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## Supporting rural carers: understanding the role of the Voluntary Sector

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### Abstract

*Findings from a small scale evaluation of one local carers' organisation in the north of England are used to discuss the commissioning of carer support services in rural areas. The issues raised match closely those identified in the new national strategy for carers both in terms of analysis of need and suggested responses. Respite in order to facilitate 'time out' and personalisation of services through a dedicated support officer emerge as the most important elements of service delivery from the carer's perspective. However, the evidence suggests that current provision is still too limited and that much remains to be done to support carers in their role more effectively.*

**Keywords:** Carers, rural, well-being, voluntary sector

### Introduction

The 'National Strategy for Carers' (Department of Health, 2008) sets out ambitious medium and long term objectives aimed at achieving substantial change in the everyday lives of carers. By 2018, it is expected that carers will be respected as expert care partners and will have access to integrated and personalised services. The strategy commits £255 million to ensure additional support for carers focusing on: breaks, income, information and advice, the workplace, training for the workforce, access to employment, emotional support, the health of carers and the specific needs of young carers. Discussing the implications for the commissioning of services in rural areas, this article reports the findings of a small scale evaluation study of one carers' support organisation (CSO) in the north of England.

### Caring in the UK

In the face of an ageing population, increasing rates of disability and a shift from institutional to home based care, there is a growing expectation that families will

care for people with chronic illness and disability. An Audit Commission Report (Pickard, 2004) highlighted that almost 6 million adults are providing unpaid or informal care in England and Wales, about 10% of the population. Of these, approximately 1.6 million (4% of the adult population) provide care for 20 hours a week or more. 75% of all informal carers look after older people aged 65 and over. Around half of all disabled older people in the UK rely exclusively on informal help (Comas-Hererra *et al.*, 2004).

Since the community care reforms of the 1990s, practical support for informal carers has become a building block of community care policy in England and Wales. The Carers (Equal Opportunities) Act (Office of Public Sector Information, 2004) places duties on statutory services to: inform carers of their entitlement to an independent needs assessment; ensure that carers outside interests (e.g. work, study, leisure) are considered when making an assessment; and improve joint working with voluntary and community organisations to provide better support to carers. However, a review of carers' support services undertaken by the

Commission for Social Care Inspection (2006) reported that services for carers remain patchy and limited and that support is still usually only forthcoming when a crisis point is reached.

Of the 6 million carers in the UK, some 51% (over 3 million people) have felt like walking away from their care duties and many experience no breaks in a "24/7 physical and emotional roller coaster of life as a carer" (Princes Royal Trust for Carers, 2006). Carers who provide high levels of unpaid care for sick or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities (Office for National Statistics, 2006). The data show that 21% of carers providing over 50 hours of care a week, say they are in poor health compared to nearly 11% of the non-carer population. Singleton *et al.* (2002) reported that 36% of those who provided substantial care and did not get a break from caring suffered ill health compared to 17% of those who accessed a break. The same study found that 35% of carers without good social support suffered ill health compared to those with good support (15%). Research by Carers UK (2000) found that 60% of carers providing substantial care said worry about their finances was affecting their health and that some 20% of carers gave up work in order to care. Pickard (2004) suggests that an improvement in the quality of support, or flexibility around it, can help to improve the carer's health, just as staying in work longer could delay financial stresses whilst caring and reduce isolation. Intensive caring can have adverse effects on the psychological health of carers, with consistent evidence that carers are more at risk of mental health problems, particularly stress and depression, than other adults of the same age (Bauld *et al.*, 2000).

