

Developing a clearer understanding of the Carer's Allowance claimant group

By Gary Fry, Benedict Singleton, Sue Yeandle and Lisa Buckner

In recent years there has been considerable attention to the situation of carers, including new national policies intended to address many of the problems which arise for those providing care. The evidence base on carers who regularly provide substantial care and are also eligible to claim Carer's Allowance (CA) is less detailed. Few studies have been carried out with large numbers of CA customers, and relatively little is known about this group of carers, their caring roles, and how they manage to negotiate their caring roles while receiving CA. This study was designed to find out more about CA recipients.

In 2009 there were 526,620 carers claiming CA¹. This study investigated how carers come to claim CA, carers' situation in relation to other state benefits, and their experiences in accessing CA. It focused on the caring roles of CA customers, on how they cope with their daily caring responsibilities, and on how CA fits in with these roles. It also explored CA recipients' experiences of paid employment and making decisions about employment or education, and the role CA plays in these.

The study used a mixed methods approach, comprising:

- interviews with carer advisers specialising in CA claimants;
- a postal survey of CA claimants (just over 500 questionnaires were returned);
- eight group discussions with CA claimants in four localities in the UK;
- individual interviews with a sub-sample of the survey respondents;

- literature review and secondary analysis of existing data.

The CA claimants who took part in the study had characteristics very similar to those of carers in DWP's full official data on CA customers at the national level. This indicated that the 504 survey respondents were reasonably representative of all CA claimants.

Data from the survey and qualitative evidence collected from 83 CA customers who took part in the discussion forums/interviews, showed most had some support from either services provided by their local authority or from friends and family. Most had found services difficult to access. Some said the support they had managed to access was inadequate, and many felt they needed more opportunities to take a break from caring. Most had accessed financial support in the form of CA when their caring responsibilities had grown particularly onerous, limiting their access to paid employment. While many were claiming other benefits, some felt there was a stigma or degree of social embarrassment attached to seeking this support. Some carers had experienced difficulties in accessing CA and other support, highlighting struggles to find relevant information about what was available, difficulties in understanding how different benefits interacted, and confusion over the rules which applied to each.

Most respondents had been caring for a considerable time, very intensively, and in difficult financial circumstances. The onset of care had involved a period of difficult and stressful adjustment, often resulting in feelings of low esteem and poor health. Carers in the study were providing many different types of care, ranging across the full spectrum from personal care to practical assistance; many provided

¹ Data acquired from the latest DWP statistics at the time of writing. <http://research.dwp.gov.uk/asd/>

many different types of support. Most were caring for a sick or disabled person who was their child, parent or spouse/partner, and there were some significant differences in the needs and experiences of these groups.

The majority of carers said they used CA for regular household expenditure (e.g. using it for utility bills, food or regular transport costs) although some wished they could spend it on themselves.

As CA claimants are required to be providing 35 or more hours of care per week, all were caring for someone full-time, many caring for over 50, or over 100 hours per week. Only a very small number were also in paid employment, mostly in low paid part-time work. Compared with all carers at the national level (as recorded in the 2001 Census), these carers were far less likely to be in paid work. Many said they had been forced to give up work soon after the onset of care. Others had taken a part-time job because they wished to remain in employment alongside their caring responsibilities. A quarter of carers (23 per cent) said they would prefer to have a paid job and a large majority of carers (61 per cent) said they would want a paid job when their caring role ended. Only a minority (14 per cent) did not wish to be in paid employment because they felt working would compromise their caring role.

Key findings

CA customers' access to benefits and services

CA plays an important role in many carers' lives and is a crucial source of income for some carers. Some carers in the study had tried to survive financially for long periods without applying for it, anticipating difficulties and frustrations in doing so. For many in the study CA was just one part of a complex package of support, drawn from a variety of sources which enabled them to fulfil their caring role and responsibilities.

Many carers in the study were angry about how difficult it had been to access what few formal services they had managed to get in place. For most,

accessing CA had involved challenges and many said obtaining information and advice on CA had not been easy.

CA customers' experiences of caring

Carers of older people were less likely than other carers to live in the same household as the person they cared for, and were the least likely of all in the study to be claiming three or more state benefits. Many reported financial difficulties and said they would prefer to be in paid work. Long-term care had had a particular impact on the financial welfare of this group.

Carers of a child were the most likely to be in paid employment; most of these carers were women who were working part-time. This group was the most likely to have a higher level of qualification, but included many who reported financial difficulties and who were claiming two or more state benefits.

Long-term carers were more likely than other carers to be in poor health; many in this group provided very high weekly hours of care (100+ hours per week). Long-term carers were also the most likely to have abandoned once-held aspirations, including hopes for their career. Many worried about their lack of pension contributions and feared for their own welfare in old age.

Nearly half the sample had no qualifications and these carers (and those with only lower level qualifications) were more likely than those better qualified to be caring full-time and to be receiving two or more state benefits. Those carers with a higher level of qualification were more likely to be a student, to be retired, and to be caring for a child, and were more likely to say that they had found it difficult to find a job which put their qualifications to use.

CA customers' decisions about paid employment

Most in the study thought jobs with a fixed number of hours and flexible enough to accommodate carers' complex caring responsibilities were very

difficult to come by. Carers who wished to return to education and/or develop new skills which would later give them an advantage in the job market reported that the 21 hours rule for studying while claiming CA made it difficult to access courses.

Half the respondents in the survey had given up work at the onset of their caring role. Difficulties in adjusting existing employment to accommodate care had often occurred despite employers being sympathetic to carers' responsibilities. Some CA claimants had managed to alter their working hours, usually to enable them to remain within the eligibility criteria for CA, and part-time work was valued as it enabled them to retain or develop work skills and keep in touch with the job market.

Although most expressed a desire to work once their caring role had ended, and nearly a third would have preferred to be in paid employment at the time of the study, only 14 per cent were actively looking for a job. Carers suggested that this was because the eligibility rules for CA were very restrictive, making finding suitable work extremely difficult. Those few carers in the study who were in paid work highlighted the advantages they felt were involved in having a job, including benefits for their health, self-esteem and confidence.

Not all carers in this study wanted to work; some regarded the care they provided as a 'full-time job' and emphasised that carers are not 'unemployed'.

Recommendations

Key aims for the carers in the study were to feel better supported in their caring role, to have a 'life of their own', and to secure paid employment, aspirations consistent with the 'vision' set out in the National Carers Strategy 2008 and reiterated in the Next Steps Carers Strategy (2010). Different parts of the system of support and services for carers should therefore be 'joined up' in practices and design, especially in the context of growing 'personalisation' in the social care system. Co-ordinated, holistic help is needed.

Additionally, a more 'human' approach, and a sounder appreciation of many carers' very demanding caring roles, is needed to deliver re-designed support appropriately. There should be clear information about the support available. In addition, more information about CA should be available to carers from the first moment they access support or services.

Preventative action in the system of care and support is greatly needed. Most carers feel they get no help until they encounter a 'crisis'; this has a negative impact on their health. More investment in preventative approaches is recommended, to avoid unnecessary damage to their health and help them hold on to paid employment.

The eligibility rules for CA are problematic for carers seeking paid employment or training. They limit them to low paid unskilled work, and a very limited range of courses; these rules should be reviewed. Carers experienced many difficulties and confusion in the way CA interacted with other benefits. This should be addressed, especially how CA relates to IS, but also to respond to carers' view that CA is 'taken away' when they reach retirement age. In making any changes to CA, it is recommended that its importance as an acknowledgement of caring roles be retained: this may involve separating different elements of the financial support carers can claim.

CA customers are more likely than other carers to be in poor health. It is recommended they be targeted in future efforts to promote carer health and wellbeing. Poor carer health leads to additional costs in the health and social care system, and concerted efforts are needed to address these.

Most carers in the study had given up paid work to care, despite their belief that combining work and care is important for carer wellbeing. It is recommended further effort be put into providing a wider range of support services for working carers and raising employers' awareness of the role they can play.

© Crown copyright 2011.

You may re-use this information (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit <http://www.nationalarchives.gov.uk/doc/open-government-licence/> or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk.

The full report of these research findings is published by the Department for Work and Pensions (ISBN 978 1 84712 973 4. Research Report 739. May 2011).

You can download the full report free from: <http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>

Other report summaries in the research series are also available from the website above.

If you would like to subscribe to our email list to receive future summaries and alerts as reports are published please contact:

Kate Callow, Commercial Support and Knowledge Management Team, Upper Ground Floor, Steel City House, West Street, Sheffield S1 2GQ. Email: Kate.Callow1@dwp.gsi.gov.uk.