

'The Right to an Ordinary Life': Carers and Equal Opportunities

**Dr Hywel Francis MP
MP for Aberavon and sponsor of the Carers Equal Opportunities
Act 2004**

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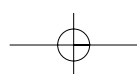
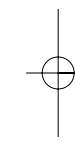
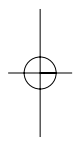
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‘The Right to an Ordinary Life’:

Carers and Equal Opportunities

Introduction

Almost exactly a year ago the Carers Equal Opportunities Bill passed through the last stage in Parliament when my friend, Lord Jack Ashley of Stoke, the redoubtable champion of people with disabilities, uttered at the Third and final Reading in the Lords, the words ‘that this Bill be now passed’. Lord Ashley, who took the Bill through the Lords, was my most important ally. His total commitment is summed up in the words which he wrote in **The House Magazine** (22nd March 2004, p. 6):

‘Carers quite simply need caring for.....Many of them do not even claim their entitlements because they are unaware of them. The new bill will ensure that they are systematically given information, that their health is considered by the social services and health departments and that they get new opportunities for education, training and employment. It can change the lives of millions of harassed people.’

I am pleased to be recalling this achievement here in the South Wales valleys because we have a disproportionate number of carers despite the advances achieved by Aneurin Bevan’s National Health Service. Carers provide freely the equivalent of £57 billion which is about the cost of the NHS.

This paper is about the campaign to achieve equal rights for carers, what we came to call in the course of that campaign ‘the right to an ordinary life’. The paper is also about what has been achieved since the passing of what is now called the Carers Equal Opportunities Act 2004 and what still needs to be done.

Why a Carers Equal Opportunities Act?

Why then do we need a Carers Equal Opportunities Act? The national advocacy body for carers, Carers UK, defines carers in this way:

‘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. Almost all of us have been or will be a carer during our lifetime’.

In 1980 my wife Mair and I became carers of our son Sam, who had Down’s Syndrome. Throughout the period we were carers, until he died in May 1997, we were unaware of the term although we were active members of a carers’ organisation, the Down’s Syndrome Association. It is only with the passing of two Private Members’ Bills for carers, the growing impact of campaigning by carers organisations, the identification of 5.2 million carers through the 2001 census, and finally the Labour Government’s launch of its National Strategy for Carers in 1999, that the scale and nature of the plight facing carers has begun to be appreciated. The actual figure of 5.2 million carers has subsequently been revised upwards and has been calculated at between 6 million and 7 million. This amounts to at least 12% of the adult population.

The headline statistics are startling. In any year, 301,000 adults in the UK become carers. Over a lifetime, seven out of ten women will be carers. Women are 25% more likely to become carers than men. Three out of five carers have had to give up work to become carers, and there are 175,000 young carers under the age of eighteen and 945,000 are aged over sixty-five. Perhaps most shocking of all, carers are calculated to be twice as likely to suffer poor health as non-carers.

In Wales, there are 350,000 carers of whom over 20,000 are in Neath Port Talbot which represents the highest proportion of carers per head of population in the whole of the UK. The county also has the highest proportion of heavy end carers (those caring for over 50 hours a week).

All of this is a legacy of our industrial past. It is not unconnected to the causes of the health inequalities in the valleys of South Wales and other post-industrial regions of the UK.

I have always believed that the personal is the political. That is why my Maiden Speech on 25th June 2001 was on people with disabilities and their carers, which I described as an essential journey of hope from social inclusion to social justice.

My objective then was summed up in these words and it remains so in this paper:

‘In my first speech to the House, I want to focus specifically on the citizenship rights of disabled people and their carers in relation to the economy and to the whole of society. Our new Labour Government should and will be measured by the extent to which we tackle, in partnership, the fundamental inequalities faced by disabled people and their carers.’¹

Two previous Private Members’ Bills made some significant progress for carers. The Carers (Recognition and Services) Act 1995 introduced by Malcolm Wicks MP gave a right to a separate assessment for people providing informal care. The Carers and Disabled Children’s Act 2000 introduced by Tom (now Lord) Pendry gave carers enhanced rights of assessment.

