



## Combining work and care: working parents of disabled children

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The pressures and challenges associated with the care of disabled children are well documented but little is known about how these parents combine paid work with caring. This study - by Carolyn Kagan, Suzan Lewis and Patricia Heaton from Manchester Metropolitan University - analysed detailed accounts of parents from 40 families who are combining employment with care of disabled children. The researchers found:

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- f** Parents felt that employment had both economic and psychological benefits for them and their children.
- f** Those parents who were able to work often did so below their skill level and capacity, because of their need to find work compatible with the requirements of caring.
- f** Benefits did not adequately compensate for loss of earnings and the extra costs associated with disability. The earnings thresholds on benefits, combined with the difficulties in sustaining secure but flexible work, trapped many families in poverty.
- f** Parents found information about locally based services, benefits and employment policies very difficult to obtain.
- f** Hospitals and other health care providers, social services and schools did not take account of parents' hours of work. There was a widespread assumption that mothers of disabled children did not work outside the home and were available at any time.
- f** Childcare provision was generally inadequate and inaccessible for disabled children.
- f** Parents needed some flexibility to adapt working time and location to respond to family needs. Some employers were very flexible and supportive to these parents; in return parents were loyal and committed workers.
- f** Self-employment was one way of achieving flexibility but could be a financially precarious solution.
- f** The researchers conclude that there is an urgent need for co-ordination between employers and service providers in the community to support these families in combining work and care.

## Background

There are some 360,000 disabled children in Britain, more than 98 per cent of whom are cared for at home. However, parents of disabled children are less likely than other parents to be in employment and this is particularly the case for mothers. Lack of opportunity to work can result in personal and financial hardship and increase stress for parents. This study set out to gain an understanding of the experiences and needs of families with disabled children in which the parents engage in paid work.

## The need to work

All the parents interviewed said they needed to work, for both financial and psychological reasons. Their incomes were important for the families' well-being. Welfare benefits did not fully compensate for the costs of disability and loss of earnings. Furthermore, even minimal involvement in paid work provided additional sources of satisfaction and esteem, and helped parents to feel that they were active citizens and not just recipients of benefits and services. Many mothers felt they needed to justify the decision to take up employment. Others felt that their children also benefited from the psychological as well as the financial spin-off from both parents being employed.

*"I need to work ... for Neil (son) because I'm better for him if I've been away and come back than if I'm there all the time."*

One self-employed mother said:

*"It gives me a little bit (of income) and I've still got the chance of pulling (the business) back ... other than that I would just sit at home and vegetate ... it's not just earning money. It's giving me some space of my own and it gives me something else to concentrate on, while I'm at work ... and it keeps you sane, keeps you sane, well I think so anyway."*

Some of the parents were working to develop services and support for families with disabled children which were not formally provided. However, these activities contributed little to household income.

Many of the parents were unable to find sufficiently flexible work in which they could use their qualifications and experience. Instead, they often undertook casual work which was often insecure and unpredictable and excluded them from any employment rights.

## Strategies for working and caring

Parents, in particular mothers, found it difficult to mix working and caring. Two-parent families, particularly those not strongly attached to traditional

gender roles, had most options. However, all the arrangements that parents adopted involved some compromise in their hopes and aspirations and often they resulted in economic hardship.

*"My wife, basically she is the breadwinner. She had ... a three nights a week job, which keeps the basic money rolling in and I do a variety of things because I have to stop when Elaine (daughter) is off. If you suddenly get a break day or a headache or a tummy upset, somebody has to stay at home and it's me, and also I'm bigger and stronger and so I can carry her about ... I just try and make a living somehow built around our daughter .... I was very happy working ... there was just enough ... I enjoyed it. We weren't mega-rich but we were getting along, and now she's having her go, and she is well regarded."*

A single mother explained:

*"I mean I was like I said working evenings, and they were good, they were really nice, and you know I just - in the end - I just said, I'm really sorry but you know I don't want to let you down ... I can't juggle, I mean if their dad would have been at home, there would have been no problem."*

Unlike other families, the tension between work and family did not always ease as the child got older and could continue indefinitely.

## Welfare benefits

There are considerable financial costs associated with caring for disabled children. Parents in this study felt that the benefits available did not cover the increased costs, nor did they make up for loss of earnings if one parent is unable to work full-time. Furthermore, the earnings threshold, beyond which benefits are deducted, is very low.

*"I think (the £50 threshold is) bad. Because like if they need looking after they need looking after, and you could really turn round and say 'OK, I'm not prepared to look after my son with his disabilities, you've got to provide a nurse' and it would cost a lot more than £50 a week for a nurse ... It would cost a lot more than that. And there is times I resent having to stay at home, I resent Mark ... no, I don't resent my son, I resent the (circumstances) ... Yes. You know, why can't I have a normal job?"*

Parents also found it stressful having to complete full and detailed assessment forms repeatedly, for several different public bodies.

### Difficulties obtaining information

Parents felt they were living in an information vacuum. Lack of information about benefits could lead to unnecessary financial hardship.

*"But at no time while we were visiting the hospitals, at any time at all, did a social worker ever come to us and ask if we were managing all right financially getting to and from hospitals ... Nobody ... then we found out that we could claim, with me being on a low income ... I was so fed up of being on the breadline ..."*

It was also very difficult to obtain information about services available, including childcare, health services and schools and about employer policies to accommodate family needs.

