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EXPERT BRIEFING PAPER 2

Community Support Services for People with Dementia: The Relative Costs and Benefits of Specialist and Generic Domiciliary Care Services

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DOMICILIARY CARE SERVICES FOR PEOPLE WITH DEMENTIA

1. Introduction

Increasingly countries are developing strategies for the care of people with dementia which include enhanced support at home. In many of the supporting documents for these strategies there is an emphasis upon the better coordination of care at home as well as upon the nature and quality of the domiciliary care provided and the development of this workforce. For example, in England, France, Ireland and the Netherlands the strategic plans for people with dementia identify care/case management as the means to coordinate the necessarily multiple service inputs as an alternative to admission to long-stay care establishments. In Australia the strategic vision for the development of services suggests a not dissimilar role, that of helping people with dementia and their families 'navigate' the community care system, with provision located within mainstream services. Within the Norwegian strategy for people with dementia, there is a strong emphasis on care planning, the extension of home care services, and the development of a competent workforce (Challis et al., 2010a).

In the development of domiciliary care services for people with dementia, there has been a concern as to whether these should be on a specialist basis (specifically for people with dementia) or as part of more generic home care services for vulnerable older people. The research summarised here was commissioned by the Department of Health to bring together evidence and provide evaluative judgement about existing models of generic and specialist domiciliary support for people with dementia in England (Challis et al., 2010b). It formed part of the work informing the National Dementia Strategy (Department of Health, 2009), particularly with respect to Objective 6, which is concerned with the provision of an appropriate range of services to support people with dementia living at home and their carers. A wider aim was to provide a sound source of guidance for those responsible for commissioning and delivering services and to indicate the direction and capacity required of workforce development and education in terms of whether it is best to provide generic or more specialist home care for people with dementia.

2. Methods

Several distinct methods were employed to synthesise and identify evidence for this:

- A literature review of existing models of domiciliary care which was deliberately UK-based.
- Extraction of evidence and reanalysis of data from a range of PSSRU studies to illuminate the outcomes of generic and specialist services for people with dementia.
- Carer consultation by means of a discrete choice experiment (DCE); a series of survey questions which are used to systematically elicit the preferences of carers of people with dementia about home care services. In this a subset of quality indicators were employed drawn from those developed in previous work (Venables et al., 2006). These selected indicators were identified both by means of data analysis and a consultation process. The DCE involved 28 carers of people with dementia attending

groups organised by Age UK, who were available at the time the study was undertaken.

- A national survey of local authority domiciliary care arrangements for older people covering 74 per cent of local authorities. Using these data, four distinct groupings of ways of commissioning and providing domiciliary care for people with dementia were identified using cluster analysis. Interviews were undertaken with commissioning managers in 21 local authorities, selected from the national data to cover a representative spread of the four groups across England. This was to gather understanding of the nature, scale, quality and interdependence of different forms of domiciliary care for people with dementia.

- A national data set analysis (93 out of 150 local authorities) was conducted using key indicators in conjunction with the local authority survey data to identify whether there were any associations between the different patterns of commissioning/providing and rates of admission to care homes. These analyses took account of area levels of need, supply of care home places and patterns of local health provision.

The available time and budget precluded primary data collection from service users and domiciliary care providers and a larger sample of carers. However, the data is sufficiently robust to support the conclusions made. The material here is summarised from the main report (Challis et al., 2010b).

3. Findings

Literature review of existing models

- Few organisations provide solely specialist domiciliary care for people with dementia although this may be offered as a discrete service within a larger organisation.

- Whilst specialist provision has been argued to be more suitable for people with dementia there is little actual evidence as to its differential benefits over more generic provision. There is a perception of better care on the part of users, carers and care workers and some studies have indicated certain benefits of more specialist care, including reduced likelihood or delay in entering long-term care and enabling carers to care for longer. However, there were few differences found in 10 quality standards between specialist and generic care. These quality standards were: *systematic assessment; flexibility; individuality; culturally appropriate care; management practices; integration; care worker good practice; carer involvement; staff training;* and *briefing documents*. Only in relation to *individuality* (or user centred practice) were specialist services apparently better. However, generic services performed better on indicators of *flexibility* (Venables et al., 2006).

