

**CARERS** look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

## PARLIAMENTARY BRIEFING

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# The Carers (Equal Opportunities) Act 2004

England and Wales

September 2004

## Background to the Act

The Carers (Equal Opportunities) Act was introduced into the House of Commons as a Private Member's Bill by Dr Hywel Francis, MP for Aberavon, in January 2004.

The Act has successfully passed through both Houses of Parliament with cross-party support and received Royal Assent on 22 July 2004. It is likely to be implemented in England and Wales from 1 April 2005.

The Act will give carers more choice and opportunities to lead a more fulfilling life, by ensuring that carers receive information their rights, to ensure that their assessments consider leisure, training and work opportunities and will give local authorities strong powers to enlist the help of housing, education and health in supporting carers.

A copy of the Act is available at: [www.hmso.gov.uk/acts/acts2004/20040015.htm](http://www.hmso.gov.uk/acts/acts2004/20040015.htm).

Explanatory notes on the Act are available from:  
[www.legislation.hmso.gov.uk/acts/en2004/2004en15.htm](http://www.legislation.hmso.gov.uk/acts/en2004/2004en15.htm).

## Support for the Act

The Act enjoyed strong cross-party support, including Government support and Frontbench support from the Conservatives and Liberal Democrats. The 11 co-sponsors of the Act include MPs from the Conservative, Labour, Liberal Democrat and Ulster Unionist parties and Plaid Cymru.

## Why do we need a new Act for carers?

Society depends on the support that carers provide to sick and disabled people. Carers save the state £57 billion every year<sup>1</sup>. However, in order to continue caring and live a more fulfilled life outside caring, carers need to be informed of their rights and their own well-being needs to be positively considered. Many carers give up work to care and find it hard, once providing substantial amounts of care, to then access learning and training opportunities and combine work with care.

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Carers National Association, trading as Carers UK, is registered in England as a company limited by guarantee number 864097  
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**CARERS** UK

## What rights do carers have currently?

- Right to an assessment – carers who provide regular and substantial care are entitled to a carer’s assessment, which will look at their needs as a carer;
- Carers can also receive services in their own right under the Carers and Disabled Children Act 2000;
- Intermediate care – carers can receive free intermediate care services, and equipment up to the value of £1,000, for up to 8 weeks following the discharge of a patient;
- Carers have a right to request Direct Payments, cash payments in lieu of social care, and can receive vouchers in lieu of break services.

## What rights were carers missing?

- Legislation up until now offered carers support “in their caring role.” Carer’s assessments did not necessarily have to take into consideration wider issues of carers’ lives, such as training, employment and leisure;
- Guidance made it best practice to give information to carers, however research consistently shows that lack of information is still one of carers’ main concerns.

## What the Act will do

The Long Title of the Act is: “an Act to place duties on local authorities and health bodies in respect of carers; and for connected purposes.”

The principal aims of the Act are to:

- Ensure that work, life-long learning and leisure are considered when a carer is assessed;
- Give local authorities new powers to enlist the help of housing, health, education and other local authorities in providing support to carers; and
- Ensure that carers are informed of their rights.

## Section 1 - Duty to inform

**Section 1** amends the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. The Section states that: **“If it appears to the local authority that it would be required to carry out a carer’s assessment on being asked to do so by (a) the carers or (b) a person with parental responsibility for a disabled child ... The local authority must inform the carer, or, as appropriate, the responsible person, that he may be entitled to a carer’s assessment.”**

The amendment to these pieces of legislation would ensure that:

- When a local authority is assessing a disabled child or a disabled adult they will have to inform the carer of their right to a carer's assessment – if it appears that they might be entitled to it;
- Likely candidates for a carer's assessment will be told about their rights.

## **Benefits of Section 1**

The aim of this Section is to ensure that carers are getting information about their rights in a more consistent way. This will mean that around the time of the community care assessment, a potential carer is informed of their rights by word of mouth, by being given a leaflet, etc. Existing guidance under both the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000 states that carers should be informed of their rights. However, the latest Social Services Inspectorate (SSI) report stated that carers were not routinely offered an assessment of their needs. The report recommended that this should be made part of the routine.

Both Northern Ireland and Scotland both have similar provisions and the introduction of these provisions were warmly welcomed by Carers Scotland and Carers Northern Ireland respectively. From the research it is clear that carers want information about rights and other vital issues so that they can decide how to plan their lives and exercise their rights when or if they wish to.

