

Caring for Sick or Disabled Children:

Parents' experiences of combining work and care



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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Hallam University

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Executive Summary

This study 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.

This 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. 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.



1 Introduction

In this report we present the findings of research conducted for Carers UK by the *Centre for Social Inclusion* (CSI) at Sheffield Hallam University. The study was developed as part of the *Action for Carers and Employment (ACE National)* partnership, funded through the European Social Fund's EQUAL Community Initiative Programme. Designed to explore carers' experiences of combining paid employment and unpaid caring, or of trying to do so, the study enabled us to track a number of carers across a four-year period. The carers whose accounts form the main focus of this report first responded to Carers UK's initial survey of caring and employment in 2002, distributed through a number of organisations which provide support to carers. They subsequently completed a second questionnaire distributed by the CSI research team in summer 2004. A group of these carers was then followed up in 2005, in detailed face-to-face interviews designed to explore their full range of experiences, attitudes and aspirations in relation to caring and employment. All those interviewed were parent carers of prime working age who were caring for their disabled children. Their situation was of particular interest, as this has been a somewhat neglected group in the research literature on carers. We refer to them in the main body of this report as 'parent carers'.

The parent carers of disabled children we studied stressed the distinctiveness of their situation. Although in some cases their children were now aged 19 or older, they almost all still saw themselves as parents first, in relation to their disabled sons and daughters, and only secondarily as their 'carers'. They emphasised that looking after a disabled child was different from, and more demanding than, 'ordinary' parenting. Nevertheless they also acknowledged that, like other parents, they were also 'just' mothers (and in one case a father) with the concerns and satisfactions of watching their children grow and develop, alongside all the other obligations of family life. The parent carers we spoke to felt that these parental obligations included the need to generate adequate financial resources for their household and family and to meet their own needs. In their case, this included their desire to have the stimulation, rewards and satisfaction of paid employment or a career.

Previous research on parents of disabled children

Most research on parents of disabled children has focused on their home situation (family relationships, stress and finances; challenges in securing services; benefits entitlements and the inadequacies of social security arrangements), and on the health, education and other needs of their children. Only rarely have researchers explored the circumstances and attitudes of those parents of disabled children who wish to, or are trying to, combine paid work with their family caring situation. Where such work has been carried out, it suggests that this group of carers has extensive needs which are not adequately met by either their employers or public policy.

In 2003, the charity Contact a Family surveyed 2,000 parents of disabled children and found that just over half of these parents were experiencing financial difficulties while a third reported 'problems at work'. In both cases, most said they felt these problems were linked to having a disabled child (Contact a Family 2004). A much earlier study of the situation of 20 London mothers of disabled children (Douglas 1994) had previously identified their concerns, which included their strongly held view that childcare and other services were not flexible enough to accommodate the needs of working parents, and had explored how the benefits system operated for working parents of disabled children.

Following the introduction of the *Employment Act 2002* Contact a Family received funding from the DTI in 2004-5 to carry out a further survey of 930 parents of disabled children, with the specific aim of exploring their knowledge and use of the new employment rights introduced in April 2003 (see below for a summary of recent developments in public policy). This found that, while 64% knew that the new law applied to those who had a disabled child up to age 18, only 52% knew that it applied to both men and women. 14% of the survey respondents were already working flexibly, and a further 11% had made use of their new rights, asking to do so under the new legislation and having their requests agreed in full. Another 3% had asked and their employer had agreed an alternative. However, 5% had asked for a more flexible employment arrangement and had their request refused, and 32% had not asked.¹ Of this last group who had not asked to work flexibly, just 17% said they did not need or



want to work more flexibly. Of the rest:

- 24% said they would like to work more flexibly but could not afford to earn less
- 17% did not know enough about their rights
- 16% did not think their employer would let them
- 14% were worried about the effect on their career or promotion
- 11% were worried about the reaction of work colleagues

This study also found that the three main problems parents of disabled children faced in combining work and care were: childcare (cited by 50% of respondents); the need to take time off work for hospital appointments (30%); and a lack of understanding/flexibility among employers (14%). A striking 38% of the parents surveyed also said that, in the past, they had not applied for, or had turned down, a job because it did not offer flexibility. More than half the parents felt they needed 'more publicity and a greater knowledge about rights', and many called for changes in the law - such as paid time off for accompanying children to hospital appointments or making flexible working an absolute right for parents. This recent survey data thus revealed major issues for working parents of disabled children, especially for those who wished to combine work and care, and that the problems identified were experienced on a large scale. While this study was extremely important in highlighting this issue some 12-18 months after new rights were introduced, survey evidence, by its nature, cannot explore the detailed stories which lie behind this worrying picture. For that, a qualitative and ideally more longitudinal perspective is needed.

Lewis et al (2000) in an earlier qualitative study of 40 working parents of disabled children found that flexibility at work was crucial, although some parents were reluctant to ask for it, and that formal organisational policies were not always well communicated to parents of disabled children. Lewis and her colleagues noted, as our other research confirms, that those working carers who had supportive employers and managers were very committed and loyal employees (Lewis et al 2000; Yeandle et al 2003; Yeandle et al 2006). Their study nevertheless noted the limits on what even the best employment policies can achieve, and underlined the importance of ensuring that service provision beyond

the workplace is good enough to enable parents of disabled children to make a full contribution at work. They concluded that it would greatly help parents of disabled children if employers:

- were aware of the dates of local school holidays
- assisted employees in finding information on resources for caring for disabled children
- worked in partnership with local childcare providers to ensure their facilities are accessible for disabled children
- campaigned for health professionals to visit children in schools rather than requiring parents to miss work for health care visits

As we shall see in the main body of this report, their analysis holds true for the parents of disabled children studied in our new research, which included parents of disabled children who were in paid employment and some who had found it necessary to give up their paid jobs to ensure their children received suitable care.

Recent developments in public policy

In public policy, the circumstances of parents of disabled children are addressed through legislation, service provision and social security entitlements involving both central government and local authorities. The rights of disabled children are addressed both through legislation protecting them as children, and through rights accorded in law to disabled people. In our companion research study (Yeandle et al 2006) we summarised changes in public policy affecting carers over the past decade, highlighting:

- *The Carers (Recognition and Services) Act 1995* – which introduced the concept of a carer's assessment.
- *Caring About Carers: a national strategy for carers (1999)* – which stressed that enabling carers to combine paid work and care was a priority for government.
- *The Employment Relations Act 1999* - which gave employees the right to 'reasonable time off' to deal with emergencies.
- *The Carers and Disabled Children Act 2000* – which gave carers the right to an assessment for carers of adults and people with parental responsibility for disabled children.



- *The Employment Act 2002* – which gave employed parents of disabled children under the age of 18 the right to request flexible working arrangements.
- *The Carers (Equal Opportunities) Act 2004* – which placed a statutory duty on social services departments to inform carers of their rights, and to consider carers' wishes in relation to education, training and employment when conducting carers assessments.
- *The Work and Families Act 2006* has extended the right to request flexible working arrangements to all carers in employment, from April 2007.
- In 2003, the Government published a green paper, *Every Child Matters*, and launched a wide-ranging public consultation. This was followed by the *Children Act 2004*, which requires local authorities to lead on integrated delivery through multi-agency children's trusts and to develop a children and young people's plan. The Act includes a strong policy emphasis on supporting families and carers, described as 'the most critical influence on children's lives'.
- In *Every Child Matters: Change for Children and Standard 8 of The Children's National Service Framework* (November 2004) the government also indicated that disabled children and children with long term health conditions should 'receive co-ordinated services which allow them and their families to live as ordinary lives as possible.'
- *The Childcare Act 2006* includes provisions relating to the 'duty to provide sufficient childcare for working parents', and specifically states that local authorities 'must have regard to the needs of parents in their area' for 'the provision of childcare which is suitable for disabled children'.

These developments provide an important backdrop to the new research findings reported here. The evidence which the parent carers we interviewed supplied shows that there is a long way to go before this group of parents can share equality of access to employment, or can routinely rely upon their employers and colleagues for effective, flexible support in combining work and care when difficulties arise. Reflecting on our interview data, we were struck by these parents' many frustrations in trying to combine their parental and caring responsibilities with employment or a career. Some of the accounts they gave revealed that at work parent carers could sometimes be met with ignorance,

disrespect or hostility. This is not inevitable, as those with happier experiences told us, and as our companion research for Carers UK, *Who Cares Wins - the Social and Business Benefits of Supporting Working Carers* (Yeandle et al 2006) confirms. We hope this new report will give voice to some of these parent carers' concerns and aspirations, and that the study can contribute to eliminating some of the misconceptions about carers and paid work which some employers, managers and colleagues hold.

