investigated.

Families were provided with information about key working through a variety of sources and from a range of professionals. In Scheme A, information points in GPs' surgeries and hospitals were used. Information leaflets were distributed through a variety of outlets by Schemes B and C.

Key workers' role and activities

In line with the general findings reported in the previous section, the majority of key workers in Schemes A, B and C were from health, social work and the voluntary sector, with health making up the majority. These key workers were predominately speech and language therapists, community children's nurses, child development centre staff or educational home visitors. Not many key workers were from education but that was mainly due to the fact that many of the children involved were under five and would have much more contact with education once they began school.

Many of the tasks undertaken by key workers fell within their job remit before they were officially designated as key workers. Aspects of the job such as providing emotional and practical support, such as benefits advice, remained consistent and respondents claimed that many of the key workers did not see their role changing significantly. They were happy to fit their key working role around other aspects of their job. One respondent reported that staff were concerned that key working would increase their workload:

There's been a little bit of resistance because I think there's a fear that it will increase their workload when in actual fact if there are enough people doing the key working it can reduce your workload (Scheme B).

Respondents agreed that it was important for the key worker to juggle the different aspects of their job and prioritise issues.

As Schemes B and C only dealt with children under the age of five and three respectively, Co-ordinated Support Plans were not regarded as of major importance (although these can be opened for three-year olds). The respondent from Scheme A stated that it was essential that the children receiving care co-ordination had a CSP. Schemes A and C stated that the co-ordinator of the CSP would liaise with the key worker. Communication problems between social workers and the co-ordinators of CSPs, who were usually located within educational services, were noted.

There was general approval for the Scottish Government's intention to introduce an integrated assessment framework with a single support plan from 2009 and respondents said that this was something that they were already trying to work towards. The respondent from Scheme A felt it was 'a bit of a romantic vision' to have a single support plan covering health, education and social work, but nonetheless it was a worthy aspiration. There was also concern that the plan would inevitably involve duplicated effort.

The organisation of effective family-centred review meetings was seen as a major part of the key worker's role. In particular, it was important to ensure that the issues raised reflected the concerns of the family as well as the professionals. The key worker was also expected to be highly professional and work as an intermediary.

So if a family's sounding off about another service, for example, about the speech and language therapist, the key worker isn't completely agreeing with the family. Basically they say let's find a way to discuss that so we can move on to the next stage (Scheme C).

The key worker was expected to meet regularly with the family in order to explore the family's needs, developing a high level of trust over time.

It takes time to build up the trust in families so that they're honest and they're able to talk about the issues that are facing them. Many families want to be seen as coping so they will not reveal what their real issues are until they trust someone (Scheme B).

The frequency with which the key workers met with the families was variable. The respondent from Scheme B stated that they required the key workers to at least phone the families once every two weeks. The respondents from Schemes A and C stated that it depended entirely on what was appropriate to the family and it varied from weekly, to monthly, to formal six-monthly reviews. However, it should be noted that CCNUK key worker standards refer to the need for a proactive approach, so that the key worker does not leave it to the family to initiate contact.

Respondents from Schemes A, B and C felt that more could be done to take into account the views of the disabled child and young person. Various reasons were given for this, for example, it was felt that accessing the views of children with severe communication difficulties was challenging. In another scheme, the majority of children were under three years old, and therefore could not contribute their opinions in an easily accessible manner. However, they all acknowledged that it was an area where further development was needed.

If we had 65 families I could guarantee that they would say no, you ask us but you don't ask our child (Scheme C).

Issues in developing inter-agency working

The respondents from Schemes A, B and C reported numerous issues which arose in developing inter-agency working. In the early stages of care co-ordination development, there were some tensions between the different agencies, but it was felt that most of these problems had now been resolved. It was felt that when people were actually working with the families, communication and collaboration worked quite well. Problems occurred when bureaucratic issues connected with funding and training arose.

