Care coordination and key worker services for disabled children in the UK

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Numerous research studies report that parents want a single point of contact with services and an effective, named person to get what they need for their child in terms of services. This has been recognized in policy for over 20 years – from the Court Report (1976) onwards. However, there is evidence that less than a third of families with severely disabled children have a 'key worker'. We report the results of a survey, carried out at the end of 2002, on the situation of care coordination for disabled children in the UK. The key findings were:

- Thirty-five local authority areas (22%) reported having a care coordination service. Fifty schemes were about to be developed over the coming year.
- The majority of the schemes had all three statutory agencies (Health, Education and Social Services) involved in setting up and overseeing the schemes. However, only eight schemes had all three agencies contributing joint funding.
- The majority of the schemes had parents involved in setting up and overseeing the schemes. However, the involvement of children and young people was less common.
- Only nine schemes had permanent funding. Eight had no dedicated funding. The majority had temporary funding, ranging from nine months to three years in duration.
- Thirty schemes provided key workers to families. Five had "designated" (i.e. full-time) key workers. Twenty-one had "non-designated" key workers, who co-ordinated care as a small part of their professional role. Three had both designated and non-designated key workers.
- Approximately half of the schemes had induction training for key workers in place and approximately two thirds had ongoing training for key workers.

Background

A key worker is a named person whom the family can approach for advice about, and practical help with, any problem related to the disabled child. The key worker has responsibility for collaborating with professionals from their own and other services and ensuring access to, coordination of, and delivery of services from the different agencies. Workers performing this role may come from a number of different agencies. Research has shown that families with a key worker service report better relationships with services, higher morale, and less isolation and feelings of burden. However, less than a third of families with a disabled child have a key worker. This study reports on the current situation of key worker services across the UK.

Findings

Response rate and number of care coordination schemes

Questionnaires were sent to 225 local authorities in the UK in October 2002. One hundred and fifty-nine questionnaires were returned (70%). Thirty-five areas reported having a care coordination service (22%). Thirty of these provided key workers to families. Of the five that did not, one scheme consisted only of a database containing information on families, which helped co-ordinate care; two schemes incorporated care co-ordination only in relation to initial planning meetings or reviews; two schemes had just started and they did not have key workers, but this was planned.

Twenty-six schemes were in England, five in Scotland, and four in Wales. No schemes were reported in Northern Ireland. Fifty areas were planning to develop a care co-ordination scheme within the next year.

Multi agency involvement

Health, social services and education were involved in setting up 28 schemes and overseeing 25 schemes, but the contribution of all three agencies to funding the schemes was more rare. Only eight schemes were funded by all three agencies.

Parent and child involvement

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

Funding

The majority of the schemes had temporary funding ranging from 9 months to 3 years in duration. Only 9 schemes had permanent funding.

In answer to questions about the use of Health Act 1999 Partnership Arrangements or Flexibility Funding provisions, one scheme reported use of both pooled budgets (i.e. where NHS and local authorities pool their funds to provide a service) and lead commissioning (i.e. where commissioning of a service is delegated to a single lead organisation). One scheme used lead commissioning by the Learning Disability Trust. Two schemes used integrated provision (i.e. health and social service staff are integrated into a single organisation). Sixteen used Department of Health Quality Protects (England)/Children First (Wales)/Changing Children's Service (Scotland) funds to support the scheme.

Eligibility for the service

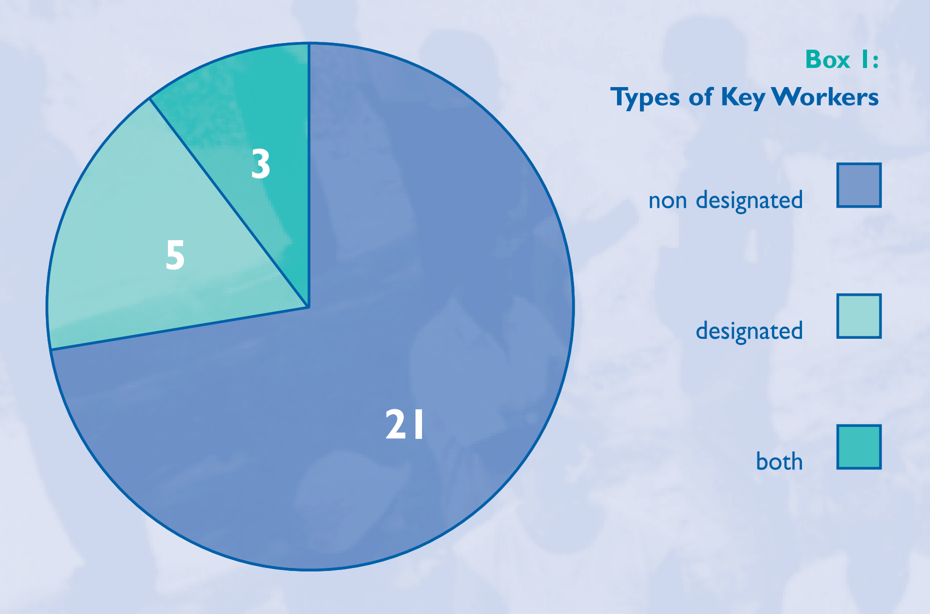
Most schemes reported that the eligibility criteria for children and families comprised having a child with complex needs, requiring the significant involvement of more than one or two agencies. Five schemes covered only children aged 0 to 5 years and four schemes covered children from 0 to 11 years. Three schemes covered the age group from 0 to 15 years and sixteen schemes 0 to 16+ years.

Planning and review meetings

Eighteen schemes held initial planning meetings between the family and all professionals involved in their care and 24 held regular review meetings.

The use of key workers

The main difference found in models of key working was between schemes with 'designated' key workers – those employed



Box 1: Types of Key Workers

specifically as full-time key workers, and ‘non-designated’ key workers – those who co-ordinate care for a few families as part of a larger caseload. The majority of schemes had non-designated key workers, who co-ordinated care for a few families as a small part of their ordinary professional role *(see Box 1)*. Five schemes had designated key workers and three schemes had both designated and non-designated key workers. One scheme did not provide information on the type of key worker.

Key worker training and supervision

Seventeen schemes provided special training for key workers on appointment. Twenty-one provided ongoing training for key workers. Five reported no training of either type.

In 12 schemes, key workers were supervised by the scheme manager; in 12, supervision was provided by line managers in the key workers’ own agencies; and in two no supervision was in place as yet. Four schemes did not provide information on supervision.

Key worker background

Fourteen schemes did not specify which professional backgrounds key workers came from. Professional backgrounds of key workers of the remaining schemes (n=16) included social workers, health visitors, community nurses, paediatricians, physiotherapists, speech therapists, occupational therapists, teachers, nursery nurses, psychologists and workers with voluntary agencies. The professionals most frequently taking the role of key worker were social workers and health visitors.

Key worker caseload

The median number of families per designated key worker was thirty. The median number of families per non-designated key worker was three.

Matching key workers and families

There was no main criterion common to all schemes for matching families and key workers. The match occurred according to a number of criteria, such as: asking families their personal preference, geographic location, caseload of the key worker, matching skills of the key worker to the needs of the families or a combination of these.

Implications

The picture of care co-ordination obtained from this survey is one of considerable diversity. However, there is much emerging from the results that can be recognized as good practice. For example, the majority of the care co-ordination schemes had all three statutory agencies involved in setting up and overseeing the scheme. This indicated a substantial commitment to promote and support multi-agency working. Furthermore, parents were often involved in setting up and overseeing the schemes, suggesting that the intention to increase user involvement and participation in decision-making is being put into practice. However, other aspects that have been suggested as good practice were less common and key recommendations for policy and practice can be made in the following areas:

- Children and young people were rarely involved in setting up or overseeing the schemes. Children’s views are different from adults’ and they have valuable and useful ideas. The results of this study show that more effort could be expended in ensuring that children and young people's views are heard.

- It was evident that, although agencies were jointly setting up and overseeing the schemes, joint funding from all three statutory agencies was still rare. In addition, short-term funding for many of the schemes is a concern. Further investigation is needed of the barriers to using joint funding in children's services.

- The extent of training received by the key workers varied greatly across the sites, and some of the schemes provided no training. The likely consequences of a lack of training are that key workers will not understand their new professional role and will not be able to provide families with the type of support they are expected to offer. More effort is needed in ensuring that key workers are receiving appropriate training.

- The survey results indicate that coverage of key worker schemes is patchy and under-developed, confirming earlier research findings from surveys of parents that less than a third of families with severely disabled children have a key worker. However, the finding that a further 50 areas are intending to implement such schemes in the near future is heartening.

Methods

The survey questionnaire was piloted with three managers of care co-ordination schemes. Following telephone calls to identify appropriate managers with knowledge of care coordination in their locality, in October 2002, questionnaires were sent to 225 Local Authority Children with Disabilities Teams across the UK.

Questionnaires were returned over October, November, and December 2002. Attempts were made to ensure a high response rate by means of reminders.

Topics covered in the questionnaire were: multi-agency involvement in setting up, overseeing, and funding the schemes, duration of the schemes, eligibility criteria for the service, age groups of the children, provision of key workers, models of key working, staff undertaking the role of key worker, key worker case loads, and supervision and training of key workers. Results were analysed using SPSS.

References

Department of Health and Social Security (1976) *Fit for the Future: Court Committee Report on Child Health Services*. HMSO, London.

Care Co-ordination Network UK (CCNUK)

Care Co-ordination Network UK (CCNUK) is an umbrella organisation promoting and supporting care co-ordination or key working for disabled children and their families in England, Northern Ireland, Scotland and Wales. CCNUK is an independent registered charity based at the Social Policy Research Unit, University of York.

For more information ring **01904 321959** or email **rh25@york.ac.uk** or visit **www.ccnuk.org.uk**

Further information

The survey was carried out in collaboration with Care Coordination Network UK (CCNUK). The research is funded by the Department of Health, the Department for Education and Skills, HM Treasury, and the Welsh Assembly. The next stage of the study includes case studies comparing costs and outcomes of these different types of key worker schemes.

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