- Judgements about the cost-effectiveness of specialist compared with generic domiciliary care are most often made in the context of a delay in the care trajectory leading to the admission of an older person with dementia to a care home. However, other factors such as carer burden influence this decision, and must also be taken into account in the analysis.

- Routinely generated data on levels and types of social care support received by people with dementia and their numbers are not readily available. However, such information is essential alongside the views of stakeholders and other factors, such as

the importance of training in dementia care for domiciliary care staff, to promote informed decision making about the balance between generic and specialist domiciliary services.

Evidence from PSSRU studies

- Most domiciliary care provided for older people with dementia is provided by generic rather than specialist organisations. Generic domiciliary care services provide assistance to a substantial number of service users with dementia and there is some evidence that the level of support offered increases with the severity of the condition.

- Definitions of specialist domiciliary care vary. Some so-called generic services may have a specialist component when providing care to those with dementia. It is thus important to develop a clear specification for the service.

- Whether sourced from a generic or specialist provider, it is important that there is a sufficient quantity and intensity of care available to provide for the multiple and changing needs of people with dementia. Specialist providers were sometimes of modest scale. There is thus a capacity issue to address as well as quality concerns when commissioning home support for people with dementia.

- Some studies in particular highlight the benefits of linkages between domiciliary care providers, specialist case managers and community mental health teams for older people. This was evident in a study locating case managers, who had close access to and influence over specialist domiciliary care, within a community mental health team for older people (Challis et al., 2002; 2009). Hence colocation of case managers and community mental health teams, and their links with specialist provision, need to be taken into account in the development of an overarching service framework for specialist domiciliary care for older people.

- Provision of support from both generic and specialist domiciliary care services can reduce the risk of admission to a care home, particularly for older people with severe dementia. Specialist domiciliary care could be effective if targeted on those with more severe needs, such as people in the later stages of dementia. However, judgments about the relative cost-effectiveness of care for these service users must be made with reference to people with similar levels of need receiving generic domiciliary care and over an appropriate time frame for the population in question.

