NHS
National Institute for Health Research

NIHR School for Social Care Research

Using recent surveys to improve support for unpaid carers

Outline of a research project funded by the NIHR School for Social Care Research

Improving the evidence base for adult social care practice

What can data from recent surveys tell councils about how best to identify and support unpaid carers in England?

The importance of unpaid care and the need to support unpaid carers are key issues in adult social care policy and practice in England today. If councils are to improve this support and target it more effectively, they need to be able to better identify carers, understand the factors associated with carers' quality of life and assess the potential impact of carer-related services.

Data from recent surveys on unpaid care can assist councils to fulfil these objectives. Such data are available through two surveys both carried out in 2009/10: the *Personal Social Services Survey of Adult Carers in England* (*PSS SACE*) was a questionnaire completed by over 35,000 unpaid carers known to councils with adult social services responsibilities; and the *Survey of Carers in Households* was a nationally representative survey of approximately 2,400 unpaid carers in the general population in England. Analysis of these data can help us to understand how councils identify and support unpaid carers, while also assisting councils to make best use of future carer surveys – which they are now required to conduct for national purposes – to improve services locally.

This project

- will provide recommendations for councils about identifying and supporting unpaid carers, and on using and interpreting data from carer experience surveys to improve practice.

It aims to

- identify the characteristics of unpaid carers who are 'visible', or known, to councils with responsibility for adult social services

- explore the extent to which individual-level factors of the carer and the person they care for account for variations in carers' quality of life

- explore the extent to which council-level factors account for variations in carers' quality of life

- describe more effective policies and practices for identifying and supporting carers

- recommend how future carer experience surveys could be used and interpreted to improve practice.

WHAT IS THE CONTEXT?

Government policy in recent years has put renewed emphasis on the importance of, and support for, unpaid carers. This has included the refreshment in 2010 of the National Carers Strategy and the inclusion of indicators of carers' outcomes and experience in the 2011 Adult Social Care Outcomes Framework (ASCOF). Within the government's carers' strategy, a key priority is "supporting those with caring responsibilities to identify themselves as carers at an early stage".

To achieve government aims, councils with adult social services responsibilities face three key challenges: better identification of carers; understanding the factors associated with carers' quality of life; and identifying and providing or facilitating the types of support required to deliver positive outcomes for carers.

However, there is evidence that councils have considerable difficulty in identifying unpaid carers and that, as a result, many carers have difficulty accessing social care support. The NHS Information Centre found that only four per cent of carers in the *Survey of Carers in Households in England* in 2009/10 had had an assessment. Even among those providing care for 20 or more hours a week, only seven per cent had had an assessment. Access to services for the people looked after by carers was low, with only 13 per cent of carers in the 2009/10 household survey saying that the person they looked after received home care or home help.

In addition to the *Survey of Carers in Households*, in 2009/10 there was also a survey of carers in contact with councils, the *Personal Social Services Survey of Adult Carers in England* (*PSS SACE*) (see Box). The availability of these two surveys together offers the opportunity to explore the characteristics of carers who are 'visible' to local councils and, as a corollary, those who are relatively invisible.

If councils are to make best use of the data they collect in future, it is important they know how to interpret them. In addition to levels of caring provided, previous research has identified that

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Surveys of unpaid carers

Two surveys of unpaid carers were carried out in 2009/2010 in England:

- *The Personal Social Services Survey of Adult Carers in England* (*PSS SACE*) was a questionnaire completed in 90 councils by over 35,000 carers who had received an assessment during the previous year or (in some councils) were 'known by association' with the person they cared for. From 2012, the *PSS SACE* will be conducted at least bi-annually, which means councils will in future be able to draw on local data when developing local carer strategies, policies and practice.

- *The Survey of Carers in Households* was a nationally representative survey of unpaid care provision, which conducted detailed interviews with around 2,400 people providing unpaid care in private households. It represents the most detailed data collected on unpaid care provision since the *General Household Survey* carers' data were collected over ten years ago.

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differences in the experiences of carers can be explained to some degree by their characteristics, including age, gender and ethnicity. These basic demographics are being collected in the 2012/2013 *PSS SACE*, but many questions remain: what do these associations tell us?; what other data might councils want to collect to interpret their findings?; and how can they use the information to target/offer support? This project seeks to answer such questions.

HOW WILL THE PROJECT WORK?

The two strands of the project will analyse data from the *PSS SACE* and the *Survey of Carers in Households*, both of which were collected in 2009/10 in England (see Box). The first strand will focus on the identification of carers by councils, and the second on variations in experiences of carers who are identified by councils.