The 2002 Carers UK survey: key findings

In 2002, Carers UK commissioned a survey of carers who were in contact with their voluntary sector partners in the *Action for Carers and Employment (ACE National)* partnership. The organisations involved were *Parents at Work*² based in London, and organisations supporting carers in three other localities: *Surrey Action for Carers and Employment*, *Sunderland Carers' Centre and People into Employment*, *Tyne and Wear*, and *Kirklees Carers Gateway* in West Yorkshire. Postal questionnaires were sent to all the parent carers on these organisations' mailing lists, yielding a sample of 1,127 respondents. 87% of those who responded were carers at the time of responding to the survey, 48% were in employment, and of those who were currently carers, 85% were living with the person they cared for.

The analysis of the 2002 survey showed that the majority of respondents felt that:

- caring had had some kind of adverse impact on their own paid employment
- tiredness and stress were among the most difficult aspects of combining work and care
- having to taking time off from paid work for caring was often a problem

A minority of respondents also mentioned sometimes feeling:

- guilt or regret about being away from the person they cared for, and
- that their relationships with colleagues at work suffered because of their caring responsibilities, or how they were treated in relation to their caring role

Of those carers responding to the survey who were not currently in a paid job, 66% said they would like



Table 1 Respondents' caring responsibilities, by circumstances of person cared for

	Number	%
Child(ren) under 18 with a limiting long-term illness	9	7
Disabled child(ren) under 18	71	55
Adults with a limiting long term illness	10	8
Disabled adult(s)	36	28
Older person(s) and others	3	3
All	129	100 ³

Source: Centre for Social Inclusion Survey, 2004

to return to employment. The problems they felt they faced in achieving this goal included:

- the difficulty of finding a flexible employer
- the cost of alternative care
- not being able to earn enough to cover their costs
- the cost of training
- low confidence or inappropriate skills
- health problems
- transport difficulties

CSI's 2004 follow-up survey: key findings

When the CSI team surveyed the 214 carers who had agreed to further research contact again in 2004, 64% of the questionnaires (136) were returned. This second postal questionnaire focussed on the respondents' current caring responsibilities, their employment situation, the impact of their caring on their work (or on their attempts to enter employment), and their hopes and plans for the future.

- The majority of these respondents (81%) were carers in the middle of their working lives (aged 35-54 when first contacted in 2002). They included 118 women (87%) and 17 men (13%). 93% were White, with just 7% identifying themselves as belonging to ethnic minority groups.
- 129 of the respondents (95%) still had caring responsibilities (7 were no longer in a caring role following bereavement).
- Of these 129 respondents who still had caring responsibilities, 80 (62%) were carers of a sick or

disabled child aged under 18, while 46 (36%) were caring for a sick or disabled adult aged under 65. (See Table 1.)

- 95% of respondents to the 2004 questionnaire were living with the person they cared for, who was usually their child, grandchild, spouse or partner.

In this second survey, these carers were able to tell us about their experiences of combining care and paid work, or of seeking to enter paid employment or take up training alongside their caring roles between 2002 and 2004. We found that:

- About half the 129 respondents had experienced changes in their employment situation between the 2002 and 2004 surveys
- 65% worked part-time (less than 30 hours per week), while about a quarter worked between 31 and 40 hours per week in their paid job

These working carers reported that their caring responsibilities had affected their paid work in the following ways:

- 65% believed that their caring responsibilities had had a negative impact on their career development
- 61% had needed to take time off from work to accommodate their caring role
- Over half felt their opportunities to develop skills at work, to improve their qualifications, or to gain personal job satisfaction, had suffered
- Half had tried to change their job; 58% had looked for new or further training opportunities; 61% had



BOX 1 – PARENT CARER CIRCUMSTANCES

When the 29 parent carers were interviewed in 2005:

- 11 were lone parents (some in new partnerships, but still acting as the main carer)
- 12 had multiple caring roles (caring for more than one person with an illness/disability)
- 14 also had other dependent children (who were not ill or disabled)
- 8 were also disabled or had a long term illness themselves
- 18 had heavy or very heavy caring commitments (more than 50 hours/week)

Their disabled children:

- ranged in age from 6 – 28 years old
- in most cases had learning and behavioural difficulties (e.g. Downs Syndrome, Attention Deficit Hyperactivity Disorder (ADHD), autism, Aspergers Syndrome), some physical disabilities (e.g. Cerebral Palsy) and other illnesses (e.g. cancer)
- were mostly living with their parent carer(s) - 3 were living in residential educational or semi-independent settings for part of the week

In relation to employment between 2001-2005:

- 10 had remained in paid work between 2001 and 2004, and were still employed in 2005
- 8 had returned to work between 2001 and 2004, and were still employed in 2005
- 8 were not in employment between 2001 and 2004 - of these, 2 parent carers had returned to work between 2004 and 2005
- 3 had left work between 2001 and 2004, and remained full-time carers who did not re-enter employment
- most of those in employment reported taking time off, and/or changing their hours or jobs, as a result of their caring responsibilities between 2001 and 2005

Employment situation of the parent carers in 2005:

- 20 were in employment
- 15 worked in the public and voluntary sectors (mainly in social work, education, carer/caring, special needs or support functions)
- 14 were employed part-time (including 1 self-employed part-time)
- 6 were employed full-time (including 1 self-employed full-time)
- 9 were full-time parent carers, not currently in employment (some doing voluntary work/training, or wanting to work)

looked for new employment; and two-thirds had thought about moving into a different type of work

- 45% had changed their working hours or shift patterns
- 42% had reduced their hours of work

Although 34 of the carers in the 2004 survey had not worked during the past three years, in this group 7 had tried unsuccessfully to find new employment, and 20 had looked for new or further training opportunities.

Overall, the data from the two surveys suggested that although this group of parent carers was keen to take



up paid employment, they often felt disadvantaged at work, and sometimes found their caring responsibilities and their employment roles in tension. Although some appeared to have been able to manage this tension reasonably successfully, others had found it necessary to leave work for a while to concentrate on their caring, and a large number were reporting that in combining paid work and caring they were suffering some damage to their careers. We were interested to learn more about the way caring and employment were experienced by these respondents, and therefore approached a sub-group of those who had participated in both surveys for a face-to-face, in-depth, interview in their own homes.

In-depth interviews with parent carers of sick or disabled children

In the spring and summer of 2005, face-to-face interviews were conducted with a sample of 29 carers who had taken part in both the 2002 and 2004 surveys. For this part of the research, we selected only parents and carers of sick or disabled children who were in the middle of their working lives. Parents of sick or disabled children tend to be younger than other carers, and often have a lifetime of continuous caring ahead of them. They may also have other dependent children, and most need to work to support the financial needs of a growing family. The challenges of combining work and care for this group are thus especially important.

Most of our interviewees were mothers with the primary caring responsibility for their disabled or sick child(ren), but they also included one father and a grandmother with legal guardianship. Of the 29 carers of sick or disabled children interviewed, 27 were White British, and 2 were from Black and minority ethnic backgrounds. All of these carers had previously been in contact with carer support services or organisations, reflecting the recruitment methods used for the two earlier surveys. Box 1 describes the caring and work circumstances of the sample.⁴ In addition to their personal experiences of caring, some of our interviewees also had professional insights into carers' issues through their paid work in education, social work or voluntary sector occupations. This meant they were often well-informed about, and well-connected to, service providers – yet despite this, the experiences they described had often been fraught with difficulties and dilemmas.

The qualitative research which formed the third stage of this study enables us to present the perspectives and voices of parent carers of sick or disabled children, and to highlight their experience in relation to the topics we explored in the interviews:

- their orientation to work and their 'carer identity' at work
- family-friendly policies and the attitudes of their managers and colleagues
- combining care and work
- what happens when care and work conflict
- how support services affect their employment

1 19% said that they were self employed or not working so it did not apply, and the remainder did not respond to this question.

2 This organisation has subsequently become *Working Families*.

3 This column does not total 100 because of rounding.

4 Details of all the respondents are given in the Appendix, Table A1.



2 The place of paid work in parent carers' lives

Parent carers' orientations to work

There were a range of reasons why carers worked (or wanted to work), or did not (or could not) take paid employment. Although they share some of these 'orientations to work' with others in the working population, some are specific to, or especially important for, carers.

