

Caring and working?

A Welsh case study

by Victoria Winckler

Foreword by Hywel Francis MP

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The Bevan Foundation

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Foreword

Dr Hywel Francis MP

This is a very timely report because of the increasing profile being gained by carers in many developments at local, all-Wales and UK levels.

As Chair of the All Party Parliamentary Group for Carers and sponsor of the Carers Equal Opportunities Act 2004, as well as President of a number of carers groups in my Aberavon Constituency, I am aware of progress being made on many fronts, especially at the UK level, through the Labour Government's growing recognition of the needs of carers: but I am also conscious of the difficulties that carers continue to face daily in accessing information and services to achieve what my campaign called in 2004, 'the right to an ordinary life'¹. That is why I have sponsored this research by the Bevan Foundation on caring and work.

There is no doubt that there have been significant advances in relation to carers in the last decade. The Prime Minister's National Carers Strategy in 1999 established the carers' special grant, the Carers Equal Opportunities Act in 2004 ensured that all carers were informed of their right to an assessment and information on work, leisure and training.² Then in 2006 the Work and Families Act gave employees the right to request flexible working (80% of working carers will qualify), and in Wales a Carers' Champion was established.

This year, with the progress of the Pensions Bill through Parliament there has been a growing recognition of the need to recognise carers' sacrifices and the need to recompense them through an enhanced state pension.

Recent Treasury announcements have also assisted parent carers of severely disabled children with more support for respite care. This was initiated by MP Ed Balls' Ten Minute Rule Bill in 2006.

Much of this recent progress has been enormously assisted by research and policy development by Carers UK's European-funded Action for Carers and Employment which has included work in Wales in partnership with such organizations as Carers Wales and Crossroads.

At the local level in Neath Port Talbot the Carers Action Movement, led by its Chair Mr Ray Thomas, has begun to provide an essential collective approach for carers and in response to this the County Borough Council, led by its newly appointed Carers' Champion, Councillor Paul Thomas, has been making progress towards an independent carers' service.

The challenge before us is to ensure that the legislative advances which have undoubtedly been made can soon be translated into real change in the quality of life of carers locally on the three fronts identified by Carers UK – respect, recompense and respite care.

This can be done through the current reviews of the Carers Strategy in England and in Wales and I hope that this Bevan Foundation research can contribute to this.

1. INTRODUCTION

‘Economic inactivity’ has been identified as a significant challenge in Neath Port Talbot as in many other industrial areas of Wales. Neath Port Talbot also stands out because it has both the highest proportion of unpaid carers in England and Wales, and also the highest proportion of ‘heavy end’ carers i.e. those who provide more than 50 hours a week of unpaid care.

Neath Port Talbot is not alone in having this combination of features. Research has shown that across England and Wales there is a strong association between localities with high proportions of the population providing care, and those with high levels of ill health and other social disadvantage.³ Older industrial areas, such as the former south Wales coalfield and those of the north east of England, stand out in this regard. Yet, in the debate about economic inactivity which has taken place in Wales in recent years, there has been almost no recognition of carers and their role.⁴ Indeed, the focus on labour supply measures that has emerged from the Assembly’s policy review of economic inactivity makes no provision for carers at all, either to help carers to find and maintain employment or to acknowledge the contribution of those who care full-time. Yet it is surely no coincidence that illhealth, unpaid care and economic inactivity are so strongly associated. This is clearly demonstrated by statistics from the 2001 Census of Population which show that carers who provided more than 50 hours a week of care are significantly less likely to be in employment than people who provided no care. These ‘economically inactive’ carers account for 17 percent of all those who are economically inactive in Wales.

The profile of carers and employment has increased substantially in England and Wales over recent years, not least because of the work of charities such as Carers UK and the Action for Carers and Employment (ACE) project. Welcome changes in legislation such as Carers Equal Opportunities Act 2004 and Work and Families Act 2006 mentioned in the Foreword to this report have, together with changes in policy, helped to ensure that the legal framework for carers to find and maintain paid work, if they wish, is in place. However, it is not yet clear if this shift is reflected on the ground and is making a difference to carers lives.

The Bevan Foundation therefore conducted a small-scale study of Neath Port Talbot in order to explore the extent to which caring impacted on participation in work, and to consider what

support would help people to remain in paid work or to seek employment at some time in the future. In doing so, it is recognized that carers have the right to choose their own lifestyles, just like everyone else, and that paid work is not necessarily what all carers want to do. The study is part of a wider project on 'economic inactivity' which will be published later in the year.

This study

This study involved a review of relevant literature and policy documents, and interviews with a total of 16 carers in Neath Port Talbot, all of whom were involved in one of the carers' support groups in the area. The carers we interviewed volunteered to participate following approaches we made to carers' organizations. Two of the sixteen interviewees also had formal roles in the carers' groups as well as being carers themselves. Dr Hywel Francis, MP for Aberavon, identified the carers' groups active within Neath Port Talbot and in some instances introduced us (by letter) to the groups. However he had no input into who we interviewed at the carers' organizations. In addition we interviewed a local charity that provides services to carers and an officer from the local authority social services department. A list of the organizations involved is given at Appendix 1.

Interviews were semi-structured and were conducted by Maggie McCollum, a research assistant at the Bevan Foundation, who recorded the discussion and transcribed it. Some were group interviews and others were individual, depending on the availability and preferences of interviewees. The questions were determined solely by us, and the interviews were, and remain, confidential. We have quoted extensively from them, however, both as evidence of our findings and to illustrate the strength of feeling uncovered. The names we have attached to the quotes are pseudonyms.

The carers we interviewed

Several carers we interviewed currently cared for more than one person – two carers had more than one disabled child, one person cared for six people in total, and two people cared for two adults.

My mum was ill as well and then 6 months later my husband became ill so I had both of them.

Joan, Stroke Club

I'm a carer for six people - two disabled kids, my father who has heart trouble, my mother who has cancer, and I also call round to a neighbour and my father-in-law.

Julie, Enablers' Project

Although we did not ask the people we interviewed about how many hours a week they spent caring, most indicated, either directly or indirectly, that they provided very significant amounts of care which were likely to be in excess of 50 hours a week. Such 'heavy end' carers are less likely to have a paid job than those providing fewer hours of care.

'I'm a carer for my husband who has been a stroke patient for ten years. He is my 24 hour responsibility. Everything is sort of built around him.

Joan, Stroke Club

'Carers are always on a clock – even though you may not always be fully caring you are on a clock 24 hours a day, 7 days a week.'

Reg, Carers' Action Movement

'I don't stop caring. I do get a break when the kids are in school but then I look after my neighbour cooking dinner etc. and then try to see my mam.'

Julie, Enablers' project

'Our lives are geared around [my husband].'