The provision of breaks from caring or respite care, such as day care and overnight respite in a residential care home, is often associated with very high levels of

satisfaction on behalf of carers, although this is not always associated with changes in their psychological health (Levin *et al.*, 1994; Arksey *et al.*, 2004). There is also evidence that both day care and residential respite care have positive outcomes for carers. In one study, day care reduced stress for about 85% of the carers of users of day care, and was particularly effective for carers of severely cognitively impaired older people (receiving up to around two days a week of day care) and carers in paid employment (Davies *et al.*, 2000). It has been recognised for some time that home care, provided to the cared-for older person, is beneficial to the carer's well-being (Twigg, 1992). The study by Davies *et al.* (2000) shows that counselling or therapeutic social work is effective in reducing the carer's burden. The authors found that relatively small amounts of therapeutic social work produced relatively large reductions in carer stress.

In a number of local authorities, almost all of the Carers Grant is routed through the Third Sector (voluntary, community and private sectors) and it is recognised that many carers prefer to deal with this sector rather than with statutory services (Department of Health, 2008). In recognition of the vital role that Third Sector organisations play in supporting carers, the new national carers' strategy commits funding over the next three years to build capacity in the sector at both national and local levels. The overall objective is that services provided by the Third Sector should have far greater reach, and that they are able to play a greater role in every local authority area in working with councils and Primary Care Trusts to deliver the best possible support for carers. Beyond the grey literature there is, however, relatively little empirical understanding and evaluation of the range and diversity of services provided to carers through the Third Sector.

## The study and methodology

This study was commissioned as a service evaluation by a local voluntary sector carers' support organisation (CSO). The overall aim was to ascertain the views of carers on the quality and range of services provided and, in terms of outcomes, how this was perceived to impact on their health and well-being. In particular, the study sought to ascertain data on how to improve the assessment of carer need and to identify opportunities to increase the number of referrals by assessing the accessibility and acceptability of current provision.

The evaluation employed a multi-method approach and included a postal survey of ninety carers, nine in-depth interviews and two focus group sessions. All those involved in the study were adult carers and all were receiving support from the CSO. The methodology for the study was assessed by the Research Ethics Committee of the University of Cumbria and was amended and approved before the work commenced. The design of the survey questionnaire was informed by an initial focus group which brought together six carers, chosen on a randomised basis from volunteers. This initiated a key phase of carer engagement in reviewing the proposal from a carer perspective and helped design the semi-structured questionnaire. The focus group was also consulted about the issues to be covered and helped to develop the broad headings/questions. This process reflected the diversity of experience of the carers and helped signpost the direction of the research, data collection and analysis. The questionnaire covered a range of issues including the type of care provided, support from the caring organisation and others, feedback on the support received and how caring affected their lives. A postal questionnaire (along with an information sheet and consent form) was sent to 90 carers who had been assessed and had received services from the CSO, and the survey response rate was just under 50%. Of

the 40 respondents to the questionnaire, the majority (23 persons; 57.5%) were female, with 13 males (32.5%) and 4 persons of unknown gender (10%) also responding. The style of response varied. Some respondents were fastidious, completing the form in full and providing a great deal of detail. At the other extreme some filled in responses very concisely, using few words, or just answered those questions they wanted to. The great majority, however, conveyed a clear sense of an individual responding and communicating. The survey was then followed by nine in-depth interviews. Each interviewee received a written explanation of what was involved and signed their consent to the process in advance. Full confidentiality was assured to the interviewees. The interviewee chose the location for the interview, which was sometimes in their home. The interviews looked at both the assessment and interventions supplied by the CSO and explored the carer's perceptions of the effects of interventions on their physical and mental well-being. The themes of the interview questions reflected the impressions and information gathered from the questionnaire. Each interview lasted between 40 and 60 minutes on average and was recorded and transcribed. Each interview followed a simple, common format of questioning designed to elicit full responses and provide a common framework of ground covered. The basic format was as follows:

- How did you become involved in caring?
- Describe for me a typical day from morning to night time, and into the night if applicable.
- What sort of support do you receive?
- What keeps you going and how do you make time for yourself?
- What services do you receive from the carers' support organisation (CSO)?
- How might the CSO service be improved or what additional services might it provide?