For those parent carers who were, or wanted to be, in employment, financial need was an important motivation for seeking or remaining in paid employment. However in most cases being a parent carer affected their orientation to work. Some had increased costs associated with caring for their disabled child, often involving a long-term commitment to doing so into their adulthood. This underlined the financial importance of paid employment for their household management. These parent carers often mentioned additional expenses, including:

- buying specialist equipment
- running a car as an essential item
- extending and adapting their home
- subsidising their disabled child's accommodation and living costs
- providing additional heating, clothing and food
- occasional holidays

These were seen as necessary to enable them to care adequately for their child and family, and this on-going financial responsibility made remaining in paid employment for as long as possible extremely important. Some of these carers said that to earn the money they needed, they worked longer hours than they would otherwise prefer:

Work is tiring, but we will need to continue to work, probably well past our retirement age, to continue to pay the mortgage for the extension and the other work we've needed on our house for [our son]. We'll still need to provide for [him] financially at a time when we would consider retiring or taking it easier at work.

Wendy, returned to part-time employment

I've got to carry on working full time, because I've got to pay the mortgage on my daughter's housing.

Amy, in full-time employment

Frank, a father in his mid-40s, had returned to paid work after 20 years of caring for his disabled child and disabled wife, as well as bringing up their other children. He was determined to earn as much as he could to make up for what he described as 'decades of lost earnings'. He was strongly committed to working in his own business, so that he could finally become financially independent:

I don't want to retire at 65. I want to keep running my own business, as well as another part-time business, selling on the internet at the weekends and evenings. I don't want to work for someone else's profit. I want the rewards, money and control of running my own business... I've got to make life work for me... Should things ever go bad again in the future, I'll actually be independent, not trapped by circumstances, because when you've got no income, it's hard to do anything.

Frank, returned to part-time self-employment

Some parent carers said they needed or would like to work longer hours, or at a higher level, for financial reasons, but felt they had limited opportunities for doing so because of their caring responsibilities. We discuss this point in further detail below.

Money is not always the main motivator for parent carers taking on paid employment. One parent carer had recently returned to part-time work, although her family were consequently £40 per week worse off, as a result of losing the Carer's Allowance they were previously entitled to, and other benefits. Val thought the financial sacrifice involved was worth making for several reasons. She valued the opportunity paid work gave her for personal longer-term career development, and - more importantly for her - she also felt she wanted to 'put some money back into the system' - to repay what she felt were her dues, and to help others who were in her family's recent position and unable to work.



Parent carers who were not currently in paid work, or who were only marginally employed (e.g. in casual, or cash-in-hand jobs), saw their family's needs and their role as the primary carer as their main priority. A positive choice for some, for others this arose from perceived or actual barriers to suitable and flexible job opportunities, or a lack of suitable alternative care support services.

For some of these parent carers, seeking out paid work, or finding additional paid work, was a move of last resort, a strategy to be pursued only if the benefits received in their household were insufficient to meet their needs, or were withdrawn (see Box 2).

Equally (or more) important for many parent carers, however, were the psycho-social benefits of working. Most of our interviewees indicated that working gave them an important adult identity outside their role as parent and carer. Work (whether paid or voluntary) allowed them 'time for themselves', a sanctuary or escape from the demands of their caring life at home, and offered social interaction with other adults. This was important in maintaining their self-esteem and mental well-being:

I gain a lot of satisfaction from working, I feel as if I'm contributing. I really do want to stay in work. It does mean a lot to me, so it would be difficult to give up work. I would even find it difficult to cut back on my hours. It keeps me sane, being able to get out and meet with other people, because I don't have much of a social life for obvious reasons, so it's nice to be in contact with other adults on a daily basis. I would really miss that, definitely.

Marsha, returned to full-time employment

[Work means] sanity. If I constantly stay in and have my life being revolved around the children and the house I think I'd go mad. [Work] brings out the creativity in my mind...I feel that I've found my niche and I'd really hate to lose it, but I've always been a carer ... and I just wanted to be myself...and I am myself when I'm studying or when I'm at work.

Fiona, returned to part-time employment

Parent carers' identities in the workplace

Some parent carers emphasised the importance of their professional identity, and of having an intellectual or stimulating challenge at work. For them, the focus on the work itself, and on accomplishing tasks efficiently, was extremely important - particularly those working part-time.

Delia told us that she worked through her lunch break so that she could do her hours in less time, even though this meant reduced social contact with her colleagues. Chatting with colleagues could also draw parent carers into discussions about their home lives, which Eve preferred not to do:

I like to maintain a professional, friendly approach at work - but I don't want to spend time chit-chatting about my home situation. The others do spend a lot more time chatting, but because I'm part-time I prefer to do my work as efficiently and quickly as I can. I like to focus on work, even when things are tough at home, although the energy isn't always the same.

Eve, returned to part-time employment

This awareness of their identity (either as a worker or as a parent carer, or both) profoundly influenced the outlook, choices and decisions each parent carer made. The changing demands of their caring role could mean that at different points in their lives, they saw work in a more positive light, compared with their other colleagues who did not have these additional responsibilities:

I looked around and I saw so many parents dealing with disabilities and medical problems, and couldn't bear to think that is all there is in my future life. Looking at them was my great motivating factor (to go out to work). People would moan at work - and I was just so pleased to be there. I think it is positive to have people like me come back to work, because I feel differently about work - very positive.

Linda, returned to part-time employment



BOX 2 IN PAID WORK, BUT 'A MOTHER AND CARER FIRST AND FOREMOST'

Pat is a lone mother in her mid 50s, caring for her 17 year-old autistic son and for her 3 other teenage children. When she gave up work 20 years before to bring up her family, she felt she had completed her 10 year career as a qualified professional. From early in her marriage, Pat had expected her husband to be the primary breadwinner, and that her role would be to care for her family until her children left home. During the breakdown of her marriage her *'confidence took a bashing'*, although she received adequate maintenance for herself and the children from her ex-husband and (with additional benefits) was able to manage financially. This enabled her to focus on providing a stable home for her 4 children as they were growing up.

When Pat first responded to our survey in 2001 she was not in paid work, although she was doing voluntary work (as she still does) to use her skills and maintain a routine of 'working'. When her eldest daughter started university in 2002, however, Pat found her reduced income and maintenance payments were inadequate to support her household, and this was her 'trigger' for re-entering (part-time) paid employment:

Now work is a necessity. We could have survived on the maintenance, but we would have had to cut back on an awful lot of things – no holidays, car...luxuries I consider to be necessities – necessary for the quality of my life. There is no spare money apart from savings – the inheritance from my father, which I've put aside for when I retire, because I'm unsure how much longer I'm going to be able to work anyway in my mid-50s.

Pat felt she needed a local or home-based job with flexible hours that would allow her to be at home for her children when she was needed – especially by her autistic son who was having a very unsettled period at school. She also needed to be able to drive her son to school at short notice when the transport arrangements set up for him through Social Services broke down. In 2002 she found a job delivering local free newspapers, and a few months later was made an Area Supervisor, working 18 hours per week, sorting and delivering heavy bundles of papers, which she found had a negative impact on her health.

Later, Pat's attempts to find a better paid part-time job in her original professional specialism led to a job offer – but her request to work 'term-time only' was rejected, and she felt she had to decline the job. At the time of her interview, Pat was sticking to her Area Supervisor position, until another change in maintenance or benefit arrangements force her to consider other, more lucrative employment options.

I would like something else, outside just being a mum and a housewife. If I still had a husband with a good income I could get that from voluntary work, for my own satisfaction. That was what I thought I was going to be – one of the ladies who wore a hat and made tea, because I'm of that generation. I didn't actually see that I would need to earn money. For job satisfaction and all the other things you get out of a paid job, like being part of a team and being part of something bigger than yourself – I could get out of voluntary work.



Our interview data also show that as demands from home increase, or if a care crisis develops, a carer's attitude and focus may shift away from work. This sometimes leads to a change in working arrangements, such as increased flexibility, reduced hours, or a period of time off from work. But for other carers, in times of difficulty, work can become more important as a source of increased support, or a refuge from the stresses at home:

When the children were younger I saw working as 'a break', and when my marriage was breaking up I saw work as a supportive environment where I could speak to people about what was going on.

Hannah, in part-time employment

Parent carers' identities and their orientation to work may revert towards employment when the situation at home settles, triggering a re-appraisal of their employment options. This may involve re-entering work, to spend time in a more stimulating environment, or regaining the energy to take on training or an educational course (see Box 3). Some of the working parent carers we interviewed told us that they had up-skilled through further training or qualifications, but had subsequently found the progression to a more demanding post too daunting. Marsha, a lone parent carer, had self-financed her studies and completed an MSc in 2001.