Mary, Stroke Club

Although this small-scale study cannot provide definitive conclusions about carers as a whole in Neath Port Talbot, let alone Wales, it does point to some important issues for further consideration and investigation, some as a matter of priority.

2. CARERS IN NEATH PORT TALBOT

A carer is someone who looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid. Across the UK, about six million people provide some form of care, and every year the about 2.3 million people begin a caring role⁵. In Wales, there are 350,000 carers, 100,000 of whom regularly provide over 50 hours of care every week.

According to the 2001 Census of Population, Neath Port Talbot has the highest proportion of its population providing care in England and Wales – in total 14.1% of the population provide at least an hour a week of unpaid care, some 18,923 people. Table 1 shows that, of these, almost a third (31 percent) provided more than 50 hours a week of care – also the highest proportion in England and Wales.

Table 1 Carers and hours of care, Neath Port Talbot

Hours of Unpaid Care (per week)	Number	Percentage of carers
No care	114,416	--
1 – 19 hours	10,618	56.1
20 – 49 hours	2,649	14.0
50 or more hours	5,652	29.8
All carers	18,919	100

Source: 2001 Census of Population (Crown Copyright)

Note: totals may not sum due to rounding

Although it is not perhaps the stereotype of a carer, almost as many men as women provide some unpaid care – 44 percent of carers in Neath Port Talbot are male, 56 percent of female. And the chances of being a carer are only marginally higher for women than men – 16 out of 100 women are carers compared with 13 out of a hundred men. Table 2 shows that the amounts of care that men and women provide during a week are broadly the same, with only a very slightly larger proportion of women providing high levels of care than men.

Table 2 Gender of Carers and hours of care provided, Neath Port Talbot

Hours of Unpaid Care (per week)	Males		Females	
	No.	Percentage of all males	No.	Percentage of all females
No care	56,408	--	58,008	--
1 – 19 hours	4,776	58.0	5,842	54.7
20 – 49 hours	1,068	13.0	1,581	14.8
50 or more hours	2,389	29.0	3,263	30.5
All carers	8,233	100	10,686	100

Source: 2001 Census of Population (Crown Copyright)

Note: totals may not sum due to rounding

Carers are all ages, and are not just older people. More than three quarters of Neath Port Talbot's carers (78 percent) are of working age, i.e. aged 18 – 65, with 45 percent of carers being of 'prime' working age i.e. 18 – 44 years old. Table 3 shows that the chances of becoming a carer rise with age - one in four of the area's 50 – 64 year olds were carers in 2001 compared with one in six of 18 – 49 year olds who were carers. In addition, the 2001 Census showed that there are 613 carers in Neath Port Talbot aged under 18.

Table 3 also shows that the provision of high levels of care rise with the age of the carer, with almost half of carers aged over 65 providing more than 50 hours a week of care.

Table 3 Age of Carers and hours of care provided, Neath Port Talbot

Age group	No. of carers	Percentage of age group who are carers	No. of carers providing 50+ hours of care	Percentage of carers in age group who provide 50+ hours of care
0-17	613	2.0	53	8.6
18-49	8,484	15.5	2,066	24.4
50 – 64	6,419	25.6	1,915	29.8
65 plus	3,403	14.4	1,618	47.5
All carers	18,919	100	5,652	29.8

Source: 2001 Census of Population

Note: totals may not sum due to rounding

The high levels of caring in Neath Port Talbot are clearly associated with high levels of ill health in the area. In 2001, 16 percent of the population reported that their health was 'not good', whilst 24 percent said that they had a health condition which limited their everyday activities – respectively the third and second highest figures in Wales. This self-reporting of poor health is substantiated by statistics on the incidence of various health conditions⁶, which show that Neath Port Talbot has:

- the highest prevalence of respiratory illness and asthma in Wales
- the 2nd highest incidence of diabetes in Wales
- the 4th highest incidence of heart disease in Wales
- the 4th highest incidence of back pain in Wales.

In addition, some 27.9 percent of the population of working age say they have a disability, the fifth highest in Wales, which includes 20,000 people with a disability within the Disability Discrimination Act definition⁷.

With 70 percent of the care provided to vulnerable people being provided by family, friends and neighbours, it is hardly surprising that high levels of ill health and disability in the population translates into high levels of caring. The care that is provided by carers in Neath Port Talbot is estimated to be worth £165 million a year⁸.

It is clear, then, that a considerable proportion of the population in Neath Port Talbot provide unpaid care to a relative or friend. Men and women are almost equally likely to provide care, and carers are of all ages although the largest numbers are aged 18 – 49. Three out of ten carers provide more than 50 hours a week of care, with almost half of carers over retirement age providing this level of care. As the next section shows, these levels of caring have a significant effect on carers' employment.

3. CARERS AND EMPLOYMENT

The provision of unpaid care and the demands of working compete for time, and whether or not someone provides unpaid care has a huge impact on their employment status and prospects, including whether or not they have a job at all, as well as the nature of job, their pay, and how far they travel.

In particular, carers are less likely to be economically active (i.e. in employment, self-employed or unemployed) than non-carers. In England and Wales, only about half of carers who were spending between 20 and 49 hours caring per week were in employment in 2001, compared with about six out of ten non-carers.⁹ Among those caring for 50 or more hours per week, only three out of ten were in paid employment. As a result, people who are economically inactive are disproportionately likely to be carers compared with people who are in employment or unemployed. However, what is less clear is the extent to which people become economically inactive *because* they are carers, or whether they become carers because they are economically inactive.

Research also shows that carers who provide more than 20 hours care a week tend to hold lower-level occupations than non-carers. This holds true at all age ranges and for women and men. Evidence also suggests that carers on average earn 12 percent less than non-carers – the so-called carer pay gap.

A similar picture emerges in Neath Port Talbot. The 2001 Census shows that, overall, 56 percent of the population was economically active i.e. in employment (either full time or part time), self-employed or unemployed. However, whilst 57 percent of those providing no care were economically active, only 28 percent of those providing 50 hours a week or more of care were economically active. Table 4 provides further details. In general, men were more likely to be economically active than women whether they were carers or not. More than a fifth of economic inactivity in the area can be attributed to people who provide care, a higher proportion than Wales as a whole.

Table 4 Economic Activity of Carers, Neath Port Talbot

	Percentage who are economically active	Percentage who are economically inactive	Number who are economically inactive
No care	57	43	33,490
1 – 19 hours	65	35	3,506
20 – 49 hours	47	53	1,318
50 or more hours	28	72	3,617
All carers	52	48	8,441
All people	56	44	41,931

Source: 2001 Census of Population (Crown Copyright)

Note: totals may not sum due to rounding

The needs of carers in employment in Neath Port Talbot has been recognized recently through the Action for Carers and Employment (ACE) project which is working to support the inclusion of carers in training and work, funded by the European Social Fund's Equal programme.

Caring and working

Recent research by Hilary Arksey et al for the Department for Work and Pensions¹⁰ showed that the decision about whether a carer worked was complex and reflected a number of different factors. These included financial issues, the carer's own health, personal motivation, work factors, the characteristics of the health recipient. The decision was made more complex because some of the factors were unknown, such as the prognosis for the care recipient. The research concluded that the circumstances of carers were so variable that no single factor shaped carers' decision to return to work.

Of the sixteen carers we interviewed, only four were currently employed, one full time and three part time (a number of others had previously held paid jobs from which they had either retired or resigned). When we discussed employment with carers in Neath Port Talbot it was very clear that carers believed it was their primary duty to provide care to their family member:

Your caring responsibilities have to come first. ... Employment gets put on the back burner and seems impossible.

Kay, Enablers' Project

The first priority is the caring role,

Julie, Enablers' project

I think that caring is more important. Carers don't always have the luxury of working.

Gwyn, Stroke Club

You have to look after them, it is expected. Therefore there is all the weight of expectation that it is your child and you have to look after it. They are not normal children and you have to be there.

Meryl, SNAC

The child is more important.

Helen, Enablers' project

Our caring commitment has to come first.

Julie, Enablers' project

Hardly surprisingly, many carers believed that their caring responsibilities were such that it was impossible for them to have a paid job:

I can't see me ever being able to work because my son will always need a carer.

Sue, Enablers' project.

How the hell can I work when I have two lads disabled, seeing to them all day and all night?

Sheila, Carers' Action Movement

It makes getting a job impossible.

Dawn, Enablers' project

Research elsewhere¹¹ suggests that the first time someone becomes a carer has no effect for a significant proportion of carers, with almost half of men (46.4 percent) who were already working carrying on as before whilst nearly a third of working women (31.9 percent) did so. However, almost one in five working women (17 percent) stopped working altogether. Carers UK suggests that the proportion of carers who stop working is as high as 60 percent.¹² The impact of caring on work was evident amongst those we interviewed, several had previously held paid jobs but had subsequently stopped working:

I had to give up work. There didn't seem any other option.

Joan, Stroke Club

I finished work due to my husband becoming ill.

Mary, Stroke club

I have been a career woman until a year ago and my husband was the main carer. ... Last year I had the opportunity to take early retirement from my job.

Meryl, SNAC

Some of those we interviewed also described how caring affected the family as a whole, and could result in both members of a couple household giving up their jobs. Sometimes, a caring role was also taken on by children in the household:

I know a lot of families where the husband has also given up his job to care so they are both out of work.

Kay, Enablers' Project

What I am finding is that if I have to go and do something it means that my 15 year old son has to become the carer and keep an eye on [my daughter] which is not ideal.

Barbara, Carers' Action Movement

Research by Mooney et al.¹³ found that most people did not want to leave work altogether; instead they wanted to achieve a reasonable balance between caring and paid employment. The carers we interviewed valued their jobs highly:

I don't want to give it up as I know I won't get back into it. I have been [in this job] 25 years and it's a career

Barbara, Carers' Action Movement

We took the decision to role-reverse as my husband is much more patient. I wanted to forge my career.

Meryl, SNAC

Flexible working

Recent research suggests that the ability to work flexibly is crucial to carers' maintaining their jobs.¹⁴ In general, one in ten men and women carers reduce their working hours when first becoming carers, e.g. by switching to part time work. Four of the people we interviewed had coped with their caring responsibilities (and for one person, her own ill health in addition) by adjusting their working arrangements, e.g. changing their hours or the location of work:

I worked nights primarily because of my circumstances
Reg, Carers' Action Movement

Because of my own health and caring role, this has meant that in 1999 I had to stop working full time. ... I know if I were to have to, in a few years time, give up the job I would never get back in at the level it has taken me twenty-five years to work up to.
Barbara, Carers' Action Movement

[with] the job I have just got I have told them I couldn't do nights
Anne, SNAC

I am lucky because I teach piano at home and I am also training to be a counsellor.
Helen, Enablers' project

Other flexible working practices have also been identified as critical to carers' employment. This includes a mixture of workers' rights through legislation and employers' own employment policies, as well as informal practices such as managers' attitudes and colleagues' support. Although the small number of employed carers that we interviewed meant that we were not able to explore issues about working practices in more detail, they did nevertheless indicate that they valued highly flexibility at work:

I had a job previous with a large bank and they didn't understand about my caring role at all. I was under so much pressure with caring, he [my son] wouldn't sleep and I would turn up very tired. And if I wanted to change shifts for a hospital appointment there was a big fuss and forms etc. had to be filled in. You don't need to be frightened to come into work. With my job [now] there is a degree of flexibility, which is good. There is never the expectation that I have to attend things in the evening or at the weekend. If I have to go home quickly there is no fuss. There is never any guilt or awkwardness. ... It makes the world of difference to have an employer who is flexible and understanding. It encourages a loyalty that I have never felt in a job before. It is give and take on both sides.
Kay, Enablers' Project

If you have got young professional people in roles in the [organization where I work] ... who have not come across any [caring] themselves, they don't understand. But in my work situation, as other staff around me are getting older they are starting to have to look after their parents etc. and they are starting to realise.
Barbara, Carers' Action Movement

As I rose up through the ranks there was some understanding about my situation ... [but] even though in my own workplace we had quite good flexible policy there was still issues that if your child is ill you go sick. Rather this than make caring an issue.
Meryl, SNAC

Returning to work

Statistics suggest that sixty percent of women who want to work, but do not do so cite care and family responsibilities (including childcare) as the main factor.¹⁵ Two of the carers we interviewed who were not currently in a paid job said that they would like to work, and one of the working carers told us that she thought many more would like to be in employment:

If I had more support I would like to get back to work.

Julie, Enablers' project

I know a lot of parents here that would really like to get back into work. As the child has got older [the employer] may see the young person as a barrier to work, because you have to be there till they get on that taxi to school or college and be there when they get home. You have to look at jobs that will allow you that flexibility of hours.

Meryl, SNAC

The Benefits of Work

Some recent research suggests that combining paid work and unpaid caring can provide positive benefits for carers, as well as bringing in an income, although it can also cause stress and other difficulties.¹⁶ Other research has identified a number of studies that found that paid employment fulfilled a 'respite' function, provided social contact, and an alternative identity for carers.¹⁷

I really like coming to work, I just have my own time. I can chat to colleagues at lunch. I don't have to worry - no one is demanding anything of me. I can have a normal life.

Kay, Enablers' Project

Work can be a way of shutting off from the situation.

Mary, Stroke club

Many say that [work] keeps them sane

Alzheimers Society

Earnings and Income

Paid work is also emphasized in government policy as the route out of poverty, as a source of income other than benefits. We found that carers who combined work and caring were heavily dependent on their earnings for an income:

To compound my situation, my husband died of cancer seven years ago which means I am the only earner.

Barbara, Carers' Action Movement

I used to work one day a week. It's money, because the money is so crap if you are a carer. It makes you want to work if you can.

Anne, SNAC

Carers' Allowance

As some recompense for their caring role, some carers may claim Carer's Allowance. Carer's Allowance is payable to a person aged over 16 who provide more than 35 hours a week of care to someone who receives certain disability benefits. It cannot be paid to someone in full time education or who earns more than £84 a week (after certain deductions). The rate is currently £48.65 a week, although the amount may be reduced if the person claiming receives other benefits e.g Incapacity Benefit or State Retirement Pension. If a person is eligible for Carer's Allowance they also receive National Insurance credits. Carers UK estimate that 6 out of ten carers actually receive Carer's Allowance.¹⁸

In November 2006, 4,670 people were entitled to receive Carer's Allowance in Neath Port Talbot, the third highest number in Wales.¹⁹ This figure is more than double the number entitled to the equivalent allowance in August 1999. Of those entitled to Carer's Allowance, less than half (2,160 people) actually received payment. The remaining 2,510 were entitled to the Allowance but did not receive payments, for example because they received another benefit. A third of all those entitled to Carer's Allowance have been claiming for more than five years, and a further half have been claiming for between one and five years. Nearly two thirds of those entitled to Carer's Allowance in Neath Port Talbot are women, and more than 40 percent are aged over 65. Table 5 provides a summary of statistics.

Table 5 Carer's Allowance in Neath Port Talbot November 2006

Description	Number of cases
Total entitled cases	4,670
Total cases paid	2,160
Duration of claim:	
0 – 12 months	850
1- 5 years	2,390
5 years and over	1,430
Male claimants	1,720
Female claimants	2,940
Claimants aged:	
Under 18	100
18 – 44	1,160
45 – 64	1,590
65+	1,900

Source: Department for Work and Pensions

Carers' organizations have long called for adequate recompense for carers, and argue that the amount of Carer's Allowance payable and conditions about eligibility for it are too restrictive. One person from such an organization in Neath Port Talbot pulled no punches calling the Carer's Allowance a 'ridiculous, pathetic thing':

This is the lowest of the means tested benefits by far. It is pathetic. There are so many restrictions around it such as being unable to go into full time education without losing it. Where is the positive thinking behind that? Also it stops when you reach retirement age - does caring stop then? It's a joke and it's an insult and many carers don't bother with it, as there are too many restrictions. It puts people in poverty more than anything else. If you can't work and you rely on benefits you better not be reliant on CA.

Dave, Carers' Action Movement

These views were echoed by other carers' organizations and by individuals. The sense of injustice in the quotations below is palpable:

It shouldn't stop, just because it is an overlapping benefit. Just because my wife is over 60 doesn't mean that the caring role stops. I have never had a penny. Because I worked I wasn't entitled to the Carer's Allowance and even if you have two children

with needs you only get it for one of them.

Reg, Carers' Action Movement

I think the Carers' Allowance is keeping people in hardship. Even though it is a small amount they are scared to lose it, if you are a carer and the Carer's Allowance is the only thing that they get then it is hard. If they want to do a course locally or work they lose [it] ... I think it is almost perpetuating the problem to an extent.

Kay, Enablers' project

I think one of the other things that would help would be if the Carers' Allowance was treated like the DLA and made non-means-tested. It is peanuts anyway, but if carers go back to work they can only earn eighty something pound before they lose that Carers' Allowance so you are going back to work for nothing. What's the point other than getting you out of the situation, particularly for those at the heavy end of [caring] when the break would be beneficial. But you are literally working for nothing.

Barbara, Carers' Action Movement

I don't feel that we are being listened to, they pay you 47 quid a week and that's it.

Helen, Enablers' project

Conclusion

Caring undoubtedly has a very significant impact on employment. Caring not only affects whether or not someone works at all, but it also shapes the hours they work and type of job they do. In our interviews we found a number of carers who had stopped working altogether because of their caring responsibilities and others who simply could not conceive that they would ever be able to work given the support – or lack of support – currently available. Many of those we interviewed also felt it was their duty to care for their relatives.

These findings raise some important issues that warrant further consideration. First, there is clearly a strong link between large numbers of carers and high levels of economic inactivity. Whilst this study cannot say that large numbers of carers *cause* low levels of participation in the workforce (it might be, for example, that low levels of employment allow people to provide care for their relatives), it is clear that the current high level of economic inactivity in Neath Port Talbot is at least partly accounted for by the significant numbers of carers, especially those providing more than 50 hours a week of care. These carers provide an essential service to society which is worth approximately £165 million in Neath Port Talbot alone, and £3.5 billion in Wales as a whole.²⁰

For those who do wish to combine caring and employment, we found, in line with national findings, that flexible working and supportive employers and colleagues were crucial. Although legislation is establishing workers' rights to work in more flexible ways it will inevitably be some time before carers are aware of their rights and able to claim them. Employers should be encouraged and helped to adopt good practice in carers' employment – just as employers have been encouraged to adopt good practice in the employment of women through organizations such as Chwarae Teg and networks such as the Equality Exchange.

Whilst some carers undoubtedly wish to combine caring and paid work, others do not. Far from being 'inactive', these non-employed carers work extremely hard for very long hours, using multiple skills, saving the public purse billions of pounds. Public policy needs to recognize and respect the work of carers who are not in or seeking employment.

4. SUPPORT FOR CARERS

This section looks at the support that is available for carers, in particular to help those who wish to work to find and stay in employment, but also to enable all carers, irrespective of their work status, to live an 'ordinary' life. A number of different research studies²¹ have shown that support services are vital if carers are to combine work and care successfully.

Policy context

The Welsh Assembly Government's Carers' Strategy, published in 2000, provided a much needed focus on the needs of carers in Wales. Building on the UK strategy 'Caring about Carers', it identified five key areas for action which were:

- health and social care
- information
- support
- young carers
- carers and employment.

The implementation plan did a great deal to put carers on the policy and planning agenda at both national and local level, for example through providing for the inclusion of a carer on local health boards, and by encouraging other organizations, from employers to GPs to NHS trusts, to take account of the needs of carers. Most recently, the profile of carers has been raised by the appointment of a 'carers' champion', who was up to the 2007 Assembly election the Deputy Minister for Health and Social Services. In terms of services, the main development was the introduction of the Carers' Special Grant, which provided over £28 million of funding over six years for local initiatives.

However, it was widely accepted that the 2000 Carers' strategy needed refreshing and refocusing, not least to take account of subsequent legislative changes as well as changes in other policy areas such as the delivery of public services and the ongoing reconfiguration of health services.

As a result, the Welsh Assembly Government issued a draft 'refocused' carers strategy in late

2006²² which, at the time of writing, is being revised in the light of comments. Reactions to the draft refocused strategy appear to welcome the updating of the strategy, but express grave concerns that the awareness of the needs of carers is 'largely theoretical' and has not been backed up by services that make a real difference to carers' ability to continue to care.²³ Indeed, Carers Wales' response to the draft strategy concludes that:

Very major changes in priorities and investment [are] needed before the government's commitment to carers can be made real for most carers. ... The re-focused strategy does not set out a clear direction of travel for carers or social care. It lacks ambition and a strong vision. The key actions, while useful in themselves, are not strong enough to drive forward the significant improvements that are needed in the lives of carers or the people they care for.²⁴

This, and other responses, go on to highlight various specific ways in which the revised strategy should be strengthened. The Carers Wales response, which drew on the conclusions of four consultation workshops held across Wales with carers and local carers' organisations, emphasized the need to improve services for carers in two key areas – carers' assessments and respite care. These two areas also emerged as priorities in our own discussions with carers, which took place shortly before the Carers Wales consultation.

Services for Carers

Local authority social services departments are the lead agencies for providing support for carers, as well as services for the cared-for person. The services provided range from domiciliary care to day centres to respite care. It is worth noting that it is not always easy to identify whether the primary beneficiary of a service is in fact the carer or the person supported, for example respite care. Services for the care recipient can be as important as services for carers themselves.

Neath Port Talbot County Borough Council has sought to put services for carers firmly on its agenda. One of Neath Port Talbot County Borough Council's fifteen aims for health and social care, as set out in its Community Plan 2005–15 is to:

'recognise the needs of carers and give them support and services that maintain or improve their quality of life'

although there are no specific targets for carers.

Similarly, Neath Port Talbot Local Health Board has done a great deal to recognise the contribution of carers. The Health and Wellbeing Strategy for Neath Port Talbot 2005-2008 (a joint document produced by the County Borough Council and Local Health Board) aims:

- to increase the number of carers' and young carers' assessments
- to raise awareness of the needs of carers in primary care
- to develop a range of flexible and responsive services to support carers and provide short breaks from caring responsibilities
- to improve information advice and training services for carers
- to help meet the needs of carers for life opportunities when their caring responsibilities are complete

These aims are supported by the following targets and early milestones (although there do not appear to be dates set for their achievement):

- to ensure that at least 90% of carers of disabled children and adults are offered an assessment of their support needs
- to finalise development of a Neath Port Talbot Carers Strategy
- to strengthen the role of primary care teams in providing information and support for carers and young carers

Neath Port Talbot Council has appointed a 'carers champion' whose role is to promote the interests of carers within the authority. It has to be said that opinions amongst those we interviewed about the benefit of the carers' champion were divided, with many feeling that someone without personal experience of being a carer could not adequately represent their interests, whilst others acknowledged that having someone to speak up for carers was a valuable step forward.

At the time of writing, the council did not, however, have a completed carers' strategy, unlike many other authorities in Wales, although it is making significant progress towards establishing an independent carers' service.

The Local Health Board has also sought to include formally the views of carers' in its business, by having a carers' representative on its Board (in line with legislation that established LHBs).

Carers' Assessments

A crucial element in support for carers is the carers' assessment, which is effectively a gateway to securing help. Earlier legislation established the ability of carers to request an assessment of their needs as providers of care, but take-up was generally low and the range of support covered by the assessment was relatively narrow. The Carers Equal Opportunities Act 2004 sought to strengthen and enhance the role of carers' assessments by placing a duty on local authority social services departments to inform carers of their entitlement to an assessment, and by requiring the assessment to take account of carers' needs in respect of employment, education and leisure as well as their needs as carers per se.

A survey in Wales published in 2004, i.e. before the Carers Equal Opportunities Act was implemented, found that across Wales as a whole only 50% of carers surveyed had been told of their right to an assessment and that only 38% had actually received one, even though more than 90% of the sample appeared to be eligible for an assessment.²⁵ Further, carers reported that their assessments were only partial, with breaks from caring being discussed in only 67% of assessments whilst employment was covered in only 17% of assessments. The survey also found that the support offered was not adequate. More than half of carers who did not accept the support offered did so because the service was not what they wanted or needed.

Awareness of carers' assessments and take-up appeared to be similarly low in Neath Port Talbot. A survey undertaken in 2002²⁶ found that only 55% of carers of adults or children with disabilities who were assessed by social services during July 2002 were offered a carers' assessment (118 people), the same as the average for Wales. However, take-up of the offer of an assessment was strikingly low – only 10 percent accepted a carers' assessment in Neath Port Talbot compared with 36 percent in Wales as a whole. It is not clear why the take-up was so very low in the authority.

Although both these surveys were carried out before the Carers Equal Opportunities Act 2004, the availability and take-up of carers assessments do not appear to have improved dramatically as both carers and social services alike recognized. For example, none of the 3 carers we talked to at the Stroke Club knew what a carers' assessment was or how it could

help them, even though the organization has close links with the local authority. This view was echoed elsewhere:

I haven't made use of the carers' assessments, I only heard about them recently with going to meetings
Mary, Stroke club

I had the social services out twice and they didn't mention carers' assessments once.
Julie, Enablers' project

You aren't told, they don't give you the information. ... I had no idea and I had been a carer for five and half years. It is our right and we aren't given it. It is all word of mouth. ... There may be legislation but nobody knows about it. ... It's only now I am aware of what I can receive.
Delyth, Enablers' project

It is only through volunteering that I have found out my rights. We meet so many carers that really are clueless when it comes to carers' rights. It is not the professionals that are telling us these things, it is the average Joe on the street.
Helen, Enablers' project

However the co-ordinator of one carers' organization suggested that carers' assessments were helping people to identify themselves as carers:

Carers' assessments have made an impact. Parent carers particularly don't see themselves as carers and once you get through to them that they are a carer they can make use of them.
Kay, Enablers' Project

One issue is the term 'assessment' which appears to deter carers from seeking one:

I think the word assessment scares a lot of people, it sounds like a means test
Mary, Stroke club

A lot of people won't take the carers' assessment up as it is a bad term, it sounds like it is deciding if they are fit as carers, and this is especially true for parents. It is an assessment of their abilities and people are frightened of that. If you are robust enough to go through it, it will benefit you but not everybody is capable of this. You need to be pretty articulate and robust and knowledgeable.
Dave, Carers' Action Movement

Five of those we interviewed had had a carers' assessment. They were unanimous in finding the process unhelpful, mainly because carers felt that the support they needed was not available:

The social worker will ask if you need support and you say 'yes' and they will say that they can't help, and then that's it. You sign the paper to say you don't want anything and then they are covered.

Anne, SNAC

If they have an assessment it shouldn't be - oh you can't have this, or you can't have that. Tell them what they **can** have because then it gives them a little bit of hope. Why will people have an assessment if it is just to be told what you can't have?

Reg, Carers' Action Movement

I am in the middle of having a carer's assessment ... [the social worker] didn't offer respite as such but I could have someone to take [my daughter] out for a couple of hours, but then they came back and said that I was doing fine and I didn't need it. I can leave the file open or pursue it, I think I will just close it though, it isn't worth the hassle.

Hayley, SNAC

I have had a Carers Assessment but only because I asked for it. I didn't get a service on the back of the Carers Assessment though.

Sue, Enablers' project

Once they saw that my husband was settled I didn't hear from them again. ... The social workers think that once you are settled then it is goodbye.

Joan, Stroke Club

Some carers found the attitude of social workers unhelpful especially towards working female carers:

they were so rude and offensive ... With every successive professional I met the question would always be 'your son has a behaviour problem - how many hours do you work?' I even had one instance when I was asked how I managed to tidy my house!

Helen, Enablers' project

Social services were very anti the fact that I was a career woman, they thought I should have been at home. ... There seems to be a real mind shift that needs to be made by social services, they need to realise that people can work and be carers. ... They got really uptight that I put my job first and wasn't always able to meet them when they wanted.

Meryl, SNAC

Our findings reflect those of a 2001 'joint review' of social services in Neath Port Talbot.²⁷ The review concluded that the authority has 'many high quality services for vulnerable children and adults' and that 'some people are already well served and that progress is being made to tackle the outstanding weaknesses'. Those weaknesses include lack of information about individuals' entitlements, with the review concluding that 'there are still gaps in the information available to the public'.²⁸ On assessments, the review found that 'current systems do not ensure that all users receive an assessment, or that their needs for services are regularly reviewed'²⁹.

There is clearly a great deal more work to be done to promote take-up of carers' assessments amongst carers in Neath Port Talbot, not least to overcome any barriers raised by the term 'assessment'. Carers' Wales has argued that the draft refocused Carers Strategy should be much more robust on the provision of information, and that the Welsh Assembly Government should require, rather than just 'urge', NHS Trusts and local authorities to provide information to carers.

Locally, whilst the Health and Wellbeing Strategy's target of 90% of carers being offered an assessment is laudable, it is not clear whether this has yet been achieved. We suggest that Social Services should publish the number of carers' assessments offered and accepted each year, along with their outcome. It should also have in place, as part of its carers' strategy, clear plans to increase take up of assessments. Working with carers' organizations as well as providers of other services will be essential if the dissemination of information is to be successful. Exchanging experience and good practice with other local authorities, including 'beacon authorities' in England, may also be beneficial.

The issue is, of course, not just the take-up of assessments but whether the assessments deliver the support that carers need. In particular, our interviews highlighted that carers' assessments need to be conducted appropriately, respecting the choices and lifestyles of carers. And crucially, assessments need to result in the provision of additional support to meet carers' needs if they are to have credibility. Our findings suggest that further work should be undertaken to investigate the outcome of carers' assessments in Neath Port Talbot. Although outside the scope of this project, it seems that social workers need to receive effective training in conducting carers' assessments, which needs to include challenging stereotypes that some may hold about carers. In some local authorities, conducting carers'

assessments is contracted out to a local carers' organization which employs a carers' worker.³⁰ They may be merit in this approach being considered in Neath Port Talbot as a means of increasing take-up.

Provision of social care

The availability – or lack of availability - of care for the cared-for person emerged as a key issue for many of the people we interviewed. Indeed the issue of services that the carer him or herself may need hardly arose in our discussions.

Neath Port Talbot County Borough Council is the provider of statutory social care services. As an indicator of the level of service provided, in 2006 the Council employed more than 300 whole time equivalents providing care directly to adults and children, such as social workers and domiciliary care workers, and employed a further 165 whole time equivalent staff providing day care and 363 whole time equivalent staff providing residential services. Altogether it provided home care to 1,326 clients and 15,487 nights of respite residential care in that year.³¹

These statutory services are complemented by those provided by the other bodies, including the local voluntary sector as well as commercial interests, both under contract with the local authority and on their own initiative. Interestingly, the independent sector provided almost as many hours of home care under contract to the local authority as the authority provided directly – 281,201 hours a year compared with 285,741 hours.³²

The local voluntary sector in Neath Port Talbot appears to be particularly active on carers' issues. As well as the services offered by carers' organizations such as Crossroads, charities such as the Alheimers Association, Stroke Association, SNAC and Age Concern have also highlighted the needs of carers of their particular client group and provide their clients and carers with a range of services. A carers' centre was established in Neath recently and provides information, advice and support, whilst carers' groups have come together to form the Carers' Action Movement (previously the Carers' Forum) to press for change. Neath Port Talbot VCS, through its Enablers' Project and other activities, has an overarching role and has been given the responsibility for developing an independent carers' service, a key aspiration of the Carers' Action Movement. This latter initiative is also receiving external

guidance from the Princess Royal Trust for Carers.

Organizations in the area have made extensive use of the Carers Special Grant, which in 2004/05 provided £312,671 to a range of local carers' projects as shown in table 6. The Carers Special Grant moneys are to be incorporated into general local authority revenue funding after 2005/06.

Table 6 Allocation of Carers Special Grant in Neath Port Talbot 2004/05

Carers Special Grant 2004/05	£
Family Link Project (NCH Cymru)	54,680
Respite care for older people with mental health problems	50,000
Flexible respite/sitting service (Crossroads)	45,024
Sebiant Project: Mental Health (Hafal)	43,359
Respite (adults with learning disabilities)	32,781
Information Project for carers (Age Concern)	21,630
Carers Resource Assistant	15,615
School Holiday packages of care (NCH Cymru)	13,020
Sitting service for carers (Alzheimer's Society)	13,500
Flexible respite breaks for young carers	10,480
Young Carers	4,441
Advocacy Learning Disability (People First)	2,869
Epilepsy Group	1,000
Mental Health Forum	256

Source: Neath Port Talbot Local Health Board

Whilst the availability of alternative care is an essential pre-requisite for carers who wish to work, it was an issue that concerned carers irrespective of their employment status:

So how can you go back out to work if you haven't got someone to look after them?
Julie, Enablers' project

You are literally just left alone, there is no support whatsoever for them. ... I personally wouldn't go back into employment as there wouldn't be someone to look after my daughter. If there were more resources it would be nice, but there [aren't].
Hayley, SNAC

Children like mine don't just have one problem but many problems so you need to have a carer that is dedicated if you are going to have the confidence to go to work. ... They say there is the support for carers to work but it is like a lot of things, it looks good on paper but it doesn't come into place.

Anne, SNAC

For those caring for children with disabilities, their main concern was the lack of out-of-school provision able to cater for their child's needs, particularly for teenagers and young adults:

We have provided lots of things like breakfast clubs and after school clubs for other children but there is no provision for children like mine.

Meryl, SNAC

One of the reasons I dropped down to part time was that I had huge problems with childcare.

Barbara, Carers' Action Movement

They offer services for younger children but you can't put a 15 year old into childcare, it just wouldn't work.

Anne, SNAC

Places that offer [the right] amount of support are few and far between. There is very little ... for that 18 to 50s age range. If you are elderly there is provision, but if you are a younger disabled person there is buggar all, and if there is [anything] it isn't age appropriate.

Barbara, Carers' Action Movement

The availability of services for children with disabilities has been identified as problematic in a number of different studies, and Neath Port Talbot seems to be no different in this respect. Given this and our own findings, we suggest that further work needs to be undertaken on services for children with disabilities in particular to identify how best their needs and those of their carers can be met.

Our findings illustrate the broader issues facing social care in Neath Port Talbot, and in Wales, today. As Carers Wales stated in their 2007 Carers' Manifesto:

There is a critical lack of good quality, flexible and affordable care services across Wales. ... Without decent services, carers, and the people they support, are denied an acceptable quality of life and have no real choices.

Carers Wales call for increased and sustained investment in public sector social care services and for greater use of private sector and voluntary care providers.

A break from caring

The availability of care to give a break from caring – sometimes called respite care or replacement care – has been identified as one of carers' main priorities and needs.³³ Such care may be residential, or be home based e.g. sitting services, as care workers temporarily relieve a carer. Some carers also have breaks when the person they care for attends a day centre or similar activity.

As Carers Wales has argued, respite care is not just about giving the carer a break for relaxation or recuperation, but includes the provision of replacement care while the carer goes about essential business such as attending their own hospital appointments. It is also an essential component of contingency planning arrangements for looking after the cared-for person in the event of the carer becoming unavailable.³⁴

Despite the number of nights of respite care offered by Neath Port Talbot Council – which the Audit Commission's Joint Review of Social Services³⁵ says is actually higher than average in Wales - and the activities of a number of charities, the people we interviewed were almost without exception dissatisfied with respite care. They had difficulties getting access to it, and had concerns about its suitability and quality as these quotations show:

I have a week every 6 weeks or two weeks every three months. But because [my husband] has missed two dates it means I have to go back through the GP again, which is a problem.

Joan, Stroke Club

My husband ... goes to the day centre which is really the only break that I get. It's a three hour break a week. He was going to respite possibly every twelve weeks for 5 days but due to a heart attack he can no longer attend.

Mary, Stroke club

[My daughter] doesn't sleep, she goes to school nine until twelve but it isn't really much of a break. ... I don't receive any assistance. ... I think the respite care is appalling, I have never had any and I have never been offered it but I know people who just won't have it due to the way they get treated.

Hayley, SNAC

The availability and the choice of respite are very poor. There are always waiting lists. The choice of respite has to change, it shouldn't be the young generation mixed with the older ones. It doesn't work.

Reg, Carers' Action Movement

The respite I had was no good because I had to travel to bring him down to the respite centre [in Swansea] and then pick him up again and it meant I essentially didn't have any respite.

Anne, SNAC

[My daughter] just wouldn't go because the place wasn't suitable for her, it was geared towards much younger children. What she needs at the moment is somehow of organising a social life, she doesn't want to go clubbing with her mum and she doesn't have reliable mates as they need support as well."

Barbara, Carers' Action Movement

There was also some confusion amongst those we interviewed about the local authority's intentions about provision of respite care in the future – some interviewees referred to plans to build a new residential centre which they believed had been put back by 5 years, whilst others referred to a reduction in the number of places for respite care. Whatever the authority's long term plans are, it is clear that they need to be communicated more effectively with carers in the area.

Whilst our sample is not large enough to be conclusive our findings do suggest that replacement or respite care is a major issue in Neath Port Talbot, as elsewhere in Wales, and that current provision falls far short of the needs of carers, especially carers of teenagers and young adults. It may be that the Council's proposed Carers' Strategy will identify what those needs are and set out how it intends to meet them, but in the absence of a completed strategy this must surely be a high priority for action.

Carers UK has argued that the failure of public bodies to ensure that carers can have regular time off could be challenged in the courts as an infringement of the Human Rights Act, notably the right to respect for private and family life.³⁶ They call for care plans to set out the carer's contribution to any care package, following discussion with and agreement by the carer. The carer's need for time off should be an integral part of the carer's assessment, and the support and services provided to the carer should be monitored. Carers' organizations could consider establishing a minimum 'right' to time off from caring, which would be incorporated into all carers' assessments.

Support for Carers

One of the main purposes of the Carers Equal Opportunities Act 2004 was to ensure that the needs of carers themselves were met. Yet support for carers hardly featured in the discussions we held. This may be symptomatic of carers putting the needs of the person they cared for before their own needs.

Indeed, only two people made reference to having needs that were not related to social care. One carer referred to gym vouchers which were offered to carers in the area, but she was unable to use as the times at which the gym was available did not coincide with the times she was able to go. Another carer said that she had had to give up a university course as the times of the lectures were so variable that she was unable to organize adequate replacement care, so she had switched to an Open University course instead, thus missing out on the companionship that she had sought during her education.

There was some discussion about the relative merits of a local 'carers' nurse', with some interviewees considering the idea to be potentially very helpful but others arguing that ensuring that carers have access to mainstream services would be preferable.

The question of whether carers need special provision of services for them as carers, or whether the cared-for person needs more support services so that the carer can access mainstream services is important and needs further consideration both nationally and locally.

Conclusion

This section has highlighted some of the key issues which face carers. They centre around lack of information about carers' rights and in particular the availability and value of carers' assessments, the availability of social care services for the cared-for person, and the availability of replacement, or respite, care. These are the same issues that Carers Wales identified in their recent survey of carers.

It appears that, notwithstanding the very considerable efforts of the local authority and local health board, there is a long way to go before carers' needs will be addressed. As a start, it is vital that the final refocused Wales Carers' Strategy has more vision and is more robust,

providing genuine direction and drive to improve services for in Wales. It is also clear that much more information is needed about both the quantity and quality of services provided, from the number of carers' assessments offered and their outcome, to the nature and availability of respite care for different age groups. This will enable more meaningful consideration to be given to current levels of provision and will help to inform future investment in services. But, most importantly of all, there needs to be a dramatic improvement in the range and quality of social care support so that carers, and the people they care for, can lead a fulfilling life.