The difficulties of funding, if a child needs a particular piece of equipment, who funds that? If you want to have joint training how is that funded? It comes down to different budgets and different managements. How do we get managers to agree on joint budgets on training? (Scheme B)

Having the administrative support to set up meetings was also found to be a problem when working with different agencies. Individuals often found this task time-consuming and worried about having the appropriate skills.

Misunderstanding of other professionals' remits and roles was reported as a source of tension. In Scheme A, collaboration with education was felt to be difficult as they appeared to use different terminology and a completely different model of practice. It was said that education tended to focus on their own service, and had little understanding of the impact of the child's health needs. Respondents from Schemes B and C reported difficulties in collaborating with social work because of staffing issues and the general demands on social workers which meant that child protection work might be prioritised over support for disabled children and their families.

We also have had difficulties getting social work involved. That was because in the past they were very under-resourced and their priorities are child protection and family breakdown (Scheme B).

Problems were also reported between health and other agencies, particularly between hospital-based staff and community staff.

The future of key working

All respondents hoped that key working services would expand in the future, with a closer emphasis on collaboration with education in particular:

I would like to see families being allocated a key worker as soon as their child's disability has been identified at a very early age and having access to a key worker for as long as they need it right through into transition into adult services (Scheme B).

The lack of a robust funding infrastructure was seen as the main barrier to the expansion of key working services, leading to problems ranging from lack of administrative support to inadequate training:

It is unsustainable for it to go on the way it's going because of the number of children and the demands that are going to be made and if the child locality teams are going to be seen as key between birth and five we have to look quite holistically at where the underpinning funding is going to come from for people to see it's not just another role onto their already burdened role (Scheme C).

In relation to having sufficiently qualified people, it was difficult to get people to go on three-day training courses in order to equip them with the skills they would need to operate effectively as key workers. However, it should be noted that the Special Needs Information

Point, a parent led voluntary organisation, has delivered training to over 500 practitioners, so some of these problems may already have been addressed.

Section 3: Summary of Key Points

- Overall, existing care co-ordination schemes were seen as highly beneficial.
- The three established schemes used slightly different referral systems but they all acknowledged the importance of gaining the family's consent before accepting a referral.
- Schemes A and B were still lead by the agency which had taken the lead in their inception and some degree of tension was reported in working with other agencies.
- All three schemes aimed to provide a single point of contact for families and to reduce duplicated effort, for example, with regard to the number of times families had to describe their child's needs, often reliving painful experiences.
- The demographic profiles of the areas affected the availability of key workers and the number of families requiring care co-ordination. Scheme A, located within a mainly urban, highly populated area catered for 427 families and was the only area to turn down service requests. The more rural areas served by Schemes B and C were far less populated so it was possible to ensure that key workers were responsible for no more than three families. It was possible to meet all requests for a key worker and every family who attended an initial planning meeting was offered this service.
- The age range of the services dealt with varied considerably. Scheme A dealt with children beyond the age of 5, whereas Scheme B only dealt with children under the age of 5 and Scheme C from birth to 5 years.
- Problems with care co-ordination schemes were attributed to parents' lack of understanding of the key worker's role, although this may have been inadequately explained.
- Information about key working schemes was provided in different ways, sometimes via information points in GPs' surgeries and sometimes through leaflets distributed through many different routes.
- Schemes A, B and C agreed with CCNUK's description of the role of the key worker underlining the importance of developing a high level of trust with families over a sustained period of time. It was felt that key working did not represent a radical change in existing working practices.
- There were differences in the frequency of meetings with families, but it was agreed that regular contact was essential even if no problems were reported.
- Respondents felt that more could be done to access the views of the disabled child or young person.
- Funding was viewed as a major problem in the establishment and maintenance of care co-ordination schemes, with most key workers incorporating this role into their existing duties. Funding problems were often reflected in administrative shortages.

- When contrasted with Area D, where there was no care co-ordination scheme, it was evident that key working led to better organised and more comprehensive services.
- The respondent from Area D worried that developing a key worker service would mean that there was only one person in the team who would be able to deal with a family, leading to problems if the key worker was sick or had to be assigned other duties. However, it seemed that services in Area D were less targeted and efficient than in areas covered by key working schemes.
- In addition, in Area D it appeared that the urgent demands of child protection work often over-rode all other service needs, including those of disabled children and their families. Prioritising service needs was a general issue, but appeared to be more acute in Area D.