In all, nine in-depth interviews were conducted face-to-face. Six interviewees were female and three were male. The aim of the interviews was to pursue the issues emerging from the analysis of the questionnaire data. The data was subjected to content analysis, including tabulation and generalisation to determine patterns in the responses as well as respecting respondent individuality. Preliminary findings were then fed back to the project advisory group (which included carers) and presented to a large group of carers to check their relevance and validity before completion of the final report.

## Findings

The CSO provides support to over 400 carers living in a rural area of northern England. The population is about 50,000, of whom 15,000 live in the main town. The area is one of the most sparsely populated rural districts in England and Wales, and some 25,000 persons live in settlements of less than 1000 residents, or even more isolated farming communities. As a result, services are sparse over much of the area, with many services being only available in the towns and poor public transport preventing many people from accessing them. The rurality of the district coupled with modest staffing and limited financial resources pose significant management challenges for the CSO and, indeed, many other local support services and organisations (Roberts, 2008). Specific issues in relation to the planning, resourcing and delivery of social and health services in rural areas include the relative distances from main service centres, the logistics of planning and delivering services to geographically dispersed populations, transport inadequacies, the patchy development of services and declining service infrastructure in some rural communities (Manthorpe *et al.*, 2008).

The 2001 census revealed nearly 5,000 carers living in the study area which

represents 10% of the entire population. All of the carers involved in the study cared for relatives and were either a spouse or one of their children. Some 20% of carers involved in the study cared for less than 20 hours a week while, at the other extreme, 25% provided care for over 60 hours. Some described their role as providing '24/7' care. Over half of respondents were lone carers. 60% of respondents recorded that they provided five or more types of care from a suggested list of nine types of care (personal care, living care, medication care, night assistance, emotional care, social care, travel assistance, financial care, and assistance with administration). 30% of respondents in the survey had been receiving support from the CSO for between one and 5 years and 10% had been in contact for 5 years or more with the remainder having received less than one year's support.

The CSO is part-funded by the local authority and is contracted by them to undertake carers' assessments on their behalf. Among interviewees, the consensus was that carer assessments did not meet all of their needs. Four carers saw their predicaments as unique to them and seemed to accept that the system would deliver limited support to them. Into this category fell carers who were looking after disabled or injured persons with highly complex needs. Three others felt the system went a long way to meeting their needs and were generally happy with it (e.g. domiciliary for older or disabled people). For the majority of the nine carers interviewed, care management did not live up to the expectation that it would be viewed as an opportunity to look afresh at sources of support. Most carers felt that it took a long time to get the right kind and level of support put in place and it was often very difficult to find help with practical tasks such as gardening and 'odd jobs'. For instance, one carer had an old freezer that he was unable to move or empty. He suggested creating an 'odd jobs' service to

look after physical tasks that may be beyond the ability of a carer or that they simply do not have the time to undertake. They might be 'one off' tasks like relocating his fridge freezer. None of those interviewed received direct payments or individual budgets.

## Discussion

All of the carers surveyed felt well-informed about the support that was available. However, over half of the carers who completed the questionnaire did not distinguish between services provided directly by the CSO and those services subsequently provided by other agencies as a result of signposting by the CSO. The distinction between signposting and service provision was often blurred. The range of support listed by the carers as being on offer from the CSO was long and included day care, respite care, listening support, emotional support, vouchers for pamper sessions, counselling, financial advice, opportunities to meet other carers, home visits, information and advice, advocacy and stress management courses. Other supports listed were: meeting other carers, a book club, newsletters, introduction to pre-prepared meals, access to information and access to specialised help such as equipment or help with bathing.

Carers sampled through the questionnaire were, on the whole, very positive about the support they had received from the CSO. 76% of respondents described the service in a positive manner and 58% described it very positively (i.e. choosing to use three or more positive terms). When asked 'what single thing has made the most difference?', 40% of carers replied that the staff of the CSO were there and that they provided a confidential, listening ear:

*[Prior to contact with the CSO] I was very stressed and cut off socially. I was unsure of how to get information or help. I felt very cut off from everything and did not know if I could cope. (Carer)*

One recommendation concerned more out of hours support. One carer described how she might steal some time for herself later in the evening and how it was important to have support which fitted in with her own time frame.