(It was) very tough and stressful, but I managed it. I really do want to use the qualification and move up the ladder, but I'm very reluctant to take on that [management] responsibility, especially now with [my 16 year old disabled son] being unsettled. I am wondering 'is it the right thing to do? Can I cope with that? Am I going to create more stress for myself?' [With a promotion], I won't have as much flexibility as I have at my level now.

Marsha, returned to full-time employment

Linda, employed as a teacher of special educational needs, was initially very happy just to be back at work, but said she now wanted something more stimulating. She was still holding back, and

deliberately doing less than she was capable of - a common experience among parent carers:

The downside [of my caring responsibilities] is not being able to do what you really want to do in terms of career. I would have liked to go back and progress to head of department, but that's completely out of the question because of the responsibilities, hours and more work stress that would be associated with a much higher position. I always feel that I always do less than I could, to make sure that what I do, I do properly - so nobody could look at me and think, 'Ah, she's got a special needs child'.

This kind of evidence from our qualitative interviews is consistent with the results of our earlier surveys (see above), which showed that more than half of the parent carers completing the 2004 survey felt their caring responsibilities had had a detrimental impact on the progress of their career. In our detailed face-to-face interviews it emerged that this could apply even to those who were strongly orientated to work, who were strongly motivated to succeed at work, and who were keen to progress in their careers and valued their professional identity.

Being valued for their skills and abilities was important to carers, but they also recognised the importance of finding a flexible employer who was 'parent or carer-friendly' and respectful of their employment rights. As our analysis below shows, some were still cautious of employers claiming to be family or carer-friendly. This was because in the past they had experienced this as mere 'lip service' to carers' issues on the part of employers, or had found that previous employers who had initially appeared supportive let them down when a care crisis arose.

Most of the parent carers in the study said they felt uncomfortable about 'declaring' their additional caring responsibilities at work, even to a carer-friendly employer. During the recruitment process, some had struggled to account positively for the caring gaps in their CV, while others thought that being a carer could prejudice their application, and concealed their home situation. Even when established in their job, some of our interviewees felt that being known as a



BOX 3 STAGES IN A PARENT CARER'S JOURNEY BACK TO PAID WORK

CIRCUMSTANCES CHANGE

- Change in caring situation – entering a settled/stable period e.g. illness stabilises, child moves into residential care, other dependent children leave home – more time available
- Change in financial circumstances – e.g. benefits reduce as (non-disabled) children leave home



Outlook changes

- Increasing boredom/frustration with being at home
- Energy and motivation increase
- Increasing need for more independence (financial and social)



Action taken (this may take several years)

- Contact/involvement with carers organisations/network support
- Confidence building/CV writing/ job search/application support
- GP/other professionals provide support – e.g. respite, sitting, counselling
- Training/education or voluntary work
- In-work benefit advice received (e.g. loss of Carers Allowance, Housing Benefit, Free School Meals etc)
- Further job seeking support (e.g. researching carer-friendly policies)
- Alternative care support arranged (e.g. informal or formal childcare)



Actively seeking work

- Overcoming rejection and set-backs
- Further job-seeking support (formal or informal)
- Advice and support for self-employment opportunities
- Negotiating flexible working, pay, terms and conditions (e.g. term-time working, leave entitlement)
- Overcoming the benefits trap



Successful entry to paid employment

- Appropriate flexible working
- Supportive managers and colleagues
- Reliable/affordable/quality alternative care arrangements
- On-going informal support

carer or as the parent of a disabled child, could compromise their manager's views of them as capable and reliable members of staff. Although they were generally more open with supportive colleagues, some said they preferred to say very little to their managers about their caring responsibilities, only

doing so if it became absolutely necessary. Despite this reticence to openly identify themselves as carers or as parents of disabled children, most of our respondents found it reassuring to know that they had carers' rights as a fallback – just in case.



3 The reality of combining work and care

'Family-friendly' employment

About half of our sample of parent carers were currently working in the public and voluntary sectors (mainly in social work, education, careworker/caring, special needs or support functions). Several of those not currently employed had also previously worked in these kinds of jobs. Many of these employers offer family-friendly, flexible employment opportunities which are attractive to women with families and carers in general.

Part-time and flexible working

Nearly all of our 20 respondents who were in paid employment had some degree of flexibility in their jobs - either as part-time employees, as full-timers working flexi-time, or through some form of individual control over their working hours. More than any other workplace policy or practice, carers indicated that flexible or part-time working was essential in balancing their paid work and caring responsibilities, particularly when alternative care services were limited.

Of the six parent carers who had full-time jobs, four had substantial support at home from a partner or friend, or had a package of alternative care services that enabled them to work (e.g. a disabled child supported in a residential care setting for part of the week).

The range of flexible working policies and practices reported by the carers we interviewed included job-share, flexi-time, time off in lieu (TOIL), term-time working, career breaks and working from home. Although all were seen as positive (and indeed crucial) for parent carers, their experiences of these flexible and part-time working practices varied greatly, depending on their post, role, manager and on the colleagues involved in each working situation. As well as the considerable advantages of these forms of working (for carers as well as for managers), parent carers also reported some disadvantages. Fourteen of the 20 working carers were employed part-time, mainly through choice, to enable them to combine their caring and employment.

In obtaining a much less stressful job with reduced hours, Eve (working for a children's charity), found a

job that enabled her to deal with her daughter's needs during a difficult period:

The work is do-able, self-contained, and means I don't have to worry about work out of hours. I enjoy being office based and not taking my worries home about what is happening to the children [I work with].

Eve, returned to part-time employment

Some parent carers mentioned that part-time working allowed them to schedule other activities, such as making phone calls to support agencies and attending appointments, on their non-working days, so that their home life and work life remained separate. However, part-time working was not without its disadvantages and limitations, as the examples in Box 4 indicate.

Parent carers often said they felt fortunate to be in their current part-time post, but regretted that they had fewer opportunities to progress (especially into management or professional positions):

When a job came up and I showed an interest, I was told 'we don't really want part-timers, we want people who are full-time at the moment'.

Delia, in part-time employment

The demands on part-timers could be intense. Some felt they were expected to perform like full-timers, despite their reduced hours and pay:

I work part-time and I feel like I'm doing the job of a 37 hours worker, that's the expectation... that's what I feel is not recognised.

Fiona, returned to work part-time

These situations were frustrating for those who would have preferred to work full time had other care support been available, or those employed in workplaces where all their colleagues were working full time.

Flexi-time and time off in lieu (TOIL)

A variety of different practices were described as flexi-leave, flexi-time and TOIL, operating both formally and informally. They were mostly welcomed by parent



BOX 4 DRAWBACKS OF PART-TIME WORKING

Some parent carers felt forced to work part-time through necessity, and said they would prefer to work full-time in a more challenging role if alternative care support services were available.

For Cath, part-time working was a compromise, forcing her to work at a lower level than she had done in her previous full-time job. She admitted:

Having less managerial responsibility in this job means I can get home in time, even though this means I'm paid a lot less.

Cath, employed part-time

Other highly skilled and well qualified parent carers had been forced to take low paid part-time work, such as cleaning, newspaper delivery, and community care work, as these were the only jobs available that provided the flexibility they needed. Jane (a former office worker), had been to the Jobcentre, but found that the jobs she was interested in, and qualified to do, were either full-time or far too many hours per week, so resorted to cleaning for a while:

I used to do a cleaning job as the hours suited. It allowed me to take [my son] out when I got home, and then he could go to college in the afternoon and I could get my housework done. But the pay was bad (£3.25 per hour). I don't class the cleaning jobs as a 'job'... I used to feel that I was an overqualified cleaner.

Jane, no longer in employment

carers, since they allowed them to fit in hospital appointments and to leave work early if necessary, without having to 'ask permission' from their line manager.

Some parent carers reported that part-timers did not have the same rights to flexi-leave as full-timers, or mentioned that despite regularly working longer hours than contracted (to save their 'positive TOIL'), they could lose their banked time if it was not taken within the specified period. Eve described it as '*an insurance against emergency events*', and proof, in case it were needed, that she puts in all her hours (and more), despite occasionally needing to leave early. She feels re-assured that she can have time off if she ever needs it.