SECTION 4: INTERVIEWS WITH PARENTS OF DISABLED CHILDREN

Three parents of disabled children were interviewed to gain some insight into their experiences of care co-ordination.

Parent 1 has a three year old son with complex medical needs including heart abnormalities, gastric problems, liver damage and speech development issues. They have been involved in care co-ordination for 18 months.

Parent 2 has a 19 month old daughter with visual impairment and developmental delay. They have had a key worker for about 17 months.

Parent 3 has a 5 year-old daughter with incontinence and mobility problems which mean she requires constant attention. They have had a key worker for 2 years.

Needs of the child and their impact on the family

It was clear from the interviews that children involved in care co-ordination schemes present very complex needs and the difficulties the children face are entirely individual to them. Dealing with their child's condition has had a massive impact on each of the families. The children require constant attention and dealing with the needs of the child can have negative consequences on the lives of the parents. All three of the parents interviewed commented that it was very difficult to have a life outside the various meetings and appointments. One parent said:

My husband suffered from depression for a really long time, and I just kind of said that I'll just get up and get on with it. I have now got myself on a waiting list for counselling because I haven't actually dealt with it (Parent 1).

All of the parents mentioned that going to and from hospital appointments was both time-consuming and stressful, since they felt that their time was not their own:

(The impact) on our family is more of a balancing act and trying not to let everything revolve around her needs and her medical appointments (Parent 2).

Parent 1 said that between January and February, their child had 26 hospital appointments, making it impossible for them to work:

If he was to have physio, he had to go to a clinical physio appointment. If he was having speech therapy, he would go to a clinical speech therapist appointment which added to the appointments (Parent 1).

According to Parent 1, education professionals were not always easy to deal as they were used to having people comply with their wishes. This parent felt that the child and the family should be accorded a more central position in the decision-making process. Parent 3 mentioned some difficulties in communicating with medical professionals since they tended to deal with the child in a somewhat detached manner:

I felt they were abrupt and felt quite intimidated (Parent 3).

Parents' views of care co-ordination services

The parents came to hear about care co-ordination through a variety of sources. Parent 1 found out through various leaflets whilst Parent 2 was referred by their health visitor. Parent 3 found out through their locality team meetings.

Because there was so many agencies involved, it would be better if we had one person co-ordinating it all and then it was like a communication thing, it was actually through a couple of people we heard about it (Parent 3).

The parents commented that it was not a conscious decision to use care co-ordination, but rather, it was the obvious route to take. Due to the number of professionals involved, care co-ordination schemes were automatically recommended to the parents.

Well we kind of had no real choice...everything just seemed to happen from the child development centre, so it wasn't really a choice, it was obvious that was the way that things should work (Parent 2).

Parents valued some elements of the key worker's role more than others. Parent 3 highlighted the role the key workers in providing emotional support to the families:

In a sense emotional support...it's more like discussing things and then we also have a phone call, we can phone them up (Parent 3).

Parents 1 and 2 both highlighted the fact that the key worker liaised with the different professionals and organised meetings. They also reported that the key worker was their main source of information:

She's a great point of contact for all sorts of information. If she doesn't know, she'll know somebody who does know (Parent 1).

The key worker ensured that the correct people were present for any meetings and Parent 1 stated that their key worker was there to represent the child's interests and to keep the meeting child-centred. Parent 2 was very impressed with the way in which the key worker was able to get in touch with the different professionals and tailor the services around their family, almost pre-empting the services which would be required in the future.

They make things as easy and straightforward for us, I mean I know there must be mountains of paperwork involved in getting any of these people kind of on our team, but it's just made so easy (Parent 2).

Parent 3 described her attempts to have shower facilities installed in her local school, which were greatly assisted by the intervention of the key worker, who was able to enlist the support of their child's consultant surgeon and paediatrician. These professionals provided evidence of the benefit to the child of attending the local school, which resulted in a successful outcome.