In amending the Carers (Recognition and Services) Act 1995, Section 1 applies to carers of all ages, including those under 18, as long as they are caring for an adult who is assessed under section 47(1)(a) of the NHS and Community Care Act 1990. Informing children of their right to an assessment must be undertaken in the context of family assessments and undertaken in an appropriate manner. The Section also amends the Carers and Disabled Children Act 2000, which applies to young people aged 16 and 17 caring for adults.

## **Why the Section is important**

Carers consistently rate information as one of their top priorities and information is amongst the primary recommendations of carers in nearly every research report carried out by both Carers UK and other carers' organisations.

Information about services and other rights is the first step for a carer about getting support at the right time. Every year, over 2 million adults become carers.<sup>2</sup> According to research by Carers UK almost half (45%) of carers who had not had a carer's assessment did not know that they were entitled to one.<sup>3</sup> Information about their rights to support can be vital in maintaining carers' health and well-being.

### **Key statistics:**

- Only half of carers were told about their rights when the person they were caring for was assessed (Missed Opportunities research, 2003).
- Carers say that the first step in accessing support is knowing about your rights and where to turn.
- Evidence from implementation in Scotland where they already have these provisions is that they have not increased costs or expenditure, but have been warmly welcomed by carers.

## **Section 2 - Work, training, education and leisure**

**Section 2** of the Act amends both the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000 by ensuring that carers' assessments include consideration of whether the carer works, or wishes to work, and are undertaking or wish to undertake, education, training or any leisure activity.

The Section would amend Section 1 of the Carers (Recognition and Services) Act 1995 and Sections 1 and 6 of the Carers and Disabled Children Act 2000. This amendment would mean that any carer's assessment carried out under either Act:

**"Must include consideration of whether the carer –**  
**a) works or wishes to work,**  
**b) is undertaking, or wishes to undertake, education, training or any leisure activity."**

**Section 2** also covers children under the age of 16 with caring responsibilities. It does this by amending Section 1 of the Carers (Recognition and Services) Act 1995, which has no age limit, though the Minister, in his response in the Committee, said that assessments of children with caring responsibilities "should routinely be assessed under the Children Act 1989" rather than the Carers (Recognition and Services) Act 1995.

### **Benefits of Section 2**

Section 2 would mean that local authorities would have to amend their assessment procedures to ensure that they incorporated issues of work, life-long learning and training. Carers UK firmly believes that it could help signpost carers to new training and learning courses, help them on the pathway back into work or to remain within work. Nearly 80% of carers discuss breaks in their assessments, but this should ensure that leisure is also considered.

### **Why the Section is important**

This Section would change the ways that carers are currently perceived. All legislation to date is focused on carers' "ability to provide and to continue

provide to care". Carers' services are based, in legislation, on "helping the carer to care" – seeing carers only in relation to their caring responsibilities and not the things that most people take for granted – leisure, work, education and learning opportunities.

### **Case study of a parent with a disabled child:**

*" I tried to talk to them [social services] about going back to work but they said my situation was just too difficult. They would not even discuss it with me. I was at the end of my tether after one particularly bad week and was close to losing it. Whilst I was sorting out yet another problem with our benefits at the Citizen's Advice Bureau I found a leaflet about the local college that had all sorts of courses for people like me – no confidence, nothing to offer! And they were on at times when I can sort out a bit of care for Danny and they are fairly flexible so that hospital appointments and the like wouldn't get me thrown off the course. I really look forward to studying and I cannot believe how my life has changed. I feel like I'm just around the corner from work, rather than 40 miles away. I feel I've got all sorts of opportunities and I feel like I'm worth something. Danny too, gets more out of me because I'm happier, and I feel like I have a life too, outside of my caring."*

### **Case Study post legislation**

*Case study: Carer of a disabled child. The policy at local authority level directs staff to consider opportunities for carers – that they might have if they did not have caring responsibilities.*

*The carer raises the issue of employment tentatively, feeling very unconfident, and it feeling that employment might be fairly impossible. The assessor knows about the duty to promote equality of opportunity through internal training and literature. The assessor is not an expert in what courses are on offer for back-to-work support, nor does he need to be, but he knows that there are flexible courses around at the local colleges. One of the results of the assessments is that the social worker sends signposting information to the carer – who then links straight into the learning opportunities. The carer feels that her social worker is helping her to have a more fulfilled life, whilst still being committed to her family responsibilities.*

### **Key statistics**

- \* 80% of carers are of working age.<sup>4</sup> Every year 2.3 million carers stop caring, appropriate information will give carers better opportunities for education, training and employment when they end their caring role.
- \* According to research by Carers UK, 6 out of 10 carers providing substantial amounts of care, had given up paid work to care.<sup>5</sup>
- \* In the same research, 7 out of 10 carers found themselves financially worse

off since becoming a carer.