Some interviewees had the freedom to alter their hours/pattern of work to suit their circumstances, operating with a form of trust-based flexi-time. Conversely, some parent carers with specialised job functions or working where services are highly time- or client-dependent, felt this limited flexible working

options and made emergency planning (e.g. in the event of a care crisis) more difficult. Examples given included cancelling patients' appointments, and needing to pull out of a meeting at the last minute. Eve explained that in the end this was why she felt forced to leave her previous job:

In the past, I had a different role in a smaller organisation, which meant the loss of one person at a meeting made a lot more difference. They should have been understanding, but because they were so dependent on each member of the small team, sometimes comments were made when things happened, particularly at the last minute. I could understand the difficulties it caused from the organisation's point of view, but I found the resentment too difficult to sustain.

Eve, returned to part-time employment



Term-time working

Finding holiday care for their disabled children had often presented significant problems for these parent carers. Term-time working was thus one of the most sought after forms of flexible working, and was mentioned as a critical factor enabling parent carers to return to employment, as well as by those seeking to progress in their jobs. Employment which was term-time only was among the major benefits of working in education, and for the four parent carers in our study who were working in these jobs was 'essential'.

I think it's fortunate in the end I was a teacher, because I don't think that if I had another job I would have been able to work as much as I have done, with the longer holidays – the biggest factor in enabling me to continue work is that I work in education. If I was working in another job I don't think that would have been possible.

Linda, returned to part-time employment

Despite this, one parent carer in our study who was working as an educational social worker, found that her term-time only position became the source of hostility and resentment from colleagues:

Some people in the team didn't really like it. It wasn't just me that had term-time working. In our service there's enough slack for a minority of people to work term-time, because we're mainly needed when schools are open. Things deteriorated from there. My working pattern didn't impact on any of my other colleagues at all – there was no issue whatsoever. It was as if they were resentful, almost, that they had to fight hard when their kids were young, and I was getting something easy, on a plate.

Wendy, returned to part-time employment

Other parent carers (working in both full and part-time jobs) had been unsuccessful in their requests for term-time working. Several felt that they needed more support and information about how to negotiate term-time or part-time working with their

employer to help them overcome some of the potential practical difficulties. Kate had been forced to leave her job after failing to negotiate term-time working:

[My employers] did not help – they were supposed to support carers, and I talked to someone about changing my pattern of work, and working in term-time, but it didn't come off...so I had to go. I could've stayed if I could've done [term-time working] but I couldn't ...it's very difficult to find a job that would fit in during the school holidays, but they are difficult, as there's nothing for my son to do.

Kate, no longer in employment

We also interviewed parent carers who had needed a range of more flexible working options, including a complete break from work, sometimes some time after initially returning to work as a carer (see Box 5.)

Combining caring and working – 'the daily juggle'

All the parent carers we interviewed described the difficulties associated with keeping their caring and work responsibilities well balanced. Many had experienced times when their working and caring responsibilities became more challenging or came into conflict. This usually occurred when there was a change in their caring role, or arose when they encountered negative responses from managers or colleagues.

Our interviewees described the normal, day-to-day juggling of their caring and working roles as a necessary part of combining work and care. Even when things were settled at home, the rushing to and from work, and dealing with transport and childcare arrangements - when these were in place - could still be the cause of much stress:

[It's] juggle, juggle juggle; changes; relying on different people. It was really hard, rushing home to get there on time, relying on sons, mothers, lots of different people. It's been such a struggle since the day she was born.

Tessa, in full-time employment



BOX 5 TERM-TIME ONLY WORKING

WENDY worked full-time in a social services department when her son was born 3 months prematurely, with cerebral palsy. Following a 'battle with personnel' over their 'rigid' maternity leave policy, a supportive line manager negotiated extended maternity leave and a period of unpaid leave, on her behalf. She very much enjoyed returning to her previous post on a job-share basis. However after 3-4 months, she was forced to give up her job because her childminder couldn't cope with her ill, constantly screaming son. She felt she had no choice but to resign, and took 5 years out of work to care for him, including nursing him through periods of illness, as there was no suitable local childcare provision for disabled children. Once her son's illness had settled down, she found she felt more tired, bored and depressed at home.

Her trigger for returning to work was a visit to her GP who wanted to prescribe anti-depressants. Determined not to take medication, she asked her doctor to help her access alternative support services. This resulted in an extended, permanent and regular sitting service from Crossroads that enabled Wendy and her partner to go out once a fortnight. With this support in place, she was able to muster the energy to plan her return to work. She applied for a post in a caring profession and was offered a part-time, term-time only post. Although she felt some of her colleagues were resentful of this, the arrangement suited her department's needs, and provided the flexibility she needed to continue her career in the absence of adequate holiday and after school cover: *'the term-time working option made a big difference to me'*.

LINDA took a 4 year break from work *'because it all became too much'* when her older child was 6, and her disabled son was 3. Her son was becoming more demanding and increasingly ill. *'So many hospital appointments and a lot of illness, so many demands that it would have been impossible to establish a routine to work'*. She used her time away from work to retrain and upgrade her skills to provide more flexible part-time options on her return to teaching. She gradually *'tested the waters'* by first doing a term's supply teaching with childcare support provided by her mother, until she felt able to cope with a permanent part-time job. (See also 'One parent carer's journey' - Figure A1)

This juggling becomes even more sharply focused and stressful when unpredictable or unplanned situations occur. These ranged from relatively minor, short-term, occasional events that could be planned for, such as routine hospital appointments, and those that could not, such as being called to school during the day or dealing with illness, or other family demands. For Carla, a widow and main carer of her 3 children, it was her older (non-disabled) daughter's ill-health and emergency admission to hospital that led to 'things toppling over' and the need for a day off work:

Everything has its own little slot. I juggle everything, but it's not good, because if just one thing topples over, the whole lot collapses. I've got a household to run, my day work, my cash in hand job caring for an older man, [my disabled son] to care for who's quite demanding,

my elder daughter who's not [living] here, but [is also unwell], so I'm up there overnight with her [in hospital], then I have to be back at a certain time in the morning to get my son ready for college, ring my work to say 'I'm really sorry I can't get into work'. Get my daughter up and out to school and then back to the hospital and come back again. So things can go pear-shaped. And it's the most immediate needs that come first.

Carla, lone parent carer working full-time

Where additional support with caring was available, parent carers explained that they would first negotiate and juggle roles and responsibility within the household or extended family network. Their preferred next course of action was to use any existing flexibility they had at work, such as flexi-time,



swapping working days or hours, or working from home. Most wanted to be seen as coping with their lives, and wanted to use the same mechanisms available to their other colleagues, who also had other issues to deal with:

I was very fortunate to work in that place, because the head was very understanding and also, I wasn't the only person who needed to have time off. I had a phobia about having leave until I went back to work and I saw that other people had different responsibilities and crises in their life, and they too needed to have leave...That was very reassuring when I needed to have time off. No-one abused it.

Wendy, returned to part-time employment

When care and work conflict

The evidence from our detailed interviews showed that most conflict between work and care responsibilities was triggered by a change in the parent carer's circumstances (at home or at work) which could not be accommodated by the daily juggling described above. Box 6 shows the 'journey out of employment', which some parent carers had made.

School holidays were cited as posing major problems for working parent carers – particularly those who were lone parents and who did not have access to holiday childcare which adequately met their child's needs. Other holiday difficulties had occurred when employers operated set holiday periods. One parent carer, working for a small engineering company, was obliged to take fixed holidays when the firm shut its operations, causing considerable difficulties in school holidays.

Marsha, a full-time working lone mother with a son with cerebral palsy, explained that she had frequently run out of annual leave to cover school holidays, sickness etc, and had therefore been forced to take unpaid leave – and on occasion, sick leave - to look after her son when there was no other option. She was one of the few parent carers we interviewed who had requested, and was eventually granted, carers' leave from her employer. When interviewed, Marsha had 5 days of carers leave in addition to her own annual leave, which she was using to leave work early when her son came home for weekends.

Special leave

Some saw special or carers' leave policies as a back-up for extreme situations:

We both have it in the back of our minds that [carer's leave/status/rights] are always there for when things get really bad. If we can manage [using our existing flexibility], we feel it's better. There's an uneasiness about flagging it up. But I know the chances are, they're there for good reasons and they should be there. I'm managing without using that, but I may well have to.

