Book review

Making a difference?: exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them

Ruth Townsley, David Abbott and Debby Watson
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Developments in medical technology mean that many disabled children now have complex healthcare needs, on top of the social, financial and emotional stresses that commonly accompany childhood disability. Parents, siblings and children themselves struggle to experience a normal family life whilst time-consuming and sometimes distressing medical and therapeutic routines are regularly carried out in the home. Social support, advice, information and regular breaks from the routines of care are vitally important. However, this help (when it is available) is usually fragmented between different services and professionals—health, education, social welfare and so on. For some families, accessing and co-ordinating these different sources of help are major tasks and additional sources of stress.

There is an extensive body of research in England on the needs of families with disabled children for better co-ordinated services and in response multi-agency collaborative projects have been established in many localities. These bring together services such as health, social services and education and aim to facilitate closer working between the various professionals and services involved. Many projects also provide the organisational base for the employment of ‘key workers’—designated professionals who provide a first point of contact for families and who access services from a wide range of statutory, voluntary and other sources [1]. In England, it is now possible for multi-agency partnerships to become fully integrated, sharing a single pooled budget and with all professional staff under a single employer.

This well-structured and clearly written study investigated the impact of multi-agency services on the professionals involved and the families and children with whom they worked. For advocates of ‘evidence-based’ policy and practice, it provides helpful guidance on the pitfalls and problems involved in establishing and sustaining effective joint working. Although the study reports on services in England, its conclusions have much wider relevance, not just for other countries, but for services aimed at other groups of people with highly complex conditions and their families. Above all, the study indicates that significant developments in multi-agency working are still required before parents and children themselves experience well co-ordinated services that address many of their own perceived priorities.

The study is based on six case studies of local projects that were established to improve the co-ordination of services to families with disabled children. Although the projects had different objectives and organisational frameworks, there is no indication of how these were selected or how representative they may be of the full range of multi-agency projects nationally. An important next step for research in this area would be to develop a typology of different organisational arrangements and to identify systematically the strengths and weaknesses of each.

Nevertheless, the study identifies some clear themes that all service developments in this area should take into account. First, the impact of multi-agency working was far more marked on professionals than for the families themselves. Whereas professionals were able clearly to identify the gains for their own professional practice and job satisfaction of working more closely with other professionals and agencies, the benefits for families were somewhat more equivocal, particularly in respect of assessment and review processes and the co-ordination of services. Moreover, there was little evidence in half the projects evaluated of any consultation with, and the on-going involvement of, parents. While families reported some benefits in improving access to services, particularly home-based support and equipment for their child, they continued to face a much wider range of restrictions relating to transport, leisure activities, home adaptations, sleep problems and help to enable them to do things together as a family. Even more significantly, all the projects lacked any systematic involvement of children themselves and this was reflected in the frequent failure to address children’s own priorities for help with communication, independence, friendships, recreation and leisure.

A second issue is the financial and organisational vulnerability of the projects studied; they were established without additional resources, including resources to support new keyworker roles. Budget
constraints meant continuing tight eligibility criteria for services and these constraints limited attempts to improve service co-ordination. Moreover, some projects had only short-term funding and this restricted staff training and organisational development opportunities. A common pattern was for a senior manager to ‘champion’ the establishment of a local multi-agency project. However, this was no substitute for the full, continuing and equal commitment of senior staff from all the agencies involved, otherwise front-line key workers had had insufficient leverage over resources and service allocation processes.

Finally, the study clearly identifies some common pitfalls. Multi-agency projects need to be fully integrated with other formal processes and activities, particularly those like ‘statements’ of special educational needs that affect a wider group of children. Indeed, the study found many projects experienced continuing communication difficulties with education services and hospital staff. Above all, multi-agency projects need to give more attention to the voices of parents and children themselves, both collectively and individually, to ensure that their priorities and needs are addressed, rather than those of service agencies and professionals. Only then it may be possible for research to identify the impacts of multi-agency working on families and children themselves as well as on professionals.

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Reference

1. Greco V, Sloper P, Webb R, Beecham J. An exploration of different models of multi-agency partnerships in key worker services for disabled children: effectiveness and costs. London: Department for Education and Skills; 2005.