Research project outline

STAGE 1: Councils' identification of carers

This stage will identify the characteristics of carers visible to councils with adult social services responsibilities. Preliminary analysis carried out by the NHS Information Centre suggests that carers known to councils have different characteristics from carers in households more generally. Compared with the wider population of carers, carers known to councils appear more likely to be caring for 50 hours a week or more; to be aged 65 and over; and to be 'spouse carers'. Those less visible to councils would appear to be carers providing less intense care; younger carers; and those caring for a parent or parent-in-law. The Information Centre acknowledges, however, that its initial results may have been affected by differences in methodologies between the two surveys.

This project will build on the Information Centre findings. The sample of carers in all 90 councils in the *PSS SACE* survey will be aggregated and compared with the sample of carers in the *Survey of Carers in Households*, controlling for differences in methodologies between the two surveys as far as possible. Although only 90 out of the 152 councils with adult social services responsibilities are included in the survey of councils, the Information Centre regards the survey as representative of councils in England. The two surveys have very different sample sizes, with over 35,000 carers in the *PSS SACE* compared to 2,400 carers in the *Survey of Carers in Households*. The latter sample is, however, based on a survey of nearly 25,000 respondents in a nationally representative sample of private households in England.

The comparison between the two surveys will focus on carers providing 'a substantial amount of care on a regular basis', as these are the current criteria for a carer's assessment under existing legislation. One of the objectives of the project is to investigate how these criteria are currently defined in practice by councils.

STAGE 2: Variations in carers' experiences

A scoping review will be carried out of the literature on the factors associated with carers' quality of life. Hypotheses will be identified about the factors that may be associated with carers' quality of life such as individual characteristics (e.g. gender), caring circumstances (e.g. co-residence) and environmental factors (e.g. rurality of the local authority). These will be tested by analysing the data from the 2009/10 P*SS SACE*. Local area characteristics will be controlled for.

During the project the team will feed back results to the Social Services User Survey Group to identify issues for councils in interpreting survey results locally in order to implement changes in practice. Researchers will also identify relevant factors that may assist councils in collecting and analysing their own data in future.

STAGE 3: Analysis of findings

The results of stage 1 will be analysed to describe the processes by which councils currently identify carers and how these might be changed, so that carers currently less visible to councils might be better identified. The results of stage 2 will be analysed to identify the types of support associated with positive outcomes for carers. The project will consider the implications for practice and how councils might make best use of carer experience survey data in the future.

Project publications

The project will produce a summary of findings and peer-reviewed publications that will cover the two strands of the research.

Presentations of the findings will be made at NIHR School for Social Care Research events, such as the *Workshop on Carers and Social Care Research*, and at events that reach senior practitioners and managers, such as the Social Services Research Group annual conference.

Through its membership of the Social Services User Survey Group, the project has good contacts with the organisations most interested in using the *PSS SACE* data, including representatives from local councils who will provide, and advise on, further channels for dissemination of the findings.

HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

The School for Social Care Research has identified, as one of its priorities, research into how "adult social care practice can improve to better meet carers' needs".

By analysing data from surveys of carers, the project aims to identify the type of carers who are not currently reached by councils and, as far as possible, the associated policies and practice that may be best able to identify carers, facilitating the spread of good practice.

Increasing understanding of how different factors affect different groups of carers should help councils to identify how support and services could be best tailored for different groups of carers, thereby ensuring that effective support is available and accessible.

The research should also help councils to make best use of local information collected through future surveys of carers. Overall, this project should facilitate local policies, practice and investment in initiatives most likely to improve carers' quality of life outcomes.

The Research Team

Professor Ann Netten, Professor of Social Welfare at the University of Kent, Director of the Kent branch of the Personal Social Services Research Unit (PSSRU), Director of the Quality and Outcomes of person centred care Research Unit (QORU), and Associate Director of the NIHR School for Social Care Research, will have overall responsibility for the project.

Dr Linda Pickard, Senior Research Fellow and *Dr Derek King*, Research Fellow, at the PSSRU at the London School of Economics and Political Science (LSE), will conduct the analysis for the comparison of carers in the Personal Social Services Survey of Adult Carers in England 2009/10 (PSS SACE) and the 2009/10 national Survey of Carers in Households in England.

Diane Fox and *Stacy Rand,* Research Officers, and *Dr Theresia Bäumker,* Research Fellow, at PSSRU (Kent) will conduct the scoping review, with library assistance from *Rosalyn Bass*, and carry out the analysis of PSS SACE 2009/10

Further information about the NIHR School for Social Care Research is available at www.sscr.nihr.ac.uk

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Recent Survey Evidence about Unpaid Carers: Implications for Social Care Practice in England

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