A number of respondents also pointed to the need for a more proactive approach to maintaining contact with them. The support that was most valued was one-to-one support provided by a dedicated worker. In the interviews, carers described how this relationship worked best when it permitted a long-term relationship to develop. Carers spoke very warmly of their support officers:

*I can feel the care and concern of this person for me and for what I am doing. I can not overstate the difference this has made. (Carer)*

In one case, a carer assumed that he was receiving no services as he was under the impression that the support worker "was visiting me as a friend". Ensuring continuity of worker is particularly important for carers. In 2007, a number of staff left the CSO and this meant that those carers with close emotional relationships felt let down and anxious. In rural areas, recruitment and retention of staff is a particular challenge which compounds this issue (Gill, 2007). Carers in the study were generally aware of the issue of staff shortages and resource constraints, and were keen to promote the use of the telephone and email as a way of supplementing face-to-face contact. The potential to make greater use of volunteers was also highlighted in the interviews.

Many comments reflected the crucial importance of respite care. Respite which enabled carers to have time for themselves was extremely important. Pastimes such as gardening, woodwork, art, archery, computing, and genealogy were all mentioned as important in promoting mental health and well-being. Social contact and doing things with other carers was also

important, yet lack of access to transport often made this difficult.

Faith was mentioned by two carers and opportunities to talk with friends or support workers was mentioned by all as providing an important source of release from cares and concerns. Specific products (provided, arranged or facilitated by the carers' support organisation) were very popular with the carers. One of the most popular services organised through the CSO was the so-called 'pamper' sessions which offered, for example, sauna, swimming and massage. These were rated very highly by female carers. Stress management and counselling courses were also highly valued by both sexes.

### **Outcomes and implications for commissioning**

Across different policy domains such as quality of life, income, health and housing there are wide variations in the outcomes that carers experience (Lloyd, 2008). In this study, which focused on health and well-being, 35% of carers recorded feeling less stressed following contact with the CSO and 43% described a perceived improvement in their health and well-being, directly linked to making contact with the CSO. However, while the CSO plays a crucial role especially in terms of alleviating the isolation of being a carer ("by just knowing they are there") the overall picture remains one of unmet need and considerable hardship among rural carers. Almost half of those surveyed (48%) recorded suffering from stress as a result of caring. Of the nine interviewees, four were the object of emotional or physical abuse from the cared-for relative. Three carers had impaired health, one with acute, continuing and progressive health problems. Three carers were in reasonably good health and the remaining three reported severe ongoing stress. Four carers were on long-term, anti-depressant medication which served to maintain their moods on an even keel:

*[Caring] dominates my social life. ... I live with anxiety on a daily basis. I have had several mental breakdowns, and there is no solution or end.*

Lloyd (2008) argues that, for many older carers, too much unpaid care is being provided by too few people for too many hours. Importantly, unpaid care provision does not itself cause ill-health, poverty or a lower quality of life. It is the 'burden incidence', in terms of which age groups the role of caring falls upon, and the patterns of unpaid care that lead to such outcomes.

### **Conclusion**

This small scale evaluative study of one CSO gives an indication of the scale of the challenge that will face commissioners in implementing the new national carers' strategy. Stress and ill-health amongst carers remain at high levels and gaps in services persist. The issues are compounded in rural areas because of recruitment and retention problems experienced by carer support organisations. Key messages for commissioners are around the vital role that the voluntary and community sector plays in supporting carers, especially in tackling social isolation through one-to-one support that is provided with warmth and friendship. Supporting carer support organisations not only to continue, but also to enhance their level of provision, must be seen as an urgent priority, as is addressing broader infrastructural issues such as community well-being, including the promotion of active citizenship and volunteering.

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