5. CONCLUSIONS AND RECOMMENDATIONS

Recent years have seen a growing awareness of the needs of carers. In Wales there has been a carers' strategy and a Carers' Champion, to name just two developments, whilst across the UK as a whole the Carers' (Equal Opportunities) Act 2004, Work and Families Act 2006 and the current Pensions Bill all provide positive recognition of the contribution made by carers.

However, our findings suggest that this progress has not yet been translated into significant improvements in services on the ground. Our interviews showed that many carers still struggle to juggle work and caring, and that services to support them and the person they care for fall short of their needs. We found that many carers were still unaware of their right to an assessment and those who had undergone one were mostly unhappy with the experience and outcome. Day-to-day care and respite care were frequently felt to be inappropriate to the needs of the care recipient.

Hardly surprisingly, the impact of high levels of care and lack of support on carers' lives is enormous. One of the areas in which this is most evident is in employment, with carers providing more than 20 hours a week of care being much less likely to be in employment than non-carers. Indeed, high levels of care giving are likely to be a key factor in the lower levels of employment and economic inactivity found in Neath Port Talbot and similar areas – a fifth of people who are economically inactive are carers.

As has been found elsewhere in the UK, our findings suggested that measures to help carers to find and maintain work are critical, with flexible working practices being particularly beneficial to carers. However, outside the ACE project there has been no real impetus to promote flexible working for carers in Wales, unlike campaigns on other issues e.g. gender equality. Nor is the role of carers identified in economic strategies such as Wales; A vibrant economy or the Wales Learning and Employment Action Plan. These are matters that needs to be addressed urgently.

Recommendations

We therefore recommend the following actions:

1. As a first priority, **carers need to be recognized in all areas of Welsh Assembly Government policy**, including economic and employment policy, as well as social care policy.
2. **The final refocused carers' strategy needs to be much more visionary and robust.** It should give much greater emphasis to employment for carers.
3. **An all-Wales campaign on carers and employment should be launched**, as a partnership between the public, private and voluntary sectors, drawing on the experiences of the 'close the gender pay gap' campaign.
4. **The rights of carers need to be part of the remit for the new Commission on Equalities and Human Rights in Wales** when it comes into being in October 2007.
5. **The Welsh Assembly Government should require public sector bodies to ensure needs of carers are met in their equality schemes.**
6. In order to inform carers of their rights, **the Welsh Assembly Government should produce public information leaflets** that would be widely available e.g. at GP surgeries, hospital outpatients, pharmacies.
7. **Local authorities should provide reliable and up-to-date data on a regular basis about the number of carers' assessments they undertake and their outcome.**
8. **Better training should be available for social workers to undertake carers' assessments** so that they do not reproduce gender (and other) stereotypes and to help them to offer services to meet carers' needs.
9. **Care packages drawn up for the cared-for person should include an agreed input of the carer's time**, so that their contribution is explicitly acknowledged and agreed.

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10. There must be **appropriate and good quality replacement care** specified in the care package of the cared-for person. This will enable carers' to meet their own everyday needs. Consideration should be given to specifying a minimum, and universal, entitlement to replacement care.
 11. **The Welsh Assembly Government should encourage the development of independent carers centres** in each county in Wales, through partnerships between the statutory and voluntary sectors in which a lead role is played by carers groups.
 12. Further **research is required on how best to meet the needs of particular groups of people**, especially care for younger adults.

Underlying these recommendations are two fundamental points. First, there is a shortage of resources for social care across Wales. Policy makers need to **grapple with the level of investment that is needed to sustain and develop the provision of care services**, across the public, private and voluntary sectors. With an ageing population, this is an issue which will increasingly be on the agenda.

Second, there needs to be a **reevaluation of the value that society places on care**. Carers are not seen simply 'economically inactive' individuals but provide an essential service. Carers' Allowance needs to be reviewed and ways identified in which it can be more flexible and encourage carers to seek and remain in employment, or to train. Clearly, this is an issue that cannot be changed overnight, but we suggest that the recommendations set out here would help to give greater recognition to carers and, in so doing, help to recognise their contribution to society.

Annex 1 Organizations Interviewed

Carers' Action Movement	4 carers
Stroke Club	3 carers
Enablers' Project	5 carers and project coordinator
SNAC	4 carers
Alzheimer's Society	project coordinator
Neath Port Talbot County Borough Council	Social Services department

ENDNOTES

¹ For an account of the background to the Act see my Bevan Foundation Annual Lecture, **‘The Right to an Ordinary Life’: Carers and Equal Opportunities**, 2005.

² For the most up to date guide to the Act, see Phillippa Russell, **Care Matters**, (The Nuffield Foundation, 2007).

³ Harriet Young, Emily Grundy and Mark Jitlal, **Care Providers, Care receivers; A longitudinal perspective**, York: Joseph Rowntree Foundation 2006

⁴ National Assembly for Wales Economic Development and Transport Committee, **Economic Inactivity in Wales**, Cardiff: National Assembly for Wales, 2005

⁵ Mike George, **It could be you: a report on the chances of becoming a carer**, London: Carers UK 2001

⁶ **Welsh Health Survey 2004-5**, Cardiff: National Assembly for Wales

⁷ *ibid.*

⁸ Carers UK, **Without us...? Calculating the value of carers’ support**, London: Carers UK

⁹ Lisa Buckner and Sue Yeandle, **Who cares wins: the social and business benefits of supporting working carers statistical analysis: working carers evidence from the 2001 Census** London: ACE National / Carers UK 2006

¹⁰ Hilary Arksey, Peter Kemp, Caroline Glendinning, Inna Kotchetkova and Rosemary Tozer, **Carers’ aspirations and decisions around work and retirement**, Department for Work and Pensions Research Report No 290, 2005

¹¹ U Henz, The effects of informal care on paid-work participation in Britain: a life course perspective, **Ageing and Society no. 24, 2004**, cited in Hilary Arksey, Peter Kemp, Caroline Glendinning, Inna Kotchetkova and Rosemary Tozer *op. cit.*

¹² Carers National Association (now Carers UK) **Caring on the breadline: the financial implications of caring**, London: Carers UK 2000

¹³ A. Mooney, J Statham, and A. Simon, A. **The Pivot Generation: Informal care and work after fifty**, London: Thomas Coram Research Unit / The Policy Press 2002, cited in Hilary Arksey, Peter Kemp, Caroline Glendinning, Inna Kotchetkova and Rosemary Tozer *op. cit.*

¹⁴ Hilary Arksey, Peter Kemp, Caroline Glendinning, Inna Kotchetkova and Rosemary Tozer *op. cit.*

¹⁵ Trades Union Congress, **Sicknote Britain**, London: TUC 2005

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