Linda, returned to part-time employment

A number of parent carers had requested other forms of leave – such as compassionate, emergency leave or time off for dependants – to cover absences from work that could not be easily accommodated using other normal means. Some had their requests denied, or, more commonly, were offered only unpaid leave, which most could not afford to accept, except in extremis. Parent carers in our study were often confused by differences in terminology, and unsure of their legal entitlements as parent carers to the different forms of leave, or of their employer's policies or practices in this area. They often felt that decisions were taken at their manager's sole discretion, and that these decisions varied according to how understanding and accommodating managers were of staff and their individual circumstances. These parent carers felt that a statutory entitlement to (additional) paid leave, that was not dependent on the vagaries of management or employer policy, was called for.

I think that if the Government brought a [policy] out where it was across the board, that it was a set rule and that you got paid, and not just depending on where you work – I'm at the grace of my employer.

Leanne, employed full-time

Attitudes of managers and colleagues

As well as the stress parent carers felt when juggling their working and caring responsibilities, they often experienced another range of emotions when a crisis hit, or if they decided to request additional leave. They were extremely appreciative of managers who



BOX 6 JOURNEY OUT OF EMPLOYMENT

CIRCUMSTANCES CHANGE

- Caring responsibilities/demands increase (e.g. child becomes ill, excluded from school, care support arrangements break down, other domestic issues)
- Work load increases or becomes more stressful (e.g. reorganisation/management change, increased responsibilities)



Working and caring roles conflict

- Use existing flexible working/time off arrangements (e.g. flexi-time, annual leave)
- Need for supportive manager and colleagues (e.g. to cover work short-term: re-arrange work/meetings)
- Negotiate/arrange additional care support (formal or informal) at home



Care crisis escalates

- (Problematic) negotiation for more flexible working arrangements (reduced/changed hours; agreed absence from work/additional time off e.g. carers, emergency, compassionate, time off for dependents; change of role/reduced responsibility)
- (Lack of) continued support from manager and colleagues (e.g. unsympathetic/unsupportive attitudes and responses, little/no on-going support or communication)
- (Limited/no) additional care support available at home/in the community (e.g. parent carer becomes sole carer; more stressed by home and work situation; multiple and complex issues)



Work/job becomes temporarily untenable

- Parent carer takes extended sick leave or unpaid leave



Work/job becomes permanently untenable

- Parent carer is made redundant; looks for another role/job within or outside current employer; resigns; takes a break from working/career break; retires early
- Parent carer dependent on benefits/ struggles to cope with loss of income
- More likely to become socially excluded, socially isolated, lose confidence, become more stressed/depressed as a result of caring situation



Benefits trap

- Complex and time-consuming benefit system to negotiate
- Hard to escape from benefits trap, to 'take the plunge'/risk back into employment
- Out-dated skills and experience, fading confidence
- Insufficient information on back-to-work benefits, advice and guidance on re-training, volunteering opportunities and job-seeking

treated them respectfully, with understanding and sympathy when things became difficult, and often tried to repay their employer's trust by making up the lost work in their own time and demonstrating a high degree of commitment:

I'm always taking time from work, but [my boss] is very understanding. He will say I can't help it, but he also knows I bring a lot of paperwork home with me. I



spent all weekend working on school. I don't like doing that, because that's my time, but I just feel I need to do that, because it's give and take. He's very good to me, and I bring stuff home and do it. And that way at least, I can get into work for ten past eight in the morning. Sometimes I can still be there at half four, even though I (officially) finish at 3.40.

Carla, lone parent carer working full-time

This reciprocity and feeling of goodwill echoes the evidence of other studies (Lewis et al 2000; Yeandle et al 2006), and is an important element of the 'business case' for supporting working carers in employment.

However, most parent carers who were or had been in paid work could recall occasions when their managers and/or colleagues had been inflexible or showed a lack of understanding about their caring role. Fiona, who had only recently returned to work, said she felt 'degraded' when she asked for compassionate leave:

I realise that she [employer] has all the pressures of funding and things, and that's why she's doing this. She's a nice person, but when it comes to things like this... you're just there to do a job, you're not there to do anything else, you've got no other life, once you walk in through that door.

Fiona, returned to work part-time

Many parent carers in our study spoke of feeling 'guilt' about the competing demands of home and work. This often related to a feeling of 'letting others down', but became worse if the employer lacked understanding. Some of our interviewees reported that although they worked for employers who had 'family-friendly' policies, this made little difference if their own individual manager or colleagues were not supportive:

I told them before I took the job about my caring commitments, and they were fine, 'Is there anything we can help you with?' But when it came to the crunch, they said, 'Well, we've got invoices that need to be

done, and we've got a target to reach. I said, 'But my son's in hospital, and I need to be with him. I can't be in two places at once.' They're all good at the beginning, 'Yeah, yeah we'll support you and everything.' But [not] when it comes to the crunch.

Liz, employed part-time

Liz's example (shown in Box 6) illustrates what can happen when a care/work conflict escalates and the job becomes unsustainable.

Work colleagues' attitudes also had a major impact on how well supported parent carers felt in their jobs, and could ameliorate the effects of an unsympathetic boss. Colleagues who were understanding and thoughtful were appreciated, and had often assisted in practical ways, avoiding an escalation of the work/care conflict into an untenable situation. However, colleagues could also undermine parent carers. One of our interviewees reported 'snide' comments, resentment and hostility from colleagues (mainly older women):

There was one time when my son was poorly and when I came into work, the first thing they said was, 'Ooh, you've had time off again have you? You've been on holiday again, have you?' These sorts of digs. She must have known why I was off, that my son was really sick, poorly. Even when I told her, she carried on with these comments and digs. Never once said, 'Oh, I'm sorry, how is he? Is he ok?' None of that. Ironic, when you think they are educational social workers supporting families where children have special needs.

Wendy, returned to part-time employment

Many of those who reported repeated negative experiences when trying to negotiate conflicting work/care demands had found their job became untenable, forcing them to leave employment altogether or to look for another job. Where a parent carer was determined to stay or had few alternatives, they 'hung on' until the manager or colleagues involved eventually moved on.



4 Support for carers and employment

The need for support

Informal support – family and friends

The amount of informal support available from family and friends varied greatly between families and over time. Some main parent carers had partners or immediate family who could help out, mainly when the child(ren) were young. Grandparents, friends and older, responsible siblings could 'babysit' initially, but were less able or willing to do so when the child got older and had more challenging behaviours and needs.

Most of the parent carers we interviewed reported that they currently had little or no regular informal support outside the immediate household. Those living in larger cities and other urban areas often lived at some distance from their family support network. Many found it difficult establishing a social network, as their opportunities for developing a social life were curtailed by caring. Those who could still call upon close friends and families to help in emergencies sometimes felt reluctant to do so. One commented:

There's this sense of responsibility, and I feel guilty having to leave him with friends, knowing all the sorts of things that he gets up to.

Chris, not in employment

Parent carers' experiences of alternative services

In the absence of informal support to enable a carer to carry out paid work, many parent carers had turned to the alternative care support provided by statutory, voluntary and private sector agencies. The services most needed by carers of disabled children include childcare, respite care and sitting services to provide a break from caring. Unless a carer directly approaches private care providers to pay for (often costly) alternative social care themselves, in most cases, carers first have to access funding and support through their social services department (SSD) and social worker.

Few parent carers in our sample used formal alternative care services regularly, and some had no

contact with their local social services department. Most viewed social workers and social services as a last resort, to be used only when absolutely necessary. Even then, many realised that resources were severely rationed and there was little assistance available to them:

We were told time and time again: unless you were in crisis there was no support for us at all. And looking back, I think we probably were in crisis, but you don't like admitting it.

Amy, in full-time employment

As discussed earlier, most parent carers were forced to rely on family and friends to help out in emergencies, or take time off work to cope alone. Occasionally, a parent carer arranged and paid for alternative care services themselves.

Linda was one of the few interviewees who reported a positive outcome from her contact with social services. A special needs teacher (whose situation is illustrated in 'One parent carer's journey' in Fig A1), Linda's situation became very difficult when her son was unexpectedly excluded from school for 6 months. Her social worker organised an additional placement at a children's centre, and although Linda found dealing with social services and education slow and arduous, and had to take time off work to recruit two childcare students to provide additional home care for her son, she felt she was fortunate. She had social worker support, and the knowledge and personal persistence to find a solution which enabled her to return to work:

I would read a White Paper from front to back to know exactly what he is entitled to. It works for us. It also works because I work in education – I know how things work.

