

Caring for Sick or Disabled Children:

Parents' experiences of combining work and care



Executive Summary

A report for Carers UK and Contact a Family from the
Centre for Social Inclusion, Sheffield Hallam University
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Published 2006

Centre for Social Inclusion



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This study presents findings from research conducted for Carers UK and Contact a Family by the Centre for Social Inclusion at Sheffield Hallam University. It has tracked parent carers of sick or disabled children over a four-year period, and gives voice to their experiences, attitudes and aspirations in relation to combining paid employment and unpaid caring. Using the findings from two carers' surveys in 2002 and 2004, and in-depth interviews with a sub-sample of 29 parent carers in 2005, the study sheds new light on the issues faced by this often neglected group. Most were of prime working age, with a lifetime of caring demands ahead. Many needed (and wanted) to work to support their families and to have an additional focus away from their caring role. The challenges of combining work and care are particularly significant for parents of sick or disabled children, whose children require more and different parental support, often over a longer period. Here we summarise key messages from the study; the full report also reviews other research and outlines recent public policy developments relating to carers, employment and flexible working. New statistical analysis about families with sick or disabled children is available separately (Buckner and Yeandle 2006).

In families with a sick or disabled child, most mothers and fathers see themselves as parents rather than as 'carers', although the majority stress the distinctiveness of their situation. Looking after a sick or disabled child is different from, and more demanding and difficult than, 'ordinary' parenting. These parents nevertheless also have all the responsibilities and obligations of other parents, and like them, many wish to have the rewards and satisfaction of paid employment or a career.

Other research shows that problems with childcare, having to take time off (to care or to attend hospital appointments) and a lack of understanding and flexibility at work, are three key problems faced by parents of sick or disabled children who combine paid work and unpaid caring. This study strongly reinforces this evidence, and highlights many other challenging and important issues. Critically:

- Most parent carers find caring has an adverse impact on their own employment; this can include a negative impact on relationships with colleagues, and a feeling that opportunities to develop or progress are denied parents in their situation.
- Although some succeed in reducing their hours or changing their working patterns to suit their needs as carers of sick or disabled children, many feel forced to look for a different type of work or to change their jobs.
- Because of the additional demands of caring for a sick or disabled child, tiredness and stress are especially difficult aspects of their situation.
- At work some have been met with ignorance, disrespect or hostility because of their need to work flexibly to meet the needs of their sick or disabled child.
- Some feel a degree of guilt or regret about being away from their sick or disabled child.

The report explores the following aspects of the situation of parent carers.



Orientation to work and 'carer identity'

- Employment is often financially very important for the everyday household management of parent carers, as they have additional costs related to their sick or disabled child's needs.
- Parents of sick or disabled children often look ahead to much longer periods of supporting their children than other parents.
- Many parents of sick or disabled children value the psycho-social benefits of working, and find it important to have an adult identity outside their parental and caring role, although some wish to remain at home with their sick or disabled child.
- If care demands increase, some parents of sick or disabled children wish and need to reduce their work commitments - but others say work is an especially important source of 'sanity' when the pressures at home are most intense.

Family-friendly policies and the attitudes of managers and colleagues

- Negative past experiences have made some parent carers distrustful or sceptical about 'family-friendly employment'.
- Some feel wary of disclosing information about their caring role to their managers or colleagues. This can be especially difficult at a job interview or when newly in post.
- Flexible or part-time working is essential in balancing paid work and caring responsibilities, especially when alternative care services for sick or disabled children are extremely limited.
- Those in part-time employment appreciate being able to work reduced hours, but many also feel disadvantaged, as part-timers have very limited opportunities to progress their careers.
- Some parent carers who had the freedom to alter their hours or pattern of work, using a form of 'trust-based' flexitime, find this especially beneficial.
- Because school holiday times are especially difficult for parent carers due to a lack of out of school services for sick or disabled children, term-time

working is greatly prized by those who have this type of contract. Others feel they would benefit from more support and information about how to negotiate this type of arrangement.