- \* A recent Social Services Inspectorate Report<sup>6</sup> shows that carers stress the value of being able to go out to work.
- \* A recent TUC report<sup>7</sup> argues that in order to achieve full employment and economic growth the Government's Spending Review 2004 should focus on getting into employment the two million people currently not in work but who want a job. This includes half a million people with caring and family responsibilities.
- \* Research by Caring Costs found that nearly 80% of carers wished to return to work if they could.<sup>8</sup>
- \* Caring Costs<sup>9</sup> found that carers lost an average of £9,000 a year by taking on significant caring responsibilities and having to reduce working hours.

## **Section 3 - Co-operation between authorities**

Under **Section 3** a local authority can request any local authority, local education authority, housing authority, or health authority to assist in the planning of carers' services.

**Section 3** provides that **if a local authority requests an authority ... to assist it in planning the provision of services ... the authority must give due consideration to the request.**

The other important provision under Sub-section 2 of the Section provides that a local authority, in carrying out a carer's assessment, can request any of the above authorities to provide services if the carer's ability to provide care might be enhanced by such services. They have to give due consideration to this request.

Importantly, Section 3 stresses that the services in question could be provided either to the carer or to the disabled person. This would be important where, for example, leisure services work to support the disabled person, whilst the carer does other things, or joins them in the leisure activity.

### **Benefits of the Section**

Section 3 would give co-operation and joint working powers in respect of carer's assessments under both the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. However, these powers will be restricted to issues concerning carer's assessments and carers who would be entitled to carers' assessments. Nevertheless, the principles are welcome.

### **Why this Section is important**

A key issue for carers is the fact that policies locally do not join up and they find it frustrating. Research by Carers UK, *Ignored and Invisible*<sup>10</sup>, found that carers' top priority was health and social services working together. Carers UK believes

that better joint working between local social services departments, different local authority departments and other local public authorities, such as health bodies would deliver better and more cohesive support for carers. It would make it more likely that carers would be linked into other forms of support.

## Broader benefits of legislation

There are a number of key benefits to the legislation:

- increase in employability of carers who wish to return to work
- more carers being able to juggle work and care and remain in employment
- more opportunities for carers to access learning and training opportunities
- more opportunities for carers to lead a more fulfilled life

There would be potential personal benefits for carers as well as benefits for the economy.

### Economic Benefits – Recruitment/Retention/Employability

Giving carers better information about training and employment opportunities will also have positive economic benefits. A recent TUC report shows that one of the main causes of economic inactivity is caring responsibilities.<sup>11</sup> Every year 2.3 million carers stop caring and as 80% of carers are of working age<sup>12</sup> this is a very large pool of potential employees.

Carers who participate in life-long learning will gain new skills, this improves carers well-being but also improves the skills pool from which employers can draw. Supporting carers in employment also delivers a key objective in maintaining the economic viability of our workforce, delivering economic benefits for employers (such as the reduction in recruitment, retraining, etc. costs) and positive contributions to the Treasury.

## References

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<sup>1</sup> Carers UK 2002, *Without Us: Calculating the value of carers' support*

<sup>2</sup> *Caring Relationships Over Time*, Michael Hirst, SPRU, University of York, 2001

<sup>3</sup> Carers UK (2003) *Missed Opportunities: The impact of new rights for carers*

<sup>4</sup> Office of National Statistics, *Census 2001*

<sup>5</sup> Carers National Association (now Carers UK) (2000) *Caring on the Breadline: The financial implications of caring*

<sup>6</sup> Jan Clark, *Independence Matters: An overview of the performance of social care services for physically and sensory disabled people*, Social Services Inspectorate, 2003.

<sup>7</sup> TUC 2004, *Full Employment – the next steps*; TUC report on working age inactivity in Britain and the rest of Europe.

<sup>8</sup> *The True Cost of Caring*, Caring Costs, published by Carers National Association, 1996.

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<sup>9</sup> Caring Costs, 1996, *op cit.*

<sup>10</sup> *Ignored and Invisible*, Carers UK, 2001

<sup>11</sup> *TUC 2004, Full Employment – the next steps; op cit.*

<sup>15</sup> Office of National Statistics, *Census 2001*

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