Linda, returned to part-time employment

At least half our interviewees described the struggle of accessing basic services (including education, health and social) as 'fighting', 'kicking up a fuss', 'a battle' or 'war'. The general experience was 'that to get anything, you have to ask, and then beg', as most services or information were not automatically given. It was believed that 'submissive carers don't get heard', therefore being assertive, pushy and doggedly



persistent was the only way to get some of what you needed. One parent carer was even considering taking legal action as a way of speeding up the process.

Service availability depended on arrangements within the local social services department and voluntary sector, which varied greatly from area to area. The support available also depended on the age of the child, the nature of his/her disability and their phase of education. Most children in the sample had behavioural/learning disabilities such as autism, Aspergers Syndrome, ADHD or Downs Syndrome. Some parent carers stated that even though their child was statemented and attended a special school, they were not considered '*disabled enough*' to qualify for social services/alternative care services. Many were aware that resources are very limited, and that other families were in much worse situations, particularly those who had children with severe physical disabilities. Their experiences of childcare, respite or sitting services provided by the voluntary sector were mixed, but in most cases these services could be accessed only through social services.

Childcare

Although there is more provision, there's still not enough, and it's still not a service specifically designed for working parents of SEN (Special Educational Needs) children. I feel very aggrieved by that. There's all this emphasis on getting people back to work, subsidised nursery places, after school clubs, breakfast clubs. But our children can't access them.

Linda, returned to part-time employment

Childcare was often the biggest hurdle facing parent carers re-entering or remaining in employment. The limited options available for disabled children left many parent carers feeling that '*back-to-work isn't for you*'. They felt they did not have the options available to other parents, as universal provision of appropriate support services to promote their workforce participation was absent. These parent carers felt they were '*expected*' to stay at home and to make up for shortcomings in social care provision – and that they were not expected to demand the same opportunities or support as other parents, nor to work. A few parent carers had been offered childcare places, but these

had often been inappropriate for their needs, their child's ability or his/her age group. Consequently their children had limited play opportunities and their parent carers became more socially isolated as they were forced to cope alone at home. Even where local provision was '*inclusive of special needs*' this often meant only that it was available to physically disabled children, rather than to children with behavioural difficulties, who were often seen as potentially '*disruptive*'.

Our interviewees claimed that this lack of appropriate provision did not always arise from inadequate funding. Emma had found that while her local social services would pay a higher hourly rate to cover the increased cost of attending clubs and childminders, these services nevertheless refused disabled children, citing the additional insurance cover needed:

The childminders are just not going to pay out for the extra insurance when there are that many other kids needing childcare. And it just appears to be no-one's problem at the moment. It's OK for them to throw money at us - they think that solves everything. Do they want for us to sit at home all day? We want help!

Emma, returned to part-time employment

Finding adequate childcare during the school holidays was another big headache for working parent carers. Unless they had term-time only contracts, most parent carers had insufficient annual leave to cover school holidays, and some were forced to take unpaid leave. Some found they did not qualify for free or subsidised places because their child's disability was not considered sufficiently severe, or where offered, was costly and/or only covered one or two weeks a year.

School

Although school is not an '*alternative care*' service, it is how many children are supervised and cared for while their parents are at work. Parent carers often find that the educational provision for their disabled child is limited and fraught with difficulties, which can be especially acute if they are working or wish to work. Although current policy aims to provide more '*joined up*' services for children – connecting education, health, and social service provision more



harmoniously than at present – the parent carers in our study had frequently encountered frustrations in dealing with issues that cut across different services, often taking up valuable work time and phone calls to resolve.

Parent carers in this study pointed out that the most appropriate special school for a child's specific needs (particularly residential schools) can be located a significant distance from the family's home. Some had seriously considered moving their home and their job to find the right school, or had moved for a term while their child settled as a boarder, with obvious implications for them as working parent carers. Even 'local' provision of secondary education for children with special needs usually entailed a much longer journey to and from home for the child - although this could be beneficial for some working parent carers, as where the child was conveyed between home and school by special transport, this gave them a longer working day.

A number of parent carers had been called into school during the day when their child had been involved in 'an incident'. These occasions were often very frustrating for working carers, as the incident in question often centred on behaviour linked to their child's disability, which they felt the school should have been able to manage. For some (such as Linda, mentioned above), these incidents led to their child being excluded from school.⁵ Several parent carers reported cases where other parents, faced with a permanently excluded disabled child, lost or gave up their jobs because the child could not be found an alternative school place.

Transition to adult services

Whatever the shortcomings of educational and social services provision for school aged children, these were still viewed as superior when compared with adult services. Their child's transition to adult services at age 18-19 years often filled working carers with apprehension and dread. Sheila commented:

You're on your own. He used to get a lot of help for his sporting activities, his social life, going off for outings and that. But once you've left school, you drop off the scale.

Sheila, no longer in employment

I look to the future and think, I've put all this time and energy and investment into giving him what I consider to be a very full life, enabling myself to work to contribute to the family financially. To think that, after all that, it's a bit of a con. They tell you when your child is born that things are different today, and you work very hard at it, and then they get to 18 - and then you are expected to give [work] up and be a carer around the clock until you die.

Linda, returned to part-time employment

Parent carers of disabled young people reported significant difficulties in dealing with the reduction in service provision as their children got older. Examples included limited day care centres, no overnight respite places for adults, erratic and changeable college and 'work training' placements, and transport problems. One parent carer was forced to reduce her working hours to fit in with her daughter's new and constantly changing schedule.

Residential placements were highly desired by parent carers, who viewed them as crucial to their child's independence and to their own freedom to pursue a more normal life for themselves – a life that often included working, even for those who had not previously been in paid employment. Those who had secured residential support for their child found that it enabled them to work longer hours (up to full-time). However, their job could still be disrupted when unexpected crises occurred, or during extended periods when their child was away from the residential facility.

Other support services

For parent carers, respite breaks were vitally important in enabling them to cope with the long-term demands of care and work, providing short periods of relief from caring, or brief opportunities for 'a normal life'. Many had been told they were not entitled to services because their child's disability was 'mild', or because the child's needs or behaviour could not be accommodated. Those who had received services had often been through a long and difficult 'fight'. Others reported that they had been offered inflexible, inappropriate or merely short-term support,



and that some arrangements (for example 'shared care' arrangements with another family) broke down after a short while.

Although transport services reduced the burden on working carers, they were frequently cited as unreliable or inflexible (variously late, on strike, cancelled or diverted without notice). This had caused frequent care emergencies which had potentially negative consequences for parent carers in the work situation. A private car was expensive, but an absolute necessity, for nearly all parent carers. For those without one, relying on public transport or on costly taxis restricted their lives and their job opportunities even further. Access to support services was more difficult, and carers in rural areas faced particular hardships.

Our interviewees also reported that the way medical services were organised adversely affected their ability to fulfil work obligations. They were often required to fit doctor's or hospital appointments in during their working hours, and some appointments were very inflexible, with clinics held on fixed days, and almost always in 'office hours'. This finding corroborates Lewis et al's earlier research, which also identified this problem.

In the voluntary sector, carer support organisations played a vital role for many parent carers, and were generally viewed as an important source of advice, guidance, social contact and support. However some parent carers noted that they did not want 'gripe groups to sit around chatting about the problems of caring', and felt that local carers' groups mainly catered for older carers. Others mentioned that they had joined local groups which supported parent carers of disabled children, and had found them a valuable source of information relevant to their situation, such as how to negotiate part-time employment at an interview. Their involvement with voluntary sector carers' organisations had been pivotal for some who were looking to return to work. Their confidence was boosted; they received information and advice on benefits, job options and alternative care services; and they could access on-going support. Nevertheless some had found that sessions ran at inconvenient times, or did not provide childcare facilities or alternative support for the looked after person:

They seem to be geared up for people who don't work. They have courses, meetings, workshops whatever, all during the day...

But I can't do this during the day, as I'm at work. There's nothing available for someone in my circumstances, looking after a teenager and an elderly person.

Carla, in part-time employment

I get the carers' network newsletter, and they say there are meetings - and they're always after 6pm. That's no good to me, there's no childcare facilities available or it's at a time when the little one might be going to bed, or they're at weekends when I'm at work, or they're miles away, so I have the transport to get there, but not the childcare.

Rose, self-employed full-time

The benefits system and 'trap' was a major problem for parent carers, and a critical issue for those returning to work (see Box 6). Even confident and highly motivated returners like Frank found moving off benefits and into work was:

...the scary bit, it's still a bit of a leap... it doesn't encourage anybody to work.

Frank, returned to part-time self-employment

Despite this, and with support and information from their local carers' organisations, two parent carers in our study had returned to work knowing they would be worse off than if they remained on benefits. Nonetheless, they decided that this short-term sacrifice would be beneficial for their longer-term prospects and development.

