



Norah Fry
Research Centre

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



Disabled children with complex health care needs routinely require support from a wide range of professionals. Many services have been established throughout the UK that aim to implement better joint working between agencies and professionals. The Family Fund in collaboration with the Norah Fry Research Centre wanted to explore what impact multi-agency services had on the lives of this group of children, their families and the professionals that support them. Working closely with six multi-agency services the researchers found that:

- The six multi-agency services included in this research were providing effective, focussed support to families in terms of managing their children's complex health care needs at home. All except one of the children included in this study were living at home, and all those who were of school age were attending a local school or nursery on a regular basis. These findings appear to indicate that multi-agency working is making a significant difference to this group of children, who in previous research, were shown to face barriers to being at home and accessing education.
- The professionals interviewed for the research were extremely positive about the process and outcomes of multi-agency working for them. They reported improvements to the quality of their working lives and to their relationships with other professionals, agencies and families.
- Two thirds of the 25 families included in this study reported that the multi-agency service had made a positive difference to their lives. There was some evidence that having a keyworker had a beneficial impact on families access to services and their perception of overall quality of life. However, many families reported that social and emotional issues, as well as some practical issues around funding and equipment, were still enormously problematic.
- Many of the 18 children who took part in the study were still experiencing multiple barriers to exercising some basic human rights. These included areas of their lives such as communication, independence, friendships, relationships, leisure and recreational activities.
- Overall, the six services had worked hard to put in place structures to facilitate the process of multi-agency working. Less attention had been paid to the outcomes of multi-agency working for disabled children and their families.

How to get further information

'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', by Ruth Townsley, David Abbott and Debby Watson is published by The Policy Press.

It is available from
Marston Book Services,
PO Box 269, Abingdon,
Oxon OX14 4YN,
Tel 01235 465500

For more information
about the Family Fund
visit

www.familyfund.org.uk

The Norah Fry Research
Centre is part of the
University of Bristol.
To find out more about
the work of the Centre
visit

www.bris.ac.uk/Depts/NorahFry/

Introduction

Almost thirty years of research has consistently shown that families with disabled children would prefer the many agencies that they encounter to work together more effectively. Since 1997, a strong policy emphasis on the importance of 'joined-up' working has promoted the benefits of partnerships. In response, many projects and services have been established throughout the UK that aim to implement better joint work whilst improving quality of life for this group of children and their families. There is, however, a notable lack of information about the nature of multi-agency services for children with complex health care needs. And, crucially, the impact that these partnerships have on families and children.

About the study

The research outlined here was the result of a study conducted by a research team from the Norah Fry Research Centre, University of Bristol, and the Family Fund. The study took place between 2000 and 2003 and was funded by the Community Fund.

The project aimed to explore the experience of multi-agency working for:

- Disabled children with complex health care needs
- Their families
- The professionals who support them.

To achieve this the research was divided into three parts:

- 1) An exploratory phase to determine the extent of multi-agency working for disabled children with complex health care needs in the UK.
- 2) Visits to 26 services to collect data about their work.
- 3) Case study visits involving six of the services across the UK (3 in England; 1 in Wales; 1 in Scotland; and, 1 in Northern Ireland). At each service interviews were conducted with professionals (115 in total), families (25) and children/young people (18) involved in the multi-agency service.

The six services: different types of multi-agency working in services to disabled children with complex health care needs

Each service had a different model for working with families and had approached the development and provision of its multi-agency services in a range of ways. For example, each of the services had different arrangements for defining and organising the resources needed to work together. In five of the six services, one sole agency was taking a lead role (at strategic level), in terms of funding or management. At an operational level, partnerships were fulfilled by financial contributions to care packages for individual children, and/or by staff from different agencies donating a proportion of their time to the multi-agency service. Only one of the six sites had established a truly multi-agency approach to resource sharing at both strategic and operational level.

The nature of services provided to families included co-ordinating administration and/or services and support, and providing services and support. All of the six sites were acting as points of co-ordination for administration or indirect elements of care provision. In addition four of the sites were also trying to co-ordinate the actual services and support offered to families through the provision of a named person (known variously as a key worker, link worker or service co-ordinator).

There were different levels of understanding and commitment to the aims of each of the multi-agency services. Across all the sites there was little evidence of Black and minority ethnic families accessing the multi-agency services.