Nevertheless the take-up of carers’ assessments was very patchy across the country. The plight of carers was still one largely of isolation, being besieged and under-valued. Carers were still denied equal opportunities. Their lives, beyond their caring responsibilities, were still not recognized.

¹ House of Commons Debate 25th June 2001 cc 455-6

Seizing the time!

My Maiden Speech had focused on this question of social justice and that feeling was rooted in the reality of Mair and I caring for our son Sam. On December 4th 2003 I came second in the Private Member’s Bill ballot. The choice of subject was already made. It was Mair who said within the family ‘this is Sam’s Bill’. Since then ‘Sam’s Bill’ became part of what has been called a ‘carers’ movement’.

The day after the ballot I wrote in my diary:

‘This is National Carers’ Rights Day. Visited Brynhyfryd Primary School. Then onto CVS for carers/enablers meeting. Turning point. Gaynor Richards of (CVS), Lynn Coleman and two young mothers — all very impressive. We worked on a carers’ charter in which lifelong learning a vital dimension. I began to think about a carers’ bill along those lines...’

That meeting encapsulated what the Bill set out to achieve: ‘the right to an ordinary life’ which were the words of one of the carers I met on that day.

The Parliamentary launch on 26th January included carers from all parts of the country, the Mayor from my County Borough, Councillor Peter Lloyd and two Health Ministers, Dr Stephen Ladyman for England and Jane Hutt for Wales.

The broad cross-party support in the two Houses of Parliament and the breadth of support outside Parliament from carers’ organisations to educational bodies, the Equal Opportunities Commission, Local Government bodies in England and Wales, trades unions and employers, ensured the passing of the Bill which received Royal Assent on 22nd July 2004, the very last day before the Summer Recess. My Bill Team included leading members of all the main parties (Conservative, Labour and Liberal Democrat) along with representatives from Plaid Cymru and the Ulster Unionists. This breadth of support was mirrored in the Lords with all parties again prominent along with crossbenchers Baroness Howe and Lord Rix (President of Mencap) very prominent.²

² The story of how we achieved success with the passing of the Bill is outlined in several articles, notably **Care and Health**, February 4-18 2004; **Adults Learning**, March 2004; **The Parliamentary Monitor**, June 2004; **ISTC Today**, June 2004; **Western Mail** 19th July 2004

My own union Community (at the time ISTC) was typical of the extra-Parliamentary backing at every stage in the Bill's progress. Its journal, **ISTC Today** in a double page spread proclaimed 'A carers' journey of hope: How new legislation sponsored by ISTC and Labour MP Dr Hywel Francis could offer carers new opportunities to build lives beyond their caring responsibilities.'²

The significant national and local media interest in the Bill's progress has, according to Carers UK, played a major role in raising awareness about carers' lives more generally and ensuring that there was public support.

It was the strength of the Bill Team and extra Parliamentary support which ensured that young carers were included in the legislation; initially the Government was not sympathetic to their inclusion.

The apparent ease of the passage of the Bill is misleading. From the outset, I took advice from experienced Parliamentarians and had the constant support of Carers UK whose Human Rights lawyer, Luke Clement, helped draft the Bill. I was told I needed to meet three essential requirements to achieve success: gain the support of the Chancellor, win Government support and also cross-party support. All were equally important and one big advantage was that the Prime Minister himself had always been supportive of carers. My first initiative was to speak to the Chancellor, Rt Hon Gordon Brown MP in the very first days. It was his words of encouragement and his advice to seek the support of Tom Clarke MP and Lord Ashley which proved crucial.

The purpose of the Carers Equal Opportunities Act 2004

This is an England and Wales Act. It required and achieved official government support in England led by the then Carers' Minister in England, Dr Stephen Ladyman and the then Health Minister in Wales, Jane Hutt. Having been negotiated with Ministers in both seats of power, it was truly a child of devolution.

It also built on advances for carers which had been achieved by the devolved administrations in Northern Ireland and Scotland.

The purpose of the Act is to recognize that carers have 'the right to an ordinary life', an equal opportunity with others in society to access leisure, work, education and training beyond their caring responsibilities.

