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Caring for a severely disabled child

Research on families caring for a disabled child often describes only the stresses of care and their adverse effect on family welfare. Whilst acknowledging the numerous stresses parents face, research by Bryony Beresford at the Social Policy Research Unit, University of York, sought to understand what keeps parents going. The ways parents deal with stress, the importance of the parent-child relationship and the role of services were explored.

- f** First and foremost, parents thought of themselves as parents. Most rejected the notion of being a carer.
- f** The pleasure and satisfaction gained through the relationship with the disabled child was the fundamental reason why parents felt able to continue to care for their child.
- f** Most parents found the stresses associated with the care of their disabled child to be wide-ranging, unrelenting and sometimes overwhelming.
- f** Parents actively sought to deal with these stresses, using a range of strategies to overcome or manage the problems and difficulties they encountered.
- f** Parents valued services which allowed them to retain the normality of family life, and were reluctant to use services which seemed to disrupt this.
- f** Support from informal and formal sources, money, practical resources and personal qualities were important in helping parents cope. However, if parents felt that services provided for their child were inadequate or unsatisfactory, this could be a major source of stress.
- f** Other aspects of the parents' lives were sometimes more stressful than having a disabled child.

A new perspective

Unlike other work looking at families caring for a severely disabled child this research sought to examine the positive aspects, viewing parents as actively managing their situation rather than being passive recipients of an onslaught of stress. In addition, the study explored how the parent-child relationship might make this particular form of caring different to others.

Parents or carers?

First and foremost parents regarded themselves as parents. Fundamentally, feelings of love and responsibility motivated parents to continue to care for their child.

She was our baby. She was our first. To us, whether there was something wrong or not, she was still a baby. She still needed us, and so we just got on with it.

Equally important were the pleasures and joys their child had brought them. These differed little from those experienced with non-disabled children, though achievements and signs of progress were even more precious.

As soon as you see her smile everything that you felt you were going to give up all just goes out of the window. As soon as she smiles you know she's happy.

Parents felt the parent-child relationship made their situation very different to that of other 'carers'.

I think it's different if you've taken on an elderly parent which isn't something you have to do, or if your spouse has become disabled then you're obviously thrust into a situation you never anticipated. But as parents you've committed yourself to care for your children for as long as they need it really.

The study suggests, however, that as the child grows older, parents do feel they assume the dual role of parent and carer. Two parents had recently come to feel this. Both had older children with severe complex disabilities.

I see myself as a carer as well as a parent. I think Lisa goes beyond the role of just parent. I think basically that you're changing her bum for her at this age now and having to put nappies on her end, and it is past just being a parent.

Sources of stress

The most stressful aspect for many was the lack of respite from problems which are likely to continue into the foreseeable future.

Nothing stops does it? You just carry on because they're there ... so you have to. There's nothing else to do.

However, for some parents, not having enough money, marital conflict, recent bereavement or simply having two or more very young children were greater sources of stress than the child's disability.

Ways of coping

Parents employed an enormous variety of strategies - and considerable creativity - to deal with the problems and difficulties they encountered. There were some common approaches, but parents used the strategies they found worked best for them.

Informal support

Parents frequently made use of informal support, but often found these resources become overtaxed. For example, emotional and practical support from family and friends dwindled over time.

We have had a lot of support from family but it's dropping off rapidly. People are very concerned, but they're concerned for a short time only. I think for them the problem's becoming quite boring and they don't want to listen any more.

Managing behaviour problems

For many parents managing behaviour problems was one of the most difficult aspects of caring for their child, causing considerable emotional distress or frustration as well as creating immediate practical problems. In some cases parents had learnt how to pre-empt difficult behaviour, watching for signs of frustration or distress which might be diffused by giving the child a small treat. Others sought to modify behaviour by withholding treats. Many parents sought to lessen their own emotional stress by trying to understand the child's perspective.

Problem-solving

Parents' ways of dealing with specific problems depended on their own situation and feelings. For example, if people stared at their child, some parents simply chose to ignore it, others would go over and explain about the child's condition.

Managing to fit in housework was a common problem. Some used disability benefits to buy in help, some chose to have a big clear-up once a day, or

waited until they knew the child was engrossed in something before doing housework. Parents also organised the family's life to make it easier to cope with any special needs; for example, all the family followed the low-fat diet prescribed for one child to avoid having to prepare two meals. Some avoided certain situations, for example, one parent, troubled by the way her child tried to pull his hair out when cross, responded by cutting his hair very short.

Information-seeking

Parents fell into two distinct groups: those who were satisfied with information provided by medical staff and other parents and those who actively sought information from other sources. Many of the latter found collecting information about their child's condition was an important aspect of coping with emotional distress and also put them in a better position to demand the level of services to which their child was entitled.

'Self-maintenance'

Parents used various ways to 'recharge' themselves. This could range from allowing themselves a good cry every now and then, talking to friends, and allowing themselves small treats.

But do you know what keeps me going? It's at the end of the day when she's out of the way, if I can watch News at Ten and have a cup of tea then the day's been worth it, no matter what day I've had.

Many parents emphasised the importance of having some interest not related to the care of their child.

