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

The Carers (Equal Opportunities) Bill

Private Members' Bill – Dr Hywel Francis MP
Second Reading: 6 February 2004

Background to the Bill

Dr Hywel Francis MP (Aberavon), came second in the Private Members' Ballot and recently introduced the Carers (Equal Opportunities) Bill. His Bill will focus on health, information, employment and life-long learning issues for carers and will have its Second Reading on **6 February 2004.**

Carers UK have been working closely with Dr Francis on the content of the Bill and believe that, if successful, it will make a real difference to carers' lives. The Bill was launched on Monday 26 January 2004.

Support for the Bill

The Bill already has cross-party support. The 11 co-sponsors of the Bill include MPs from the Conservative, Labour, Liberal Democrat and Ulster Unionist parties and Plaid Cymru.

The Bill also has the backing of a wide range of organisations, including the ADSS, NIACE and the Guidance Council. Several major employers have also pledged their support for the Bill, including British Gas, British Telecom, the Metropolitan Police, Listawood, HSBC, Price Waterhouse Coopers and Nestor Healthcare, who welcome the benefits they would receive in terms of retention and recruitment of carers. The Bill also has the support of various voluntary organisations concerned with carers issues, including: Crossroads Caring for Carers, Contact a Family, Help the Aged, the Stroke Association, the National Autistic Society and the Childrens' Society.

Why do we need a Bill for carers?

Society depends on the support that carers provide to sick and disabled people. Carers save the state £57 billion every year[1]. However, in order to continue caring and live a more fulfilled life outside caring, carers own health and well-being needs to be positively considered.

Research shows that caring can have a negative on the physical and mental health of a carer[2]. Many carers also 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.

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 also have a right to services in their own right under the Carers and Disabled Children Act
- Intermediate care – carers have a right to 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 vouchers in lieu of break services.

What rights are they missing

- Current legislation offers carers support "in their caring role", i.e. assessments do not need to take into consideration wider issues of carers' lives, such as training and employment
- Current Guidance makes it best practice to give information to carers, however virtually all research shows that lack of information is still one of carers' main concerns
- There is no direct obligation on the NHS to have regard to promote the health and welfare of carers.

What would the Bill achieve?

The Bill will give carers more choice and opportunities to lead a more fulfilling life, by ensuring that carers receive information their rights, on training and work opportunities and it will also ensure that carers' own health is given more consideration. The Bill covers England and Wales.

It would achieve three main things:

- Ensure that carers are systematically given information, including about their rights, so that they can make informed decisions about their lives.
- Ensure that carers' health, in its broadest sense, is positively considered by social services and health.
- Help to give carers more opportunities in leisure, education, training and employment.

The Long Title of the Bill is: *A Bill to make provision about life-long learning for, and the employment of, carers; to place duties on local authorities and health bodies in respect of carers; and for connected purposes.*

How would the Bill do this?

The Bill would achieve these aims by placing:

- a duty on social services to promote equality of opportunity for carers, particularly in relation to their health and well-being. They would have to look at what services they provided (or secured) to ensure that they were sufficiently flexible to allow carers to work, have a break or enter training or life-long learning opportunities, whilst caring;

- a duty on local authorities to tell carers about their rights to an assessment;
- a duty on local authorities to systematically plan information delivery for carers
- a duty on health and social services to promote and safeguard the health and welfare of carers;
- a duty on other parts of the local authority to ensure that they work with social services, if social services asks for their assistance, to deliver the aims set out by the Bill.

What the Bill would achieve for carers – health, information, choice and opportunities, joint working

Health issues for carers

- Carers providing substantial amounts of care are statistically more likely to suffer from health problems.[3]
- Those caring 50 or more hours per week are twice as likely to be "permanently sick or disabled" and twice as likely to describe their own health as poor.[4]
- Carers UK's own research found that over half of the carers surveyed had suffered a stress related illness since becoming a carer and half had suffered a physical injury.[5]
- Other research has also shown that, with support, and the right interventions, carer illness and injury can be reduced.

