

Supporting families with two or more disabled children

Around 7,500 families in the UK have two or more children with severe impairments, representing well over 15,000 children. The particular experiences, needs and circumstances of these families have generally been overlooked by research and social services. A detailed qualitative study involving 24 families explored their ways of managing from day-to-day and identified the types of service support that were most helpful to them. The research was conducted by Rosemary Tozer (University of York) with Robina Shah. The research found that:

- f Meeting the needs of two or more children with severe impairments simultaneously presented major difficulties for families and meant that the availability of two carers was crucial, especially at busy family times such as before and after school.**
- f The importance of having two carers meant that few parents were in a position to work, even though almost all said they would have liked to do so.**
- f The failure of benefits agencies to recognise the *cumulative* impact of having two or more severely disabled children meant that financial support was far from adequate for most of these families, who relied on state benefits.**
- f The *whole* family was involved in providing care and support – including disabled children and their non-disabled siblings; and the *whole* family was affected by restrictions on their lives and by feelings of isolation.**
- f The families valued support that was flexible, was designed around family routines and crises, met the whole family's needs and provided opportunities for a complete break.**
- f Co-ordinated support and inter-agency working seldom happened even though families saw it as vital. Families were often in touch with many different agencies and professionals for each child (especially where children had different impairments).**

Introduction

Around 17,000 families in the UK have more than one disabled child. Up to 7,500 of these families have two or more children with a severe impairment. Their numbers were estimated for the first time in the first stage of this project and comparisons made with families with one disabled child. This found that families with two or more severely disabled children were more likely to be disadvantaged through not working and reliance on benefits, with greater incidence of lone parenthood and parental ill health or impairment (See *Findings 218: The numbers and characteristics of families with more than one disabled child*). The second stage of the project set out to investigate the situation of these families more fully, to find out the particular difficulties they are likely to face, and to identify how service agencies can provide appropriate support.

Restricted family lives

Despite the rewards of caring for their children, many parents reported feelings of being different and isolated. There were limited opportunities for family members to get out and socialise. Few knew other families with more than one disabled child. Most found it difficult to attend support groups because they were very busy or could not find sitters to stay with their children.

Apart from school and occasional short-term care, the disabled children in this study had few opportunities to go out except with their family. Even these family outings were restricted by lack of suitable transport, the inaccessibility of leisure facilities, and negative public attitudes. Public curiosity, even hostility, when out and about (including in their own neighbourhood) increased families' feelings of being excluded from mainstream life.

Employment and income

In only one-third of families was either parent in paid employment. Only one mother worked (and this was part-time). Yet virtually all parents said they would like to work. For most families, this was not possible due to the need for two carers to manage the simultaneous demands and support needs of their children. Any work would need to fit around school hours and the demands associated with the children's impairments. Further, loss of benefits meant low-paid work was not financially worthwhile. In some families, fathers or step-fathers had given up work to meet the family's requirements for extra care provision.

The experience of those parents who did manage to work pointed to the importance of flexible working arrangements and benefits structures, increased childcare and help at home.

Many of the families relied on benefits. However, benefits were felt to be inadequate given the high extra

costs associated with having two or more children with severe impairments. A particular problem arose wherever need assessments for benefits failed to take account of the cumulative financial impact of this on the family.

A family enterprise

"I look after Farouk. I accompany him to the shops, help with picking things up ... I help Farouk and he helps me with my homework."

"Before Alex was ill last year, he used to look after Chris all the time. If they took Chris to the nurse at school, Alex used to go down in his electric wheelchair and say 'What are you doing? Write it down to tell my mum'."

The care of the disabled children and the extra tasks generated involved everyone at home. In some families, this included siblings, parents/step-parents and grandparents. In other families, levels of family support were much lower – for example, where there was a lone parent or where grandparents were unable or unwilling to help. The contribution of disabled and non-disabled siblings was an important part of managing from day to day, even though professionals seldom recognised or actively supported this. Likewise, the importance of the emotional relationship between the disabled children was frequently overlooked.

More than double

A key problem for most families was trying to supervise and meet the needs of two or more children with severe impairments at the same time while providing individual attention. This was harder if children didn't get on, liked different things or had different impairments which meant that some of their needs for companionship could not be met by each other. In some families, parents had to keep children apart because they might be of risk to each other.

Ordinary household tasks increased, and activities like going shopping took more time and careful planning. However, only one of the 24 families in the study was currently getting any help from social services that included housework. A few families who could afford it employed someone to help clean or do the ironing.

Families usually managed by having tight routines and clear divisions of labour. This was most important at the busiest times, when two carers were essential, as this mother explained:

"Then I dress Kerry and Josh and you dress Sam, don't you, and see to him. And then I get the breakfasts ready. Then Keith sits and feeds them while I'm getting the coats out, shoes out, or whatever, and bringing [Sam's] buggy down ... and making sure their

bags are packed with the things they'll need for school. You know one's doing one thing whilst the other's doing another. And then when the bus pulls off we have a coffee and say, 'Morning!'