Careers advice - relating to career direction, how to present a CV, job searching, making a job application and job interview techniques - was also needed, especially by parent carers wanting to return to paid work after a spell of full-time caring. When parent carers had found this type of support it was highly valued, but for most this sort of help had not been available. Bev had been to see her New Deal for Lone Parents adviser, but had not found the help there that she needed:

I should go in and talk to careers really, I don't really know where to go and what to do, I don't know where to head. I don't even know whether I'd enjoy going back



and working in an office, but because that's what I've always done, that's what I've headed towards.

Bev, not in employment

Most of the parent carers we interviewed reported high levels of stress, anxiety and depression, and so it is not surprising that counselling services were often mentioned as a helpful source of support. Although paid work enabled a lot of parent carers to '*retain their sanity*', combining work and care also created a lot of additional stress as they juggled different responsibilities.

Our interviews with parent carers thus showed that they had experienced a complex range of issues related to their constantly changing caring responsibilities. Employment practices and policies (both within a place of employment and as laid down in law); issues of personal and individual identity; the availability and flexibility of informal and formal support services, were all factors which had helped or hindered them in their attempts to combine paid work with the unpaid care of their disabled child. The most important ways for parent carers to hold on to a job or to re-enter employment were: opportunities to work flexibly; employment policies, practices and attitudes that support carers in times of crisis; and crucially, support services that are responsive to the varied needs of a diverse range of sick or disabled children and those who care for them.

⁵ Wilkin et al (2005) show that, in England, SEN pupils (including those with behavioural, emotional and social difficulties) are four times more likely to be permanently excluded from school than other children.

5 Conclusion

This report on 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, shows 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, as we have seen, 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 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 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 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 a 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.

6 Co-resident, unless stated otherwise

7 Intensity of caring established in 2004 survey: Very heavy >100 hours/week; heavy 50-100 hours/week; moderate 20-49 hours/week; low <20 hours/week

8 Not a carer of a disabled child, so not included in the main discussion

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Figure A1: One parent carer's journey

LINDA	1987	1988-90	1991-94	1994-98	1999	2000	2001	2002	2003	2004	2005
WORK	f/t teacher	Returned to p/t teaching following maternity leave	Returned to teaching 1 day/wk following 2nd maternity leave	CAREER BREAK College courses to update teaching skills; conversion courses to teach primary and SEN (to offer more flexible options)	p/t supply for one term "testing the waters"	p/t SEN teacher	Supportive head, but school far from home		p/t SEN teacher CHANGED JOB TO BE NEARER HOME TIME OFF WORK		
CARING RESPONSIBILITIES		1st son born in 1988	2nd son born with Downs Syndrome in 1991	1994 6 year old at school 3 YEAR OLD DISABLED SON BECAME ILL, MANY HOSPITAL APPOINTMENTS Difficult being at home FT					DISABLED SON EXCLUDED FROM SCHOOL FOR 6 MONTHS		
INFORMAL SUPPORT					Informal childcare support mainly from husband and mother. Occasionally friends.						
					Mother's childcare support returning to work after career break	Privately employed 2 students/care workers to cover after school care				(Mother died). Some emergency support from sister and older son	
FORMAL SUPPORT SERVICES					Difficulties finding 'inclusive' childcare/ after school care - delayed return to work	Successfully campaigned for more local inclusive SEN childcare					
					'Waving not Drowning' conference - trigger to 'bite the bullet' & return to work	Supportive social worker Good care plan: SEN holiday play schemes; after school club x2/wk					1st respite care break in 14 yrs



Table A1: Carer characteristics

Pseudonym	Region	M/F	Ethnicity	Carers of: age of disabled child (+ other dependent children) + others	Family circumstances	Intensity of caring	Employment status in 2005
Carers who remained in employment 2001-2004							
Cath	Yorks	F	White	10 yr (+1)	Co-carer husband. No other informal support	very heavy	p/t employed (changed from ft)
Delia	Yorks	F	White	18 yr (+1)	Lone parent/new partner. No other informal support	heavy	p/t employed
Hannah	Yorks	F	White	17 yr (+1)	Lone parent/new partner. Former carer of both parents (recently died). No other informal support.	heavy	p/t employed (on-call 24/7); considering self- employment
Liz	Yorks	F	White	15+13yrs (both sick/disabled)	Husband helps. No other informal support	moderate	p/t employed; temp jobs; 5 jobs in 3 years
Tessa	Yorks	F	White	20yr	Lone parent/new partner. No other informal support.	very heavy	f/t employed
Iris	N East	F	White	14 yr (+2)	Co-carer husband. Supportive family	very heavy	p/t employed (looking for career change)
Leanne	N East	F	White	12 yr	Husband (not employed) full time carer. No other informal support	heavy	f/t employed
Pat	S East	F	White	17 yr (+3)	Lone parent. No other informal support	moderate	p/t employed
Carla	S East	F	White	20+18yrs (both disabled/sick) (+1); occn carer of grandmother	Widowed lone parent. Informal support from live-in friend	heavy	f/t employed; also paid elder carer (cash in hand)
Eve	London	F	White	3 yr	Co-carer husband. No other informal support	heavy	p/t employed
Ray	S East	M	Asian	Disabled wife (no dependent children)	Sole carer of his wife. No other informal support	moderate	p/t self employed; voluntary work





Pseudonym Region M/F Ethnicity Carers of: age of disabled child (+ other dependent children) + others Family circumstances Intensity of caring Employment status in 2005

Carers who returned to employment between 2001 and 2004

Emma	Yorks	F	White	19+17+10yrs (2 disabled & 1 ill)	Lone parent /new partner. Very limited informal support	very heavy	p/t variable hours; term time only
Fiona	Yorks	F	Asian	13 yr (+2)	Husband. Very limited informal support.	very heavy	p/t employed
Gill	Yorks	F	White	23 yr + ill husband	Some informal support. Has health problems herself	heavy	p/t employed
Amy	Yorks	F	White	25 yr non-resident daughter, mainly living independently. Carer of elderly mother.	Husband. Very limited informal support	moderate	f/t employed
Wendy	N East	F	White	9 yr (+1)	Co-carer husband. Very limited informal support	very heavy	p/t employed
Rose	N East	F	White	6 yr granddaughter; carer of sick step father (non-resident)	Lone carer. No informal support	heavy	f/t self-employed
Linda	London	F	White	14 yr (+1)	Co-carer husband. Some informal support.	heavy	p/t employed
Marsha	London	F	Black	16yr at weekly residential school (+1)	Lone parent. Very limited informal support. Care-related health problems.	moderate	f/t employed

Carers who left employment between 2001 and 2004

Bev	Yorks	F	White	14 yr (+1)	Lone parent/new partner. Very limited informal support. Has long-term illness	moderate	Seeking employment
Jane	N East	F	White	25 yr, (+2 with healthproblems)	Husband (not in employment). No other informal support. Has health problems	moderate	Not in employment – left work to care f/t
Diane	London	F	White	16yr (weekly residential school); carer of non-resident elderly mother	Lone parent. Health problems. No informal support	heavy	Early retired – due to caring related ill-health

Pseudonym Region M/F Ethnicity Carers of: age of disabled child (+ other dependent children) + others Family circumstances Intensity of caring Employment status in 2005

Carers not in employment 2001-2004

Sheila	Yorks	F	White	28 yr; + ill husband	Has health problems; nearing retirement age	heavy	Not in employment
Val	Yorks	F	White	22+18 yr (disabled/ill); husband with MH problems; & ill elderly mother	Supportive family (but not local).	highly variable	Now p/t carer of employed
Kate	N East	F	White	16 yr (+4);	Lone parent. Health problems. No informal support	very heavy	Not in employment
Frank	S East	M	White	15 yr (+2); carer of his disabled wife	Very limited informal support	moderate	Now p/t self-employed
Marie	S East	F	White	14 yr; former carer of father-in-law (recently died)	Husband. Some informal support.	moderate	Seeking p/t employment
Nicky	S East	F	White	9 yr	Husband helps. Has disability and health problems. No other informal support.	heavy	Not in employment
Chris	London	F	White	19+15yrs (+1)	Disabled lone parent. In temporary housing. Very limited informal support	moderate	Not in employment
Nora	London	F	White	8 yr	Husband helps. No other informal support	very heavy	Not in employment





Finding Out More

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Published November 2006

ISBN 1-873747-31-4

Code UK4020

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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