

A review of key worker systems for children with disabilities and development of information guides for parents, children and professionals - Summary

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Background Information

Theme: Disability
Region/Nation: Wales / Cymru
Commissioned by: Welsh Office for Research and Development (WORD)
Carried out in collaboration with: Welsh Centre for Learning Disabilities

Objectives of work

To identify the main issues arising from the literature, in terms of:

- Managing key worker systems
- The key worker's role
- Families' needs and requirements for a successful service

Methodology

- Searches were made on Datastar, ChildData, CommunityWise and CareData. Keywords used were *key worker* (together and with truncation) in combination with *children*, *disability*, *case co-ordination* and *multi-agency*. Hand searches were carried out in appropriate libraries.
- Contact was made with UK sources where relevant work was being conducted, or recently completed.
- An advisory group comprising people from health, education, social care and voluntary fields guided the review.
- Information guides were drafted based on the review.

Synopsis of findings

1. The main function of key worker systems is to enable professionals to respond flexibly to parents' and children's needs, rather than focusing on the needs of services.

2. If a key worker system is in place, the overall quality of life of families with disabled children is improved.
3. Specific outcomes are better relationships with services, better and quicker access to statutory and discretionary benefits (both financial and environmental) and reduced levels of stress.
4. Families with disabled children identify a lack of money as their greatest overall concern. They believe that key worker systems can have an impact on this and there is some supporting evidence.
5. Good personal relationships between key workers and parents are reported as an important factor by parents, and of value in itself.
6. There is no evidence that key worker systems result in variations in quality of medical or para-medical care.
7. Key workers report a high degree of satisfaction with the role, even when organisational difficulties have been encountered, and believe that it makes a positive difference to the lives of both children and parents.
8. While a key worker in the role of an independent advocate can be effective, a key worker who works for a service appears more able to exercise the degree of leverage necessary to meet families' needs.
9. Organisational obstacles are seen by many agencies as greater than the perceived benefits of the model – restricting its use.
10. The key worker model is available to only one third of families with disabled children.
11. Statutory services are often of high quality, but a consistent finding is lack of flexibility and poor co-ordination between agencies. Key working aims to overcome this.
12. Due to their wide reaching base, key worker systems are vulnerable to wasting away. The following core requirements guard against this: a multi-agency steering group and supporters at a senior level, dedicated administrative support and both individual and joint training.
13. While reports are continually positive, robust studies of key worker systems are lacking.
14. The focus of the literature is on parental needs and we can not assume that the needs of children will in all cases be congruent with these.

Key messages

1. Current research strongly supports the key worker approach. Services should take this on board and offer all families with disabled children the *opportunity* to access such a system.
2. When establishing a system a clear model is needed, including mechanisms to identify and allow change.

3. During the key worker appointment process certain personal characteristics should be considered due to the particular emotional and practical relationship required with the family.

Next steps

1. To finalise information guides and distribute to a wider audience.
2. To participate in a Children's Services conference in collaboration with The Health and Social Care Research Support Unit for South-East Wales.
3. To disseminate the findings via papers for journals, research summaries and guides for local / national organisations for carers and professionals and statutory organisations.

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