The impact of multi-agency working on professionals and agencies

Working with families as part of a multi-agency team was said by professionals to be enjoyable and rewarding. They said that they had better relationships with parents and could be more effective in supporting them. Working in multi-agency services provided professionals with enhanced opportunities for personal and professional development. Staff said that they had greater insight into the work cultures of other agencies and felt enabled to look jointly at common issues.

Professionals involved in joint work reported clearer and more efficient channels of communication. However, some problems remained due to different statutory frameworks, incompatible IT systems, and a lack of commitment from some agencies and individuals.

Overall, professionals were almost unanimous in their belief that the multi-agency services they worked in were making a positive difference to the lives of families. However, relationships between staff and families were problematic in the areas of advocacy and scarce/limited resources.

The impact of multi-agency working on families

Multi-agency services appeared to be providing effective, focussed support to families in terms of managing their children's complex health care needs at home. Nearly two-thirds of the families we interviewed reported that the multi-agency service had made a positive difference to the overall quality of their lives. However, many of the families still had difficulties with daily routines, particularly sleeping.

Of those children who were of school age, all were attending a local school or nursery on a regular basis, and families expressed a high degree of satisfaction with the support and educational input their children received.

Very few families had received a co-ordinated response from the multi-agency service in relation to physically adapting their homes, even where there was evidence of access to a named person or co-ordinator.

Three quarters of the families we interviewed had a gross family income that was below the national average. General help from multi-agency services with financial management was often absent.

The families we interviewed all experienced major difficulties in finding and organising social activities for themselves and for their disabled children. The shortage of flexible, adequate and appropriate sitting or short breaks services was thought to be responsible for this. Most families had a very strong desire to do things together and to be perceived as a whole family. Multi-agency services did not appear to be able to respond to this and the focus of support was very much on the disabled child with complex health care needs, to the detriment of the family unit as a whole.

Families reported numerous sources of emotional pressure some of which were directly related to a lack of co-ordinated and flexible support from the multi-agency

services. A large proportion of families felt they had no one outside the immediate family unit to turn to for emotional support. However, nearly half of the families we spoke to felt confident that they could get this support from the multi-agency service if they so wished and where this was offered it was highly valued by families. Children with complex health care needs were not given access to emotional support, despite a need for this being apparent.

Over half of the families we interviewed had access to a named person, or key worker, with a specific remit to co-ordinate services for them. Despite this, there was a distinct lack of clarity regarding the role of this person, and only six out of 25 families felt that the key worker or multi-agency service did actually co-ordinate services for them. Many of the families we interviewed were still experiencing multiple assessments and reviews. Families did not appear to have access to regular reviews of their needs or to have a clear picture of their entitlements.

The views of disabled children and young people with complex health care needs

The vast majority of children and young people we spent time with had close, but extremely dependent relationships with their parents or carers. Very few children could spend time alone with friends, or begin to develop some independence away from close family members.

The children and young people we spent time with had limited opportunities for developing friendships and relationships, although children with verbal communication were more likely to have significant friendships, underlining the importance of support for communication. It was also clear that this group of young people wanted to do the sorts of 'ordinary' things that all children do, not necessarily activities that were 'specially designed' for them.

There was little evidence of effective consultation between the multi-agency services and disabled children with complex health care needs about their care and support. Even where families had access to a key worker, we did not get a strong sense that there were many primary relationships between this person and the children themselves. Some children were unaware of the identity of their key worker even when named and described.

Conclusions: Multi-agency working for disabled children with complex health care needs and their families – has it made a difference?

In a relatively short time-span, the multi-agency services, which were part of this study, had brought about significant changes for families and children in terms of better support for children's complex health care needs at home and improved access to education. What appeared to be missing, however, was a wider appreciation of what still needs to be achieved in terms of social and emotional support for families, and in terms of facilitating basic human rights for children and young people. The project team recommends that multi-agency services build upon their important work on the structure and process of multi-agency working, and develop an increased appreciation of impact and outcomes for families. Professionals are aware that multi-agency working has had a positive impact on their quality of life. Now it's time to focus attention on using the process of multi-agency working to achieve a better quality of life for disabled children with complex health care needs and their families.