Parents were happy with the range of professionals involved in their case, and said that if they felt a particular form of support might help then the key worker was always willing to discuss different techniques including alternative therapies. However, Parent 1 felt that the medical professionals were not involved in care co-ordination in this particular area, although their input was needed. It was felt that health professionals did not take into account the other appointments which the family might have to attend and sometimes insisted on too many appointments.

The parents believed that the main benefits of care co-ordination were fewer appointments, so that, for example, the child no longer had to attend separate appointments for physiotherapy and speech language and occupational therapy. They also valued the advice and information and emotional support provided by the key worker.

The parents were unable to list any obvious downsides to keyworking and felt that within their area it was operating very well. Parent 1 felt that services could be improved in the future by appointing people who were employed solely as care co-ordinators so they would have more time to devote to key working, rather than having to fit it in alongside other duties.

Section 4: Summary of main points

- Children in care co-ordination schemes have unique and complex needs and this takes up a large part of the parents' time. The parents of severely disabled children felt that it was very difficult to have a life outside the various appointments and meetings which they had to attend.
- One parent found that there were some difficulties in working with education professionals as they expected parents to comply with their wishes. Another parent mentioned objected to the rather detached manner of some health professionals.
- The parents found out about care co-ordination through a variety of sources and it was seen as the obvious route to take. The parents valued the information provided by the key worker, as well as their emotional support.
- One parent felt that the medical professionals needed to work more closely with other professionals and plan their appointments more carefully, bearing in mind other aspects of parents' lives.
- One parent felt that it would be beneficial for key workers to be employed to undertake this task alone, rather than having a wider job remit.

SECTION 5: CONCLUSION

Care co-ordination has moved in a relatively short period of time from being a radical new form of service delivery towards the mainstream. Almost half of Scottish local authorities now offer key workers to families of children with complex needs, and this represents a rapid phase of service development. The evidence presented here, drawn from a survey of care co-ordination providers, practitioner interviews and interviews with a small number of parents, highlights some of the challenges facing care co-ordination services over the coming years. These are summarised briefly below.

Funding issues

It is evident that, despite their popularity with parents, the financial future of care co-ordination services is far from assured. Many were initially funded through special initiatives such as Sure Start or the Changing Children's Services Fund. The advantage of such programmes is that their ring-fenced funding allows specialist services to be developed. The downside, however, is that funding is guaranteed for a limited period only, and subsequently services have to compete with others for funding from the core budget. If mainstreaming is achieved, it may be the case that a less lavish service is provided, leading to fears that the initial gains may be lost or diminished.

On-going challenges of inter-agency working

Despite the endorsement of the principles of key working by all parties, it was clear from the various accounts presented above that joined-up working was more easily achieved in theory than practice. Ownership of care co-ordination schemes tended to rest with the agency which had initiated the scheme in the first place. It was quite rare for health, education and social work to be equally involved in the delivery and funding of care co-ordination services. With regard to their disciplinary background, key workers were more likely to be social workers or health professionals, and less likely to come from education. It was reported that some professional difficulties emerged when schemes were being set up initially, sometimes disappearing once the scheme was up and running, but occasionally persisting. The specific discourses employed by health, social work and education continued to contribute to lack of understanding of different professional practices. Problems in successfully implementing multi-agency working are amply illustrated in the research literature (see, for example, Lightfoot et al, 2001). It is evident that a huge amount of energy is needed to overcome these challenges, so that skirmishes over professional boundaries are not allowed to damage the quality of service delivered to disabled children and their families.

Qualification criteria

It was evident that, in different geographical areas, a range of practices were used in terms of determining access to key working services. In rural and semi-rural areas, where pressure on services was less intense, all parents whose children required multi-professional input were offered a key worker, and most accepted. In urban areas with considerable pressure on services, demand for key workers often out-stripped supply, and as a result more stringent qualification were applied. In some areas, the child's age determined access to care co-ordination services. Sometimes, key workers were only allocated to pre-school children or those under the age of three. These services were typically run by health or social work, and deemed to be no longer necessary once education became the main service provider.