How the Bill addresses these problems

Clause 1 (1) of the Bill provides that **a local authority … shall have due regard to the need to promote equality of opportunities** between carers and those people without caring responsibilities with regard to **carers' health and well-being.**

Clause 5 Section 1 b) places a duty on NHS bodies and local authorities to co-operate with one another in order **to promote and safeguard the health and welfare of carers.**

Currently there is no direct obligation on the NHS to have regard to promote the health and welfare of carers. If the Bill became law, it would mean that NHS bodies, for example, Primary Care Trusts in England and Local Health Boards in Wales, would have to examine their policies and procedures to ensure that they promoted the health and welfare of carers. It would mean that they should be aware of the health issues faced by carers: for example that carers are more likely to suffer mental ill-health and likely to suffer a physical injury if moving, lifting and handling[6].

NHS bodies might implement the duty by developing policies and programmes to teach carers how to move and lift safely and programmes to identify carers and link them into appropriate support – both statutory and non-statutory.

Clause 1 of the Bill would mean that local authorities would have to examine their policies and procedures to ensure that carers' health and well-being, in their broadest sense, was being considered. This would mean examining their assessment procedures, services, whether direct payments are offered, etc. to ensure that carers' health and well-being was considered.

Case study post legislation

A carer awareness programme is delivered whereby the health professionals are made aware of health issues for carers for example, needing training in moving and handling, even if they are not new to caring. When the doctor is told John seems to have had a relapse, he refers the case to a district nurse who makes a home visit. The nurse notes that John cannot transfer and puts in a bit of training for the carer to ensure she and John are safe.

Information and carers

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.[7] 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.[8] Information about their rights to support can be vital in maintaining carers' health and well-being.

How the Bill addresses these issues

Clause 3 places a duty on local authorities to inform carers of their right to an assessment of his ability to provide, or continue to provide, care for the person cared for.

The aim of this section is to ensure that carers are getting information about their rights in a more consistent way. This would 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 these 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.

Clause 2 provides that **it shall be the duty of local authorities, in co-operation with NHS bodies, to ensure that the community strategies they prepare … make specific provision for informing carers … of the services that the local authority provides.**

The purpose of this section is to promote more effective planning of the provision of information for carers. Clause 2 suggests that this would fit in with the local authority's development of their community plan (community strategy in legislation). The evidence shows some local authorities have well-planned information strategies which cover carers' rights, support, benefits, etc. Others are neither systematic about information provision nor well-planned. The development of an information strategy was seen as a key target in the National Carers Strategy.

This Clause would ensure that information for carers was part of longer term planning and would offer a more strategic basis on which carers could be informed of their right to an assessment. Local authorities would need to review the information they provide for carers, and work with other bodies, such as the NHS, to ensure that they had the right information in the right places.

Opportunities to work and access training and life-long learning

- According to research by Carers UK, 6 out of 10 carers providing substantial amounts of care, had given up paid work to care.[9]
- In the same research, 7 out of 10 carers found themselves financially worse off since becoming a carer.
- A recent Social Services Inspectorate Report[10] shows that carers stress the value of being able to go out to work.
- 80% of carers are of working age.[11] 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.
- A recent TUC report[12] 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.[13]

How the Bill addresses these issues

Clause 1(1) places a duty on local authority social services **departments to promote equality of opportunity between carers and persons without caring responsibilities with regard to carers' health and well-being**.

Clause 1 (2) would impose a duty on local authorities to have **due regard to providing or securing services which they consider likely to encourage, enable or assist (directly or indirect) effective participation by carers in education,**

training employment and leisure opportunities.

This Clause 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.

The legislation defines well-being in its broadest sense to mean education, training, employment and social well-being. Local authorities would have to examine their policies and procedures to ensure that carers were given equality of opportunity. This would mean, for example, ensuring that carers' assessments covered issues of leisure, social contact, employment, training, etc. It would mean that assumptions could not be made about carers not being able to access training courses, etc. It would also mean that local authorities would have to examine the way that services were delivered to ensure that there were not any artificial barriers to carers being able to access these opportunities. That would mean services being more flexible, or being provided as a direct payment. The following case study illustrates how this might work.

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.*

Joint working

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,* 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.