Approaches to life

Virtually all parents spoke of learning to take life one day at a time. Most also felt that dwelling on present or future difficulties was not helpful, although this was not always easy:

The fact that she doesn't chew, that really grinds at me while I'm feeding her because I know she loves her food. I find myself thinking that she's never going to sit down and enjoy a meal like we do. All this goes through my mind while I'm feeding her. So I do have the telly on, and I try and switch off, I just gaze at the telly so that my mind's elsewhere.

Commonly, however, when parents felt depressed or over-burdened they compared their circumstances with others they perceived as more badly off. It was not unusual for a parent to say 'I'm lucky; or 'we're fortunate that...'

I get fed up the same as other people but I snap out of it. Because I consider myself to be better off than some people and luckier in a way as well.

The kinds of help parents wanted

Not regarding themselves as carers, most parents found it difficult to seek formal help with what they saw as essentially parenting as opposed to caring tasks.

I don't want him in respite care or anything like that because he's my son, he's my responsibility. I don't believe in shoving him off.

Parents would not use respite care unless they were satisfied about their child's welfare.

She did go once or twice to the respite care centre at school but she used to come home very disturbed and unhappy from that.

As well as meeting the child's medical and educational needs, parents wanted help from services that would ensure they would continue to enjoy the pleasures of parenthood.

You should get more back-up with help so that you're not doing so much of the caring and so you do more of the parenting. Because I can see ... the point where somebody could come to resent the child because they're having to do all that.

Where a problem seemed intractable, such as sleeping and behaviour difficulties, parents sought professional advice.

Feelings about needing help

Seeking or receiving formal help was often seen as stigmatising. Lack of awareness of the role or function of a particular professional contributed to this.

I tend not to be involved with social workers 'cos all you hear is bad stories ... you hear that they're ready to drag your kids out of the door.

In addition, parents felt they had failed in some way if they used respite care services.

It makes you feel like you're giving up. You feel like you're giving up on your own child.

Achieving some degree of 'normality' in their family's life was very important. Parents were reluctant to use services at the cost of losing this sense of normality.

If someone came in and helped to put him to bed then that wouldn't be normal. We cope on our own. That's how we keep it sort of normal.

Help or hindrance?

Feeling that services for the child are inadequate or unsatisfactory was a major source of stress for parents. Particular problems included lack of information, slow responses, inadequate or inappropriate services, and encounters with professionals.

Many parents felt that information about the various services and benefits available was difficult to obtain.

It's up to you to chase them because they're not going to offer it to you. You don't get the information sent to you. You have to go out and dig for it.

Delays in formal agencies' ability to respond could thwart parents' efforts to plan ahead. For example, some parents were concerned about how they would manage when their child got heavier. But delays following formal applications to social services meant that they ended up having to cope for considerable periods without the necessary aids or adaptations, and to the detriment of their physical health.

Parents sometimes found that inflexibility about when support could be offered and the type of assistance available did not complement the ways they had chosen to cope. One parent wanted help with housework but was only offered relief from care tasks.

They'll send someone round to bath her or dress her, but there's no point in that 'cos my husband's here when I'm doing that.

Conflict with service providers was one of the greatest sources of stress for some parents.

The education authority are the worst. They're obstructive. They're not only unco-operative, they're positively obstructive.

However, some parents had a good relationship with formal support, feeling they were working in partnership with services. Such relationships could also meet some of the parents' own emotional needs, leaving them feeling supported in caring for their child.

Because if they can be bothered to care like that then so can we.

About the study

Twenty parents living throughout England and Wales were interviewed in-depth on two occasions, with four to five months between visits. All were caring for a severely disabled child between the ages of two and ten (including children with physical impairments, learning difficulties and social and communication problems). Lone parents and parents from minority groups were represented, as was a range of living circumstances. Parents were recruited through a screening and selection process using the Family Fund as the sampling pool.

The study was part of a two-year project about how families cope with the care of a severely disabled child forming part of a joint Joseph Rowntree Foundation and Economic and Social Research Council initiative entitled 'The Management of Personal Welfare'.

Further information

For further information about this project contact Bryony Beresford at the Social Policy Research Unit, University of York, Heslington, York YO1 5DD, Telephone: 0904 433608.

A full report **Positively Parents: Caring for a Severely Disabled Child**, is available from HMSO (ISBN 0 11 701837 6, £12.50). Second book based on the study, *Taking Care* by Alison Cowen, provides advice and information for the parents of disabled children. It is available from Alison Cowen, The Family Fund, PO Box 50, York YO1 2ZX.

Related Findings

The following *Social Care Findings* look at related issues:

- 12 *Dissatisfaction with essential respite care* (Feb 91)
- 15 *Applications to the Family Fund* (May 91)
- 16 *Helping parents of children with severe disabilities manage sleep disturbance* (Jun 91)
- 32 *The effects of the Children Act 1989 on short-term breaks for disabled children* (Apr 93)
- 53 *Trends in applications to the Family Fund* (Jun 94)

For further information on *Findings*, call Sally Corrie on 0904 654328 (direct line for publications queries only).



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