Proliferation of co-ordinated planning mechanisms

As the need for joined-up services has gained recognition, so the mechanisms for achieving inter-agency working have increased. Care co-ordination services, often led by social work or health, have spread, and at the same time Co-ordinated Support Plans, with education as the lead agency, have been established. Although the Scottish Government

wishes to have an integrated assessment framework in place by 2009, associated with a single support plan, it is evident that the care co-ordination services run by different agencies are often operating separately. In some areas, it appeared that a child's key worker might have little involvement with, or indeed knowledge of, the person with responsibility for the child's Co-ordinated Support Plan. In addition, a child or young person with learning disabilities might have a key worker linked into the area learning disabilities team, whose responsibility for the young person would continue after they moved into adult services. Clearly, the task of harmonising co-ordinated services planning mechanisms has yet to be undertaken and, as one interviewee mentioned, much work will be needed to achieve a single assessment framework and support plan, compiled and used by all agencies working with the child.

Providing family and child-centred services

The need for services focused on meeting the needs of families and children was recognised by all interviewees. At the same time, placing parents' concerns at the heart of all planning and review meetings was clearly difficult to achieve, since each professional was likely to have their own concerns and preoccupations which might often pre-dominate. Furthermore, allowing children to communicate their experiences of services was recognised as a major challenge. Some professionals felt that children might be too young to articulate their views, or might be hindered by communication difficulties. However, it was evident that the various imaginative ways of providing severely disabled children with communication opportunities, perhaps using ICT or low tech communication aids, had not been fully explored. This clearly is an area for future development.

Understanding of the key worker's role

It is evident that a number of different models of key working are used in Scotland, for example, sometimes key workers are employed to carry out this role as the main or only focus of their work, whereas in other cases key working may be part of a much wider job remit. Whichever model is employed, it is of vital importance that practitioners and service users are aware of what makes key working different from other forms of service delivery, as spelt out in the CCNUK key worker standards. It is telling that some interviewees expressed the view that key working was not that different from the normal working practices of health or social work professionals. Such attitudes suggest a lack of awareness of the distinctiveness and challenges of care co-ordination. Indeed, earlier work conducted by the Social Policy Research Unit at the University of York (Greco et al., 2004; 2005), found that the belief that key working was no different from normal practice tended to indicate a lack of understanding of and adherence to the central aspects of the key worker's role.

The training and development of key workers

Recognising the distinctiveness of the key worker's role is linked to the importance attached to initial and ongoing training. It is evident that, whilst most new key workers are provided with initial training, on-going training is far less widely available, and is often contingent on the presence of a manager with time dedicated to this task. There is clearly a cost attached to delivering training to new key workers, as well as those who have been undertaking this work for some time. However, as demonstrated by earlier work (Greco et al., 2004; 2005), failure to invest in initial and ongoing training is likely to result in an under-developed service with insufficient awareness of best practice.

To summarise, it is evident that the principles of care co-ordination have received widespread acceptance over a relatively short period of time, and yet much further change will be needed to ensure that new ways of working become embedded. Safeguarding and building on the gains will be extremely important over the coming years, particularly in times of greater financial stringency when funding for innovative projects may be less readily available.

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Appendix 1

Care Co-ordination Network UK keyworker standards



Organisational Standards	Fully met	Nearly met	Not met	Don't know
1. Multi agency commitment at a strategic and practice level. Evidence				
2. Multi-agency management group including families and, at the minimum, representatives from education, health, social services and voluntary sector if a stakeholder in the area. Evidence				
3. An agreed referral system and specific guidelines for eligibility for the key worker service. Evidence				
4. A joint policy for information sharing between agencies. Evidence				
5. A multi-agency protocol for joint assessment, drawing up an inter-agency care plan and review of the needs of the disabled child and their family. Evidence				
6. A communication strategy for professionals, parents and children and young people. Evidence				
7. A key worker manager to manage the service on a day to day basis and to report to the multi-agency management group. Evidence				

Organisational Standards	Fully met	Nearly met	Not met	Don't know
<p>8. Ongoing resources to run the service including the provision of administrative support, induction and ongoing training and supervision for key workers.</p> <p>Evidence</p>				
<p>9. A defined job description for the key worker manager, key workers and administrators.</p> <p>Evidence</p>				
<p>10. An agreed system for cover for key workers in the event of long term absence.</p> <p>Evidence</p>				
<p>11. Setting up and maintaining links with other agencies that impact on the lives of disabled children and young people e.g. housing, benefits, leisure, voluntary sector.</p> <p>Evidence</p>				
<p>12. Identifying the cultural needs of the local population, including minority ethnic groups, and ensuring that the service provides for these needs.</p> <p>Evidence</p>				
<p>13. Monitoring, reviewing and evaluating the service.</p> <p>Evidence</p>				

Practice standards	Fully met	Nearly met	Not met	Don't know
1. Providing information. Evidence				
2. Identifying and addressing the needs of all family members. Evidence				
3. Providing emotional and practical support as required. Evidence				
4. Assisting families in the dealings with agencies and acting as an advocate if required. Evidence				
5. Pro-active, regular contact. Evidence				
6. A supportive, open relationship based on respect for the views of parents, children and young people. Evidence				
7. A family-centred not child-centred approach. Evidence				
8. Working across agencies - including agencies such as housing, leisure and the Benefits Agency. Evidence				

Practice standards	Fully met	Nearly met	Not met	Don't know
<p>9. Working with the families' strengths, acting as an advocate or enabling parents, children and young people to access advocacy support as required.</p> <p>Evidence</p>				
<p>10. Provision of induction training and ongoing training and development for key workers.</p> <p>Evidence</p>				
<p>11. Regular supervision of key workers, including both professional/clinical and management supervision.</p> <p>Evidence</p>				
<p>12. Non-designated key workers should have protected time for their role.</p> <p>Evidence</p>				
<p>13. Disabled children, young people and their families should be given a clear explanation of the role of the key worker/care co-ordination service and the responsibilities of this role.</p> <p>Evidence</p>				
<p>14. An inter-agency care plan giving key workers the agreed power to access resources and credibility with the agencies involved in provision for the family.</p> <p>Evidence</p>				
<p>15. An information resource covering local services and their roles, information about different conditions and impairments, and national organisations.</p> <p>Evidence</p>				

Practice standards	Fully met	Nearly met	Not met	Don't know
<p>16. Inter-agency assessment leading to an inter-agency care plan, building on and linking with any other assessments undertaken.</p> <p>Evidence</p>				
<p>17. Agreed system and timing for inter-agency care plan and reviews in line with the families' wishes.</p> <p>Evidence</p>				
<p>18. Supporting parents' and young people's preferences regarding assessment and review meetings.</p> <p>Evidence</p>				
<p>19. Ensuring appropriate support for children and young people to participate in their assessment and review process.</p> <p>Evidence</p>				
<p>20. Appropriate support for parents to participate in their assessment and review process.</p> <p>Evidence</p>				
<p>21. Consideration of support needs related to ethnicity and culture, including provision of translation and interpreters.</p> <p>Evidence</p>				
<p>22. Agreed system for record keeping.</p> <p>Evidence</p>				
<p>23. Parent and/or young person held records.</p> <p>Evidence</p>				



APPENDIX 2

CARE CO-ORDINATION NETWORK UK (CCNUK)

KEYWORKING /CARE CO-ORDINATION: INFORMATION ABOUT LOCAL SCHEMES IN SCOTLAND

Preamble: A research team led by Professor Sheila Riddell at the University of Edinburgh has been asked by CCNUK to investigate the operation of care co-ordination schemes in Scotland. This study will inform the development of future policy and practice in this area. We would be very grateful if you could complete and return this questionnaire to Sheila.Riddell@ed.ac.uk or [s0567643@sms.ed.ac.uk](sms:s0567643@sms.ed.ac.uk).

Name of scheme _____

Organisation _____

Address _____

Telephone number _____ Email _____

Name of manager _____

SECTION A: CARE COORDINATION SCHEMES

A1. Is your care coordination scheme:

- A separately identifiable team recognised by management, with its own budget
 - Part of another team
 - Other, please describe.....
-

A2. What geographical areas does the scheme cover?

.....

A3. Which agencies were involved in setting up the scheme? (please tick all that apply)

- NHS Trust
- Community Health Partnerships
- Social Work Services
- Children's Services
- Education
- Voluntary Agencies
- Other (please describe)
-

A4. Were any parents with disabled children involved in planning the scheme?

- YES
- NO

A5. Were any disabled children and young people involved in planning the scheme?

- YES
- NO

A6. Which agencies are involved in overseeing the scheme, e.g through membership of a steering group? (please tick all that apply)

- NHS
- Community Health Partnerships
- Social Work Services
- Children's Services
- Education
- Voluntary Agencies
- Other (please describe)
-

A7. Are any parents with disabled children involved in overseeing the scheme?

- YES
- NO

A8. Are any disabled children and young people involved in overseeing the scheme?

YES

NO

A9. Is there a lead agency?

YES

NO

IF YES, which agency is this?

A10. When did the scheme start?monthyear

A11. Is the scheme a pilot project or a mainstream part of service provision?

PILOT For how many years do you have funding agreed?

.....

MAINSTREAM For how many more years do you have funding agreed?

.....

If appropriate, please describe your funding situation

.....
.....

A12. Has anything in particular been done to make the scheme accessible to families from minority ethnic groups?

YES

NO

If YES, please describe

.....
.....

A13. Has there been any evaluation of the scheme?

YES

NO

IF YES, we would be grateful for any details you could send us (e.g. evaluation reports)

The next questions are about how the scheme is funded. Please provide as much detail as you are able to. If you are able to send us a recent copy of your income and expenditure accounts, that would be very helpful.

A14. Which agencies contributed money or resources (staff) to the scheme during the financial year 2006-2007?

Agency	Currently provide finance? (Y/N)	Proportion of scheme's finance (%)	No. wte* staff from this agency
NHS Trust			
Primary Care Trust or Group			
Social Work Services			
Children's Services			
Education			
Voluntary Agencies			
Other (please describe)			

* full-time equivalent

A15. Have any of the following funds been used to support the scheme?

- Changing Children's Services Funds
- Surestart
- Mainstream
- Other (please state what fund):

A16. Do you have a separate budget that is ring-fenced for your care coordination scheme?

- YES
- NO

If YES can you tell us what the ring-fenced budget was for 2006-07:

.....

SECTION B: THE CHILDREN AND FAMILIES

B1. What age groups does the scheme cover? *(Please tick all that apply)*

- 0-5 years
- 6-11 years
- 12-15 years
- 16+years

B2. What are the eligibility criteria for children and families?

.....
.....
.....

B3. How many families are currently being supported by the scheme?

B4. Do you have an open referral system?

- YES
- NO

B5. Who refers families to the scheme? *(Please tick all that apply)*

- NHS Trust
- Primary Care Trust or Group
- Social Work Services
- Children's Services
- Education
- Voluntary Agencies
- Other, please describe

.....

SECTION C: THE COORDINATION SYSTEM/PROCESS

C1. Once a referral has been accepted, are initial planning meetings held between the family and all professionals involved in their care?

- YES
- NO

IF YES, please provide brief details

.....
.....

C2. Are regular review meetings held between the family and all professionals involved in their care?

YES

NO

IF YES, how frequently?

C3. Do families have one person as a key worker (or similar)?

YES

NO

If your scheme does not use the term key worker please state what you use to describe your workers _____

C4. Which professionals working within this scheme act as key workers? (Currently or in the past) *(please tick all that are relevant)*

Staff Category	
Social workers	
Health Visitors	
Community nurses	
Paediatricians	
Physiotherapists	
Speech therapists	
Occupational therapists	
Teachers (school)	
Teachers (pre-school)	
Home visiting Teachers	
Nursery nurses	
GPs	
Psychologists	
Workers with voluntary agencies	
Other (please describe)	

C5. Are the key workers designated or do they key work with a few families as part of a larger caseload? *(Please tick as appropriate)*

- Designated key workers – How many key workers?
- Part of larger case load – How many key workers?

C6. Do you have vacant posts within your scheme?

- YES
- NO

If YES, please provide a brief description

.....
.....

C7. Is there a waiting list of families requiring key workers?

- YES
- NO

If YES, how many families are on the list?

.....

How long on average does a family wait to get a key worker?

.....

C8. How are the key workers supervised?

.....
.....

C9. Is any special training provided for key workers on appointment?

- YES
- NO

If YES, please provide a brief description

.....
.....

C10. Is ongoing training provided for key workers?

- YES
- NO

If YES, please provide a brief description

.....
.....

C11. What does the role of the key worker cover? *(Please send a job description or describe below)*

.....
.....
.....
.....
.....

C12. How are key workers and families matched?

.....
.....
.....

C13. Do families have a choice as to who is their key worker?

- YES
- NO

C14. Do key workers regularly visit families at home?

- YES
- NO

C15. Does the scheme have a coordinator/manager who oversees the day-to-day running of it?

- YES
- NO

If YES, who employs the coordinator/manager?

.....

How much time does the coordinator/manager spend on this role – as proportion of w.t.e?

C16. Where is the scheme based?

- NHS Trust
- Primary Care Trust or Group
- Social Work Services
- Children's Services
- Education
- Voluntary Agencies
- Other, please describe

.....

If available, please could you send any written information about the scheme (e.g. annual reports, publicity material or user information).

Please add any additional information or comments below.

.....
.....
.....
.....
.....
.....
.....

SECTION D: LINKS WITH OTHER PLANNING MECHANISMS

D1. Do you know how many children in your local authority have a Co-ordinated Support Plan (CSP)?

- YES
- NO

Please could you tell us approximately how many?

.....
.....

D2. How does the number of children with a CSP compare with the number of children who had a Record of Needs (RoN)?

- More children had a RoN
- Fewer Children had a RoN

Don't Know

D3. Do children who have a Co-ordinated Support Plan have a key worker?

Always

Sometimes

Rarely

Don't Know

D4. Do children who are involved in a care co-ordination scheme have a Co-ordinated Support Plan?

Always

Sometimes

Rarely

Don't Know

D5. Are key workers generally involved in Co-ordinated Support Plans?

YES

NO

Don't Know

Please

comment.....
.....

D6. Are there other relevant individual planning mechanisms operating in your local authority?

YES

NO

If YES, could you tell us which are the most important in your view and why this is the case?

.....
.....

D7. Do you have any other comments about Co-ordinated Support Plans?

.....
.....
.....
.....

SECTION E: AWARENESS OF CCNUK

E1. Have you heard of Care Coordination Network UK (CCNUK)?

- YES
- NO

E2. Are you familiar with the CCNUK Key Worker Standards?

- YES
- NO

E3. If you are familiar with the CCNUK Key Worker standards are you using them?

- YES
- NO

Please comment.....
.....

E4. Would you like to receive information about CCNUK?

- YES
- NO

E5. Would you be willing to participate in a telephone interview?

- YES
- NO

If YES, please give your name and contact details

.....

DATA PROTECTION

The information you have provided will be held on a data base within CCNUK and kept in accordance with the Data Protection Act 1998. Please tick the box if **you agree** to this information being shared with other organisations and individuals.

CCNUK produces a directory of schemes on its website. We would check details with schemes before inclusion. In principle, would you be prepared to discuss with us inclusion of details of this scheme in the directory?

- YES**, I would be prepared to discuss inclusion of details of this scheme in the CCNUK directory.
- NO**, I would not wish details of this scheme to be included in the directory.

Many thanks for your time in filling out this questionnaire. We will send you a copy of the report and you will be invited to the CCNUK Scotland seminar in June 2008 when the findings of the questionnaire will be presented. If you have any further questions please contact:

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Date of completion _____