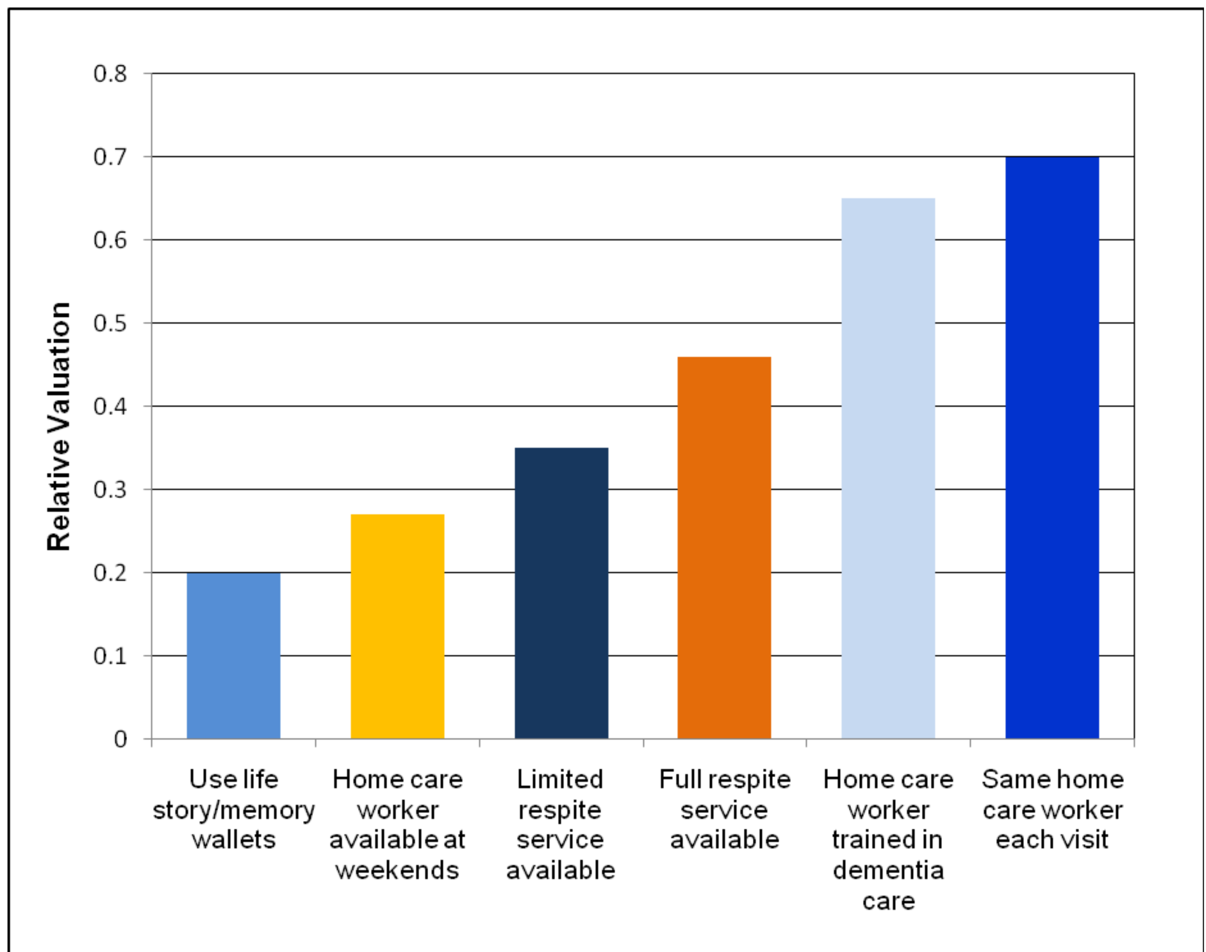
Carer consultation

- Attributes that may characterise a more specialist domiciliary care service were reviewed and these were presented to groups of carers who were asked to choose which attributes they would value most highly. Responses were analysed in terms of the relative value placed upon a particular attribute in relation to others. Findings from this exercise are shown in Figure 1. Having the same care worker visiting each time was most highly valued by carers whilst having home care workers specially trained in dementia care was also strongly preferred. Interestingly, the attributes of having to wait longer for a service or increased costs borne by carers were not judged to be as important in terms of whether or not they would choose a specialist service.

- Carers strongly expressed the view that it is the personal qualities of the domiciliary care worker that are preferred above all else. They indicated that whoever provides care must be trained to such an extent as to understand the particular subtle demands that might be made by a person with dementia. Such workers should have what could

be termed 'clinical nous'; that is sufficient knowledge to recognise the particular nuances of expression and unique features characteristic of dementia and therefore the ability to respond appropriately. This indicated again the importance of specific training for caring for people with dementia.

Figure 1: Carer consultation – attributes identified as of most value in supporting someone with dementia (2010 data)



Survey of local authority domiciliary care arrangements

- Four broad groupings of local authorities in England were identified that exhibited different mixes of specialist and generic domiciliary care provision for people with dementia in terms of commissioning; joint commissioning; contract specification; and service delivery as shown in Box 1. None of these groups exhibited solely generic or specialist provision, although one group showed predominantly generic and one predominantly specialist features.

Box 1: Categorisation of local authorities in commissioning and provision of domiciliary care in old age mental health care (n=93)

Group 1: local authorities *who jointly commission specialist domiciliary care services* with health, with many also stipulating dementia specific training as a contractual requirement, and also have an explicit focus on old age mental health in service provision (26%).

Group 2: local authorities who have *mainly generic domiciliary care provision* but some of whom also have a specific focus on older people with mental health problems in service provision (26%).

Group 3: local authorities who *maintain a specialist focus through contractual requirements in respect of training a*nd additionally commission specialist services or have an explicit focus in service provision on old age mental health services. Joint commissioning with health for specialist domiciliary care services was not a feature of this group (31%).

Group 4: local authorities who display *multiple approaches to commissioning and providing specialist domiciliary care*. All commission specialist services for older people with mental health problems. A substantial number jointly commission specialist domiciliary care services with health and also have an explicit focus on old age mental health in service provision. A sizeable minority also stipulate dementia specific training as a contractual requirement (17%).

From interviews with commissioning managers in a sample of authorities it appeared that:

- Specialist home support requires greater precision in definition: for example, within a model of domiciliary care where generic provision was the predominant focus, some authorities still placed a specific focus on old age mental health or dementia (through perhaps training or experience). It appeared that certain quality attributes could mark out specialist provision in contrast to generic domiciliary care.

