

Carers' aspirations and decisions around work and retirement

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The Department for Work and Pensions (DWP) commissioned the Social Policy Research Unit at the University of York to conduct research exploring the aspirations and decisions around work and retirement of people looking after disabled or sick relatives, friends, or older people. The study involved three elements: a literature review; in-depth interviews with 80 carers; and focus groups with professionals from Jobcentre Plus, social services departments and carers organisations who worked with carers.

Key findings

- A complex interplay of factors influenced carers' decisions about work, retirement and care-giving. These included financial issues, carers' health, personal factors, work-related issues, support services, issues related to the care recipient, and distances and travelling times.
- Generally, decisions were the result of clusters of factors. Uncertainties and unknowns regarding factors such as the carers' or the care recipients' health, or changes at key transition times, made decision-making even more complicated.
- Carers' knowledge about pensions in general and the impact of care-giving on pensions in particular was low. Many carers prioritised managing current financial pressures and commitments above planning and making financial provisions for their future retirement.
- The few carers who had had work-focused interviews said they did not influence their decisions about obtaining employment whilst their current (caring) situation lasted.

- Social services support did not easily accommodate work hours or patterns.
 Services that would make it easier for carers to combine work and care included longer day centre hours, childcare and after school clubs for disabled children and practical help with domestic chores.
- Both carers and professionals felt that the value of Carer's Allowance, the main welfare benefit for carers, was too small. In addition, carers believed that the earnings threshold was too low. There was evidence that the benefit might not act as an incentive to work; it could act as a disincentive to work more hours. It was not flexible enough for some carers because earnings could not be averaged out over a number of weeks.
- Working carers reported benefiting from both formal and informal workplace policies and practices. Flexible starting and finishing times were important, as was the ability to take time off in emergencies and for planned appointments.
- Carers centres indirectly helped carers remain in work by providing listening services, counselling, advocacy, referrals to social services and access to short breaks.
- Inter-agency collaboration between Jobcentre Plus, social services departments and carers organisations to help carers maintain, or find, work was limited, reflecting information gaps about what organisations existed to support carers and what services they offered.

Background

There are an estimated 5.6 million people in Britain looking after a relative or friend in need of support because of age or frailty, physical or learning disability or illness. The government aims to support carers in their caring role, and enable them to continue care-giving for as long as that is their wish. Many carers will be working when the need to care arises, and most wish to carry on working. DWP commissioned research designed to help ascertain what can be done to assist carers to remain in work, or to return to work during or after an episode of caring.

Research methods

The first stage of the study was a national literature review to identify existing evidence on carers' employment and retirement issues. This was followed by qualitative research in four research sites selected to reflect different labour market conditions. In-depth interviews were conducted with 80 carers with substantial caring responsibilities to explore their hopes and decision-making in respect of working and retirement. Subsequently, a series of separate focus groups were held with front-line professionals from Jobcentre Plus, social services departments and carers organisations who worked with carers to provide advice or support. The fieldwork took place between Autumn 2004 and Spring 2005.

Summary of relevant literature

The literature review indicated that most carers wish to remain in work and many are very reluctant to quit. Many employed carers find it difficult to care at the same time; it appears to become more difficult once people provide over 20 hours of care per week. It is co-resident, rather than extra-resident, carers who face the biggest obstacles. Interrupted or short working careers, or moving from full-time to part-time work, have implications for earnings and subsequent pension entitlements, especially if the caring episode lasts for many years.

The evidence suggests that most carers appear to have little access to potential carer-friendly workplace policies and practices, and even where they do exist carers can feel unable to take advantage of them. Most employers, in particular those in the private sector, give little consideration to carer-friendly work practices.

A range of factors influence carers' decisions about whether to remain in work or change their employment status. These relate to whether they can afford to give up work, if they enjoy their job, stress levels at work, being out of work, and access to support. Being able to retire early with a full occupational pension or favourable retirement deal can be a significant incentive to leave work in order to undertake caring duties, especially for men.

Qualitative research with carers and professionals

Carers' decisions around employment and care-giving

Carers' thinking and decisions about work, retirement and caring took into account a wide range of factors, primarily: finances; their own physical and mental health; personal factors, for instance commitment to careers; work-related issues; availability of formal and informal support; issues related to the person looked after; distances and travelling times. The relative importance of these various factors varied according to whether or not carers were working, and how many hours per week they worked. Generally, no single factor dominated, and decisions tended to be the result of combinations of factors, which could even be contradictory. However, carers' perceptions of their own health and well-being were very important considerations in decisions about whether to work and if so, how many hours per week to work. Uncertainties and unknown factors, for example relating to changes in health status of both the carer and the care recipient or changes at important transition times such as moving from children's services to adult services, made decision-making even more complicated for carers.