- Those whose managers/employers are flexible and supportive greatly appreciate this approach, and many respond by making up lost time, undertaking some tasks at home, and by increased commitment and loyalty at work.

When work and care conflict

- Parent carers with paid jobs are extremely conscious of the intense pressures of the 'daily juggle' needed to manage their multiple responsibilities.
- This juggling becomes even more stressful when unpredictable or unplanned caring situations occur.
- When such additional care demands arise, most parent carers look first to renegotiate roles and responsibilities within their household or extended family.
- Next they usually look to using any flexibility they have at work, such as flexi-time, swapping working days/hours, or working from home.
- Many have to use their paid annual leave to cover the care needs of their sick or disabled children, meaning they do not themselves get the break they need from work and care. Some request special, emergency or compassionate leave when their paid leave runs out – but this can be refused, and is difficult to use because it is unpaid and causes problems in managing their household.

Support services and their impact on employment

- Most parent carers in this study had very little regular informal support from family or friends outside their own household.
- Although some were in urgent need of childcare, short term breaks (respite care) and sitting services, few had the regular support of formal alternative care services, and many had no contact at all with their local social services department.
- Many viewed social services and social workers only as a 'last resort'. Most said accessing basic services



for their sick or disabled child was a difficult, stressful and at times distressing struggle, requiring them to be assertive and doggedly persistent when they were already under pressure.

- Some complained that despite having a formal Statement of Special Educational Need, their child was not considered 'disabled enough' to be entitled to the support services they need, for example out of school activities. This left them feeling 'back to work' is not for them, and that they are 'expected' to stay at home.
- Parent carers often feel educational provision for their disabled child is limited, and many feel frustrated by their dealings with schools, social and healthcare services. Some feel their child has been excluded from school inappropriately, as a result of behaviour arising from their condition or disability.
- Transport services for their sick or disabled children are a critical support for working parent carers, but are often unreliable or inflexible, causing 'care emergencies' which can undermine or compromise the parent carer's position at work.
- The organisation of medical services for their children also sometimes adversely affects their ability to fulfil work obligations, with appointments often at fixed, inflexible times and almost always in 'office hours'.
- Carer support organisations in the voluntary sector are an important source of support for some parent carers, although some parent carers feel they are primarily focused on older carers, or provide their services for carers only during 'normal working hours'.
- The relationship between paid employment and the benefits system does not work well for carers of sick or disabled children, often facing them with 'benefits traps' and posing both short and longer-term risks to the financial security which is so critical to their family's well-being.

The full report addresses the situation and attitudes of parent carers of sick or disabled children who are in paid employment, or who would like to return to paid work, showing that some parent carers still have to give up work, or find it very hard to re-enter employment, because of their difficulties in finding an appropriate way of combining work and care. There remain many sources of tension for working carers, felt particularly acutely by parents of sick or disabled

children, whose circumstances are often not well understood either by employers, managers or colleagues, and who are often faced with inadequate support services.

Parent carers in this situation highlighted:

- That the responsibilities of caring for a sick or disabled child change and develop over time in ways that are very different from those experienced by parents of non-disabled children, and that this needs to be more widely understood by employers, schools and service providers, in particular at the transition to adult services.
- That service provision for sick or disabled children, notably after-school provision and provision in school holidays, remains very inadequate – and that this weakness is highly problematic for them as employees as well as for their children as service users.
- Their need for flexible employment options, and for attitudes in the workplace which are responsive to their changing and sometimes unpredictable circumstances as mothers and fathers with especially demanding parental roles.
- The desirability of part-time and, for some, term-time only, employment, as a means of enabling them to combine paid work with care for their sick or disabled child.
- That there needs to be more flexibility in the timing of appointments and clinics for their children's health, educational and other services.
- That paid employment is crucial for many parents of sick or disabled children for financial, social and health reasons, and that caring for a disabled child goes on for many years.
- That they experience considerable stress and frustration in their dealings with employment, advisory, social and educational services.
- That caring for a sick or disabled child involves significant extra expenditure over a much longer period of time than caring for other children, and that this underscores the commitment of some parent carers to remaining in paid employment.
- That employment can be extremely important in maintaining a personal equilibrium and in participating in 'normal' life, especially for those



whose children have serious illness, severe disabilities or who exhibit challenging behaviours, and are at risk of social isolation and exclusion.