Unexpected events, emergencies, one carer falling ill, or changes related to the children's impairments could throw everything off balance. Despite the suitability for these families of support which provided an 'extra pair of hands' at home or for outings, only three families were receiving help of this kind, and this was very limited in terms of hours and scope.

Getting a break

Most of the families in the study had access to some sort of short-term break (respite or 'shared care'). However, none of the six Pakistani families involved in this study were receiving this kind of support.

Short-term breaks were usually provided in a residential unit or with another family or, occasionally, through carers coming to the family's home.

Only three sibling pairs who were close in age and had the same impairments had short breaks at the same-time. Most of the families who used short-term care never had a complete break from caring outside school hours. It was difficult to arrange things so that the breaks offered by different providers to different children in the same family coincided.

"One's away, one's back at home. So you're only getting half a break."

Those families able to access a children's hospice were the most satisfied, even though this was generally only available twice a year. Key factors were that the whole family was included, there was a positive attitude towards the children and parents had a choice in how much they cared for their children while staying in the hospice.

Those children who indicated their wishes about getting a break wanted more opportunities for accessible leisure activities. Most children, especially those with high support needs, had no such opportunities. In a few families, the services of a support worker enabled children to participate in mainstream activities, but examples like this were scarce.

The importance of suitable housing

It was not unusual for families to spend a lot of time together, due to the restrictions of low incomes, lack of accessible leisure, transport etc. This added to the importance of suitable housing and equipment. Suitably adapted housing made an enormous difference to what children could do in their home. This in turn reduced the physical and emotional stress for the family as a whole.

Problems arose where changes were made that suited one child but not another or where adaptations had not taken account of children's changing and future needs. Adaptations were complicated and costly. Considerable delays in some cases meant that the needs of children had still not been met by the time they were teenagers.

The service jigsaw

Families preferred to deal with one or two key professionals whom they trusted, who understood the family's total situation, and who could negotiate on the family's behalf to put in place the particular care package that the family required. This was crucial, since these families were likely to be in touch with a large number of different professionals, especially where children had different conditions.

The lack of key professionals who could co-ordinate services meant that busy parents had to negotiate on several fronts at once with a range of professionals and agencies. One community nurse explained:

"The other thing is the need for input from all areas. It should be smooth. They [families] shouldn't have to fight for everything – but they have to. And it's harder to battle for two than it is for one."

Several professionals also recognised the need for a more co-ordinated and thereby effective service to families. They indicated that more support and resources were needed for professionals in this role.

Review procedures did not always look at the whole family's circumstances, the support received and the support required. The more usual practice of holding separate meetings about individual children could make it harder to identify gaps in support to the family and could also overlook the way that different services to different children might impact on each other.

What families value in services

The lack of recognition of the *particular and cumulative* difficulties faced by families with more than one disabled child meant that services were often inadequate (even when valued) and sometimes unhelpful. It appears that services have generally been designed on the assumption that families have only one disabled child.

The families in this study highlighted several things they felt professionals (policy-makers, service planners and providers) should know:

- Families value all of their children and want professionals to do the same.
- Having disabled children also brings rewards. Through family placement, some parents had 'created' a family with 2 or more disabled children.

- Attitudes of professionals, availability of information and appropriateness of support from the time that children are diagnosed as having an impairment can have a major impact on the family.
- Managing *simultaneous* demands is a key issue, and is made more difficult by unsuitable housing, lack of transport, low incomes, restricted opportunities to access leisure and get paid work, the need for two carers, and the number of different professionals and agencies involved in the family's life.

While recognising that many services were currently overstretched and under-resourced, families also had clear ideas about what they valued from the services they received, or what they would like to see put in place. This included:

- A whole-family approach to assessing and reviewing support needs
- Service providers who are positive about disabled children
- A key professional who negotiates on the family's behalf
- Co-ordinated care packages
- Co-ordinated appointments and visits
- Flexible support
- Reliable support
- Support at the busiest times of the family day
- Support that fits around family routines
- Contingency plans to provide support in emergencies
- Help at home with childcare and/or household tasks
- More options to access leisure and short breaks which allow both individual time with children and a complete break.

Conclusions

Families with two or more severely disabled children lead busy and complicated lives. Delivering services to these families is bound to be more complex. The wishes and feelings of individual children need to be ascertained and located within a whole-family approach to providing support. These families are likely to need both more support and more flexible support than families with one disabled child. The timing of support is crucial to its effectiveness.

About the study

Twenty-four families in the north of England took part, including 6 from south Asian communities and 2 adoptive families. Variation on several dimensions

was included in the sample: family composition, socio-economic circumstances, area of residence, ages, gender and impairments of children. Six families had 3 or more disabled children. Families were visited on three occasions on average, and research methods were used that suited all family members, including the disabled children. Reference groups of parents and different professionals also contributed.

How to get further information

The full report, **At the double: Supporting families with two or more severely disabled children** by Rosemary Tozer (ISBN 1 900990 53 9, price £10.95 for non-members, £7.95 for NCB members).