Retirement and pension planning

Carers found planning for retirement difficult, partly because it was influenced by many unknown factors related to the caring situation. However, there was evidence that some carers did not plan ahead because of reasons specific to care-giving. These included a lack of time because of caring responsibilities, not knowing whether adult disabled children would be living independently or still at home with parents, and the possibility of having to pay for residential or nursing home care. For many carers, it was more important to attend to current financial affairs and commitments rather than make financial provisions for a future retirement that for many people could be a considerable number of years away. Carers who were still buying their own homes emphasised the need to pay off mortgages as they did not want to risk losing their homes.

Many carers had limited knowledge about pensions generally, and the impact of caregiving on pensions in particular. Likewise, frontline professionals from all three occupational groups felt they had information gaps relating to pensions and tended to refer carers on to specialist agencies rather than provide carers with misleading or incomplete information themselves.

Support from statutory agencies

Jobcentre Plus

Work focused interviews with Jobcentre Plus personal advisers were unlikely to influence carers' decisions about obtaining paid work as long as their current (caring) situation prevailed. However, carers appreciated the advice, information and better-off in-work calculations provided by advisers. A key weakness identified by carers related to advisers' perceived lack of knowledge about caring in general, and the impact of caring on carers' ability to work in particular.

Personal advisers conducted fewer work focused interviews with carers compared with other

customer groups, which hampered their ability to acquire detailed knowledge of the main challenges and issues for carers wanting to work and care. Advisers believed that many carers had already made the decision not to work before they participated in a work focused interview. Consequently, they concentrated on raising carers' awareness about how Jobcentre Plus could help them once their caring situation changed. Personal advisers identified a range of organisational constraints (e.g. carers not being a priority group as in the same way as Incapacity Benefit claimants or disabled people were; the inflexibility of electronic diaries) that restricted the effectiveness of the support they could offer to carers.

Social services departments

Many carers (or care recipients) were unwilling to accept assistance from social services. Whilst some carers who did receive help were full of praise, others were critical. There was no evidence of a direct link between the number of hours that carers worked and the levels of support they received. Generally, social services support was not essential to the ability of carers to undertake paid work partly because it did not easily accommodate work hours or patterns - for instance, day centre hours did not always cover the full working day. Services that carers said would make it easier for them to work and care included longer day centre hours, childcare and after school clubs for disabled children and practical help with domestic responsibilities.

Financial support for carers

Carer's Allowance is the main welfare benefit for carers. Both carers and professionals regarded the value of the benefit as too small. Carers commonly agreed that the earnings threshold was low and therefore restrictive. There was evidence that the benefit might not act as an incentive to work, and that it could act as a barrier to working more hours. Carer's Allowance was not flexible enough for some carers, for example paid work could jeopardise receipt of the benefit because of the rules regarding spreading earnings over a reasonable time period. The

ceiling on earnings meant that carers who were working were unable to offer employers flexibility by occasionally working additional hours.

Workplace policies and practices

Employed carers benefited from both formal and informal workplace policies and practices. For many, these were essential to their ability to combine work and care. Flexible start and finish times, together with the ability to take time off in emergencies or for planned hospital or doctor's appointments, were particularly important. So, too, were sympathetic line managers and colleagues.

Professionals believed that employment opportunities did exist for carers who wanted to combine work and care, but such jobs were typically low paid, unskilled and possibly part-time and/or seasonal. They suggested that a combination of legislation and awareness raising had the potential to encourage employers to change workplace practices to better accommodate the needs of working carers.

Carers centres

Carers centres provide information, advice and support to assist carers obtain the services they need. Not all carers wanted assistance from carers centres, but those who were in touch commented favourably on the help they received. Centres indirectly helped employed carers to sustain paid work by helping to reduce their levels of stress. They achieved this by offering listening services, counselling, advocacy, referrals to social services departments and access to short breaks. Employed carers, especially those working full-time, could find it difficult to access help from carers centres because the latter's office hours and their working hours were often the same.

Inter-agency collaboration

Inter-agency collaboration between Jobcentre Plus, social services departments and carers organisations was limited. This was in part a reflection of important information gaps about what organisations existed to support carers and what services they offered. Jobcentre Plus staff were the most isolated professional group; personal advisers' knowledge of the support provided by carers centres and social services was very limited.

The full report of these research findings is published for the Department for Work and Pensions by Corporate Document Services (ISBN 1 84123 896 1. Research Report 290. November 2005).

It is available from Paul Noakes at the address below.

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