*"The whole scenario (could) have been so different, and again maybe, given the help and advice in the beginning, the marriage might have survived."*

*"Nobody explained to me at work, that if you want time off you can have time off, nobody it was sort of a taboo thing at work, nobody talked to you."*

Sometimes information and support were not offered until parents reached crisis point.

*"I had to be put in a hospital ward because I was out of control, and Helen (daughter) had to be that ill and we had to get to that pitch before ... we could get (help)."*

### Services in the community

Parents found that health, welfare and education service providers in the community assumed that mothers of disabled children did not work outside the home, and were constantly available. Transport agencies also often assumed that a parent was at home at all times. Many hospital and education appointments were made in the day time and required parents to travel, meaning they had to miss work or make complex arrangements.

*"Some of them (appointments) we get through the post and there's no say in that at all."*

*"I normally manage to swap my shifts or get something changed so that I can take her and then arrange appropriate childcare for the other two."*

Where professionals negotiated convenient times to see parents or to visit children at school, the parents were better able to combine work with caring.

*"The speech therapist and physio go and see her in nursery so we don't have to take time off work."*

Childcare provision was generally inadequate. There are very few nurseries and child-minders with accessible buildings and with appropriate training and expertise. Short-term care services are inflexible and often have to be booked ahead. Parents found occasional support in the home, maybe for a few hours at a time, helpful.

Children also needed care and supervision well beyond the school age years.

*"I think he's going to need that kind of help for longer ... for later than most children do, and I don't know how that will go, because now he's nearly twelve, he's started secondary school. In another sort of year or so you'd expect that most kids would just come home with a key for the two or three days and that it would be reasonably safe, but we're not sure how that will go yet."*

**Support and lack of support at work**  
Parents were often reluctant to ask for the flexibility they needed especially if this was regarded as a favour rather than an entitlement, and particularly if jobs were insecure.

*"I preferred not to have time off work ... jobs are very scarce these days ..."*

Some employers were very flexible and supportive, sometimes looking beyond what parents requested and providing what was needed to enable them to fulfil their caring commitments and accomplish what they needed to do at work. Parents who had supportive employers were very committed and loyal.

*"There would have been no problem [taking time off to accompany wife and son to London for the son's operation], but I'm a conscientious person and I felt that it was my duty to be at work from the point of view of all the help that they had given me over the years."*

Self-employment can provide the flexibility and control which these parents need. However, it could be a financially precarious solution.

*"[If daughter is ill] I'd just have to stay at home and lock the office, and then what happens in that kind of a business, people start seeing your office closed and locked ... and you lose business because clients start worrying and thinking well ... what's going on?"*

## Conclusion

The researchers conclude that the following measures would help alleviate some of the difficulties faced by these parents:

- Greater provision of accessible childcare, with improved provision for older children.
- Improved communication about benefits etc., with parents being offered information and support even if they seem to be coping.
- Greater recognition by health, welfare and education professionals of parents' employment commitments.
- Greater support from employers. Self-employed parents with disabled children would benefit from business support such as subsidised help for sole practitioners with caring commitments and a pool of temporary staff to help out in emergencies.
- A review of the benefits available to parents of disabled children, with a view to removing financial barriers and disincentives to work.
- Greater co-ordination between employers and service providers.

## About the study

In-depth interviews were used to explore the ways in which parents in 40 families manage to combine work and caring, the difficulties they face and the factors which make integrating work and family life easier. The families include lone parents and two-parent families, with children between the ages of 15 months and 29 years with a range of impairments. The parents' employment arrangements include full-time and part-time work and self-employment. Issues raised in the interviews were explored in more depth in local parent group meetings, where strategies for bringing about change were identified. The issues raised in interviews and parent group meetings provided the basis for the development of a workplace audit which can be used by employers to look at ways in which they can support these parents.

## How to get further information

A full report *Caring to Work: Accounts of working parents of disabled children* by Carolyn Kagan, Suzan Lewis and Patricia Heaton, is published by the Family Policy Studies Centre in association with the Foundation (price £9.95, ISBN 1 901455 09 2). It is available from the Family Policy Studies Centre, 231 Baker Street, London NW1 6XE.

Further information about different strands of this research project, as well as publications arising from it, are available from Suzan Lewis or Carolyn Kagan, Interpersonal and Organisational Development Research Group, Manchester Metropolitan University, Hathersage Road, Manchester M13 0JA (Tel: 0161 247 2556/2563, Fax 0161 247 6842).

The following *Findings* look at related issues:

- Trends in applications to the Family Fund, Jun 94 (*SC53*)
- The needs of disabled children and their families, Dec 95 (*SC76*)
- Working with children and 'lost' parents, Oct 97 (*SC98*)
- Independent Visitors and disabled children, Jan 98 (*F138*)
- The number and characteristics of families with more than one disabled child, Feb 98 (*F238*)
- Disabled children and the Children Act, Mar 98 (*F378*)

Full details of all JRF *Findings* and other publications can be found on our website: <http://www.jrf.org.uk>. If you do not have access to the Internet or have any further queries on publications, contact the Publications Office on 01904 615905 (direct line/answerphone for publications queries only).