- That special support for carers at work, including carers' leave, the right to request flexible working, and the right to time off to deal with caring emergencies, has been very important in giving parent carers peace of mind at work and in dealing with crisis situations, but usually involves a personal or a family cost, as these arrangements, and any concessions given in terms of reduced hours or additional time off, normally reduce their income from work.
- That the relationship between paid employment and the benefits system does not work well for carers, often facing them with a 'benefits trap'.

Recommendations for policymakers

- Steps need to be taken to raise the awareness of employers, teachers and service providers about how caring for a sick or disabled child differs from ordinary parenting, and the stresses that can result for children and families.
- In implementing the *Childcare Act 2006*, government and local authorities need to ensure that significant improvements are urgently made, enabling sick or disabled children and young people to access out of school and school holiday provision.
- Health, education and other service providers supporting sick or disabled children need to plan arrangements for appointments and consultations carefully to minimise disruption to the routines of working parent carers, recognising that paid work is extremely important to many parent carers for financial, social and health reasons.
- The effectiveness of the *Work and Families Act 2006* in enabling parents of sick or disabled children to work flexibly, and in changing employment culture to accommodate this, needs to be monitored. Consideration also needs to be given to how working parent carers could be helped to deal with caring crises and emergencies without loss of earnings.
- That in the light of the *Children Act 2004* and the *Carers (Equal Opportunities) Act 2004*, local authorities should use, in their service planning, a

full review of local alternative care services in relation to parent carers' access to paid work. This needs to pay special attention to the transition from Children's to Adults' services for sick or disabled children, and to the impact this can have on working parent carers.

- That all relevant agencies should urgently review the extent to which local alternative care services discriminate against parent carers' opportunities to work by being insufficiently accessible.
- That the new *Commission for Equalities and Human Rights* take on the responsibility of examining discrimination against parents caring for sick or disabled children in terms of: the lack of availability and accessibility of good quality childcare; discriminatory attitudes at work; and their status as parent carers.
- That voluntary organisations supporting carers or providing services, including childcare, should review whether working parent carers are being excluded from their current support and networks, and whether new or different support services need to be developed.
- That employers take steps to create more and better opportunities for part-time work in good quality jobs, to ensure that in choosing to work shorter hours, parents of sick or disabled children do not become confined to low paid work with poor prospects for career development.
- Those providing employment, advisory, social and educational services to parent carers need to be made aware of the stress and frustration many experience in trying to access support; this could be achieved through appropriate training and guidance to professionals.
- The 'benefits trap' experienced by many parent carers when they try to enter paid work is an undesirable disincentive to employment. A review of the benefits system as it affects carers is needed, to take account of and address the situation of parent carers.
- That in developing their local strategies for economic development, regeneration and social inclusion, local authorities and *Local Strategic Partnerships* pay positive attention to developing services, including transport and 'back to work' support, that actively support carers of sick or disabled children.



Finding Out More

The full report, *Caring for Sick or Disabled Children: Parents' experiences of combining work and care* can be obtained from Carers UK and Contact a Family.

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Published November 2006

Code UK4021

This research was commissioned by Carers UK and Contact a Family on behalf of the ACE National partnership, and part-funded under the European Social Fund's EQUAL Community Initiative Programme. The Action for Carers and Employment (ACE National) partnership, led by Carers UK, was created to tackle the barriers facing carers wishing to work.

New research on carers and services is currently being undertaken for ACE National by Professor Sue Yeandle, who is now with the University of Leeds.

Carers UK is the voice of carers. Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers UK improves carers' lives through information provision, research and campaigning, training and advising employers on supporting working carers.

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Registered in England and Wales as Carers National Association, Number 864907
Registered Charity Number 246329

Contact a Family is the only UK wide voluntary organisation providing advice, information and support to parents of children aged 0-19 with any kind of disability or medical condition.

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Registered in England and Wales No 1633333
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