How the Bill addresses this issue

Clause 4 would enable a local authority to request the help of any other authority listed, in the exercise of their functions under this Bill. This includes housing, local NHS bodies, other parts of the local authority and the local education authority. If the local authority asks, then these bodies have to comply with that request.

A similar provision already exists in the Children Act 1989 and local authorities have found this useful in trying to facilitate joined up working. For example, if the social services department wishes to improve benefit take-up across their carer population, they could ask the welfare rights department of the local authority for assistance and housing too. They plan together to distribute and target key information amongst the local population. The Clause effectively means that social services could bring important partners to the decision-making process to promote equality of opportunity, to plan and deliver their information strategy and to provide information to carers.

Clause 5 (1)(a) **states that NHS bodies and local authorities shall co-operate with one another in order to…. promote and safeguard the health and welfare of carers.** This differs to Clause 4 in that it places an equal duty on both bodies to work together to achieve the goals set out in the Bill. At present there is no direct obligation on the NHS to have regard to the needs of carers. This has resulted in some NHS bodies viewing the needs of carers as a local authority responsibility – rather than a shared obligation.

Broader benefits of legislation

There are a number of key benefits to the legislation:

- decrease in health problems for carers
- 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.[14] Every year 2.3 million carers stop caring and as 80% of carers are of working age[15] 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.

Costs

Carers UK has looked carefully at the Bill and its drafting to examine the costs in detail and have concluded that the Bill would not impose any additional costs. There would also be some longer term savings through better health of carers, more sustained employment, and return to work for some carers.

The Bill is consistent with Government policy objectives, as outlined for example in the National Strategy, and spending can be met within existing resources. Carers Grant spending in England will increase in 2004/5 to £125 million, with further increases in 2005/6. In theory, these funds are available to improve services for carers and fund information programmes. Good authorities have implemented many of these policies, as have some local NHS bodies.

Clause 1 does not impose additional costs, but would require local authorities to think about the ways in which they operate existing policies and procedures, including services. Many local authorities already produce information for carers about their rights.

The issue is about ensuring that policies and procedures work for carers' opportunities and not against them. Carers talking about the Bill have described it as "changing minds about how we are perceived and the way we wish to be supported".

There is no evidence to suggest that there will be a significant increase in carers' assessments and services as a result of the Bill. The experience of the implementation of policies in Scotland since 1 September 2002, is that the legislation has not incurred great expenditure for social work departments. Monitoring systems have been put in place by the Scottish Executive to track progress and developments and to date there is no evidence to suggest that social work departments have been inundated with requests for assessments.

For further information

Regular updates on the Bill's progress can be found on Carers UK's Epolitix Forum website: www.epolitix.com.

For further information please contact Dave Clark on 020 7566 7616, Davidc@ukcarers.org.

This briefing is supported by funding from British Gas and the European Social Fund.

References

---

[1] Carers UK 2002, *Without Us: Calculating the value of carers' support*
[2] Carers UK (2003) *Missed Opportunities: The impact of new rights for carers*
[3] Caring Relationships Over Time, Michael Hirst, SPRU, University of York, 2001
[4] National Statistics Office, Census 2001
[5] Ignored and Invisible, Carers Experience of the NHS, Melanie Henwood, Carers UK, 1998.
[6] Ibid.
[7] Carers UK (2001) *It Could Be You…*
[8] Carers UK (2003) *Missed Opportunities: The impact of new rights for carers*
[9] Carers National Association (now Carers UK) (2000) *Caring on the Breadline: The financial implications of caring*
[10] Jan Clark, *Independence Matters: An overview of the performance of social care services for physically and sensory disabled people*, Social Services Inspectorate, 2003.
[11] National Statistic Office, Census 2001
[12] TUC 2004, Full Employment – the next steps; TUC report on working age inactivity in Britain and the rest of Europe.
[13] The True Cost of Caring, Caring Costs, published by Carers National Association, 1996.
[14] TUC 2004, Full Employment – the next steps; TUC report on working age inactivity in Britain and the rest of Europe.
[15] National Statistic Office, Census 2001

This briefing is supported by funding from British Gas and the European Social Fund.