The Chief Executive of Carers UK, Imelda Redmond, has said that the very title of the Act has made a significant difference:

'...one of the most radical and far-reaching elements of the Act is the title. This has really helped bring about a culture shift, it has shifted people's mind sets from thinking they should be kind to these people to a rights based equality of opportunity. The change in language is noticeable to us'

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;
- ensure that carers are informed of their rights.

Breathing life into the new Act

Shortly before the Bill entered the Statute Book, one of its key supporters, Tom Clarke, the Scottish Labour MP who had been the first Disability Minister in the 1997 Government said to me 'Don't let the Act gather dust on the shelf: we must breathe life into it.'

With that wise advice ringing in my ears, the Bill Team which I had constructed in Westminster, along with supporters in the Welsh Assembly and carers organisations throughout the country set about organising celebrations which focused principally on plans for the future.

In Wales within days of Royal Assent the then Health Minister, Jane Hutt, announced an All Wales Carers Summit. Held prior to the General Election, the delegates came forward with a range of radical proposals including a Carers' Commissioner. Nearer home the Leader of Neath Port Talbot County Borough Council, Councillor Derek Vaughan and I held a meeting on 28th July involving professionals and carers in order to run pilot schemes ahead of the implementation of the Act last April. The result was a range of initiatives negotiated with carers. They included young parents learning opportunities at SNAC, a local parent-led charity; life skills learning for young carers; informal courses for the local Alzheimer's Society; and a primary care initiative working with GPs to refer carers under stress on to learning and leisure opportunities, with guidance and support.

And most encouraging of all, a Carers Action Movement — the first in the UK — was launched in Neath Port Talbot during this year's Carers Week. Led by carer Ray Thomas, it is a self-help organisation which stems from the desire to improve the welfare of carers locally. Facilitated by the body which hosted my carers meeting in December 2003, Neath Port Talbot Council for Voluntary Service, the Movement has already achieved the appointment of a Carers Development Officer and is pressing for the appointment of dedicated assessment officers (a role which already exists in Barnet).

At the UK level, in the Autumn the adult learners' body NIACE and Carers UK came together for the first time in a collaborative exercise to highlight lifelong learning opportunities for carers with an excellent pamphlet entitled **Carers and Learning**. This was followed by a parallel publication in Wales, **Balancing Life**

and Caring, produced by Carers Wales (which has also previously been published in England in a different form).

Then shortly before the General Election an All Party Parliamentary Group for Carers was established to monitor progress on the implementation of the Act and to be an advocacy body for carers in Parliament, to liaise with the devolved bodies in the UK and internationally. A parallel All Party Group was set up in the Welsh Assembly recently.

The Westminster All Party Group held its first seminar in July on the theme of lifelong learning, identifying good practice already developing in a number of educational bodies including the Open University, the National Extension College and City and Guilds. And the Princess Royal Trust for Carers and the National Extension College are publishing their report 'Making Learning Accessible to Unpaid Carers', a three year distance learning project funded by the Big Lottery Fund.

The Westminster All Party Group will hold further seminars on flexible working and women carers and pensions (following on work by the Equal Opportunities Commission and my former parliamentary colleague, Helen Jackson).

Alongside all these developments, there is the distinct campaign by the shop workers' union USDAW 'Supporting Parents and Carers'. This latter initiative is the culmination of a wider trade union campaign for more support for parents and carers including flexible work opportunities and this is enshrined in the Trade Unions/Labour Party Warwick Agreement prior to the General Election.

The Wider Policy Context

All these developments beg the question: What is the wider policy context? It is of course the transformation of the Welfare State through a new work-life balance, including the National Childcare Strategy: the principles which underpin that strategy apply equally to carers. Many think-tanks have entered this debate, most recently the Fabian Society with its interim report on life chances and child poverty.³ In the specific areas of carers, pioneering policy work by Barbara Keeley (now a new Parliamentary colleague) and Malcolm Clarke in 2003, on behalf of the Princess Royal Trust for Carers, raised awareness of the crucial questions of support and information particularly amongst GPs and primary care professionals.⁴

The Social Exclusion Unit (SEU) of the Office of the Deputy Prime Minister (ODPM) has identified the key drivers of social exclusion as low income, education, ill-health, housing, transport, social capital, neighbourhood, crime and the fear of crime.

In its review of the literature for the SEU in the *Breaking the Cycle* series, the ODPM correctly states that:

‘Social exclusion was also driven by policy issues.....Policy is critical and we now benefit from it being driven by the social exclusion agenda with targets and monitoring.....’

For too long, carers have not been recognised as a socially excluded group worthy of proper consideration and respect. That is now thankfully changing.

³ Fabian Society, **Why Life Chances Matter: The Interim Report of the Fabian Commission on Life Chances and Child Poverty** (series editor: Jonathan Heawood, June 2005)

⁴ Barbara Keeley and Malcolm Clarke, **Primary Carers – identifying and providing support to carers in primary care** (Princess Royal Trust for Carers, 2003)

That invisibility in relation to policy development is being diminished as a consequence of two related initiatives. Firstly, the growing impact of the Action for Carers and Employment (ACE) Project will inevitably result in further recognition of carers' potential in the labour market and more widely in social policy. ACE National is a development partnership led by Carers UK and funded by the European Social Fund's Equal Programme. Its purpose is to raise awareness of the barriers facing carers who wish to work and tests and promotes ways of supporting them.

Secondly, the research work undertaken on behalf of ACE National by Sheffield Hallam University has for the first time examined in detail the data on carers provided by the 2001 census. The future need for carers; the relationship between carers, employment and health; the relationship between carers and family responsibilities; and the geographical distribution of carers: all these major factors will have a significant impact on the planning of the NHS, on social services and on the voluntary sector.⁵ The recently published Green Paper on Social Care will be massively influenced by the detailed analysis of carers and their needs by Sheffield Hallam University. It should also be acknowledged that the Green Paper has been influenced by the Act: the acknowledgement of carers having a life beyond caring is seen as a significant driver in the vision for social care.⁶

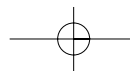
In a recent interview with **Contact**, the Carers Wales publication, Dr Brian Gibbons AM, the new Welsh Assembly Health Minister stated that his key objectives for carers included:

more general recognition that while many carers are service users, they are also a resource. Carers are part of the solution.....carers' issues should not be regarded as an add-on to 'mainstream' services but should become an integral part of the planning process'.⁷

⁵ This work on behalf of ACE National has been undertaken by Lisa Buckner and Sue Yeandle of the Centre for Social Inclusion at Sheffield Hallam University.

⁶ The Green Paper is entitled **Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England**. (Department of Health, March 2005, Cm 6499)

⁷ **Contact** (Newsletter of Carers Wales), Winter 2004/2005, p1.



Carers are undeniably a resource. This Act recognizes them as human beings too.

With that in mind I will be working with the Bevan Foundation, other MPs, local authorities and most of all with carers to identify ways in which my Carers Equal Opportunities Act will be implemented at community level involving former carers as key drivers of policy change, emphasizing active lives rather than economic inactivity.⁸ This will build on the Bevan Foundation's report **Ambitions for the Future** published in 2003.

Finally, on October 12th I hosted a Parliamentary reception to launch a Carers UK book by Luke Clements on carers' rights information. This will coincide with the Government's publication of the policy and practice guidelines in the Carers Equal Opportunities Act.

My experience in different parts of the UK during National Carers Week in June, from Swansea to Sunderland and from Port Talbot to Barnet, is that there is a perceptible attitudinal shift with carers moving from the shadows to centre stage in policy and practice. But we have a long way to go before carers win 'the right to an ordinary life'.⁹

⁸ Audrey Jenkinson, **Past Caring** (Promenade Publishers 2003) is a remarkable story about the problems and challenges after caring has ended.

⁹ Further information on advocacy work for carers can be obtained from Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT (visit www.carersuk.org) and Carers Wales, River House, Ynysbridge Court, Gwaelod y Garth, Cardiff CF15 9SS (visit www.carerswales.org)