- Only a minority of local authorities commission what they would designate as specialist domiciliary care for people with dementia. The number of providers of specialist domiciliary care is currently small with only about 9 per cent of total hours commissioned from specialist providers.

- Using a subset of 12 quality indicators of specialist provision, drawn from a set of 10 standards (Venables et al., 2006), in the sampled local authorities indicated that certain factors were more often present than others in specialist home care. More prevalent were attributes concerned with assessment of abilities/needs and participation in planned reviews by home care staff. Less prevalent were aspects related to more individualised care such as culturally appropriate practice or the use of life story/memory wallets. However, some of these attributes were also shared by generic domiciliary support services.

- Although the costs of specialist domiciliary care appeared higher than generic, an average of £16 per hour against £13 per hour, there was a considerable degree of overlap in the costs of different types of home care between different local authorities. Hence, a cost of £16 per hour could represent either a generic or specialist domiciliary care service in some local authorities. The cost variation appeared to represent variations in the commissioning and contracting processes in different local authorities.

National data set analysis

- At the local authority, rather than the individual user level, there was no evidence of a significant relationship between the type and mix of domiciliary care (generic/specialist) and the number of care home admissions for older people with dementia. Indeed, over time, all four groups of authorities identified above had experienced a reduction in care home admissions in line with national trends.

- These findings were the same even when taking into account and controlling for a number of factors influencing authorities' decisions to admit older people to care homes. Factors relating to user need (e.g. living alone, referrals through hospital admissions) and the supply of care home places ('capacity') were far more important in influencing care home admissions than the type of home care provided.

4. Conclusions

The lessons from this study may be summarised under five headings which reflect key attributes relevant to the decision to commission different types of domiciliary care for people with dementia. These are: Quality; Intensity; Service mix; Service linkages; and Costs and effectiveness.

Quality

Clearly, one concern is whether specialist or generic domiciliary care offers higher quality support for older people with dementia. Quality in the provision of domiciliary care for older people with dementia could be defined in terms of both the standard of care provided and its availability. Previous work noted the importance of flexibility, where generic services appeared to perform better, and individuality, where specialist services appeared to have an advantage (Venables et al., 2006). Further work with carers of people with dementia suggested that they placed particular emphasis upon continuity and staff training. This provided four domains of quality relevant to the decision as to whether to employ specialist or generic domiciliary care. These quality indicators were:

- *Individuality (or user centred practice)* – practices such as use of memory wallets, culturally appropriate care;
- *Dementia specific training for staff* – whether at the induction stage or specific subsequent training (Hughes et al., 2008);
- *Continuity of care* – support from the same care worker; and
- *Flexibility of response* – care available at different times of the day and at weekends; offering live in support where needed; possible 24 hour care and the capacity to respond differentially and more individually as required to the needs of older people with dementia.

It appeared that these attributes may be provided by both generic and specialist domiciliary care services for people with dementia, albeit with different emphases.

Intensity

Intensity of provision of support, in terms of the amount and frequency, is central to enabling older people with cognitive impairment to live at home. This was found to be more likely to be provided by generic domiciliary care services, which are generally larger organisations, than specialist services. However, assistance from both services may be appropriate and in

these circumstances the case manager role, whether undertaken by a nurse or social worker, in coordinating and integrating two types of domiciliary care with other services is important (Challis et al., 2002; 2009).

Service mix – complementarity and substitution

For service commissioners the challenge is to determine the balance of provision between generic and specialist domiciliary care. Such decisions must take account of existing service configurations within both health and social care for older people with mental health problems. Since both may operate jointly as complementary parts of a care plan, in such circumstances specialist services may be primarily oriented towards specific needs associated with the condition, such as behaviour, and more generic domiciliary care as focused more on needs arising from the loss of Activities of Daily Living (such as toileting and dressing) and Instrumental Activities of Daily Living (such as meal preparation and managing affairs).

Service linkages

Currently links between community mental health teams for older people and domiciliary care services often appear to be poorly developed. One possible hallmark of a specialist as distinct from a generic domiciliary care service could be its relationship to other services providing support to older people with dementia. Such arrangements then provide a mechanism for targeting the service both in terms of user characteristics and the type of care offered.

Costs and effectiