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REPORT ON THE DEVELOPMENT OF CARE CO-ORDINATION SERVICES IN SCOTLAND

Richard Purves, Sheila Riddell, Elisabet Weedon
Centre for Research in Education Inclusion and Diversity,
University of Edinburgh

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Summary

The policy context

Parents of disabled children have responsibility for nurturing the disabled child, along with other family and employment responsibilities. Care co-ordination is based on the principle that establishing a workable network of services involving health, education and social work should not be their sole remit. 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 disputes over professional boundaries and funding. The principles of care co-ordination fit closely with the policy agenda set out 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. Close inter-agency working 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).

Funding for this small research study was provided by CCNUK, a voluntary organisation set up to promote care co-ordination and key working as a way of avoiding the dangers of service duplication. Service standards on care co-ordination have been developed by CCNUK and have been endorsed by Westminster and the Welsh Assembly, and recognised by the Scottish Government. This research up-dates 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 question

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

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

Research Methods

The research was carried out between September 2007 and May 2008. Research methods included a questionnaire survey administered to all thirty two Scottish local authorities and interviews with a small number of practitioners and parents.

Questionnaire survey: summary of key points

- Earlier research (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.

- 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 most schemes being initiated in 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 no particular strategies in place to make them accessible to ethnic minority groups. Three respondents said that interpreting services were made available.

- 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 schemes 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. The lack of ongoing training should be seen as a potential problem, since earlier research suggests that this is critical to long-term success.

- A range of professionals acted as key workers with social workers and community nurses mentioned most frequently. 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 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.

Practitioner interviews: **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, B and C were still lead by the agency which had taken the lead in their inception. In each case, relationships with other agencies were not without their difficulties.

- The aim in all three cases was 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 rehearse their child's needs.

- 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 over 400 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 dealt with children from birth to 5.

- Problems with care co-ordination schemes were attributed to parents' lack of understanding of the key worker's role, although this may not always have been clearly communicated.

- 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 adding this role on to 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 only one person in the team would be able to work 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.

Interviews with parents of disabled children: summary of key points

- Children in care co-ordination schemes have unique and complex needs and require intensive parental support. 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 challenges in communicating with education professionals since they sometimes found it difficult to deal with parents' questions. Another parent found it difficult to establish an emotional rapport with some health professionals.

- The parents found out about care co-ordination through a variety of sources. They 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.

Conclusion

Over a relatively short period of time, care co-ordination is moving 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. Ongoing challenges include the following: achieving joint ownership of care co-ordination schemes which cross professional boundaries; mainstreaming care co-ordination schemes without losing sight of the guiding principles and standards; fully involving parents and finding innovative ways of involving children and young people; consistency of access to care co-ordination services across Scotland; avoiding duplicated service planning mechanisms; the training and development of key workers.

References

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The research team

This research was conducted at the Centre for Research in Education Inclusion and Diversity, University of Edinburgh (www.creid.ed.ac.uk). Further information may be obtained from:

Professor Sheila Riddell, Centre for Research in Education and Diversity, The Moray House School of Education, University of Edinburgh, Simon Laurie House, Holyrood Road, Edinburgh, EH8 8AQ, sheila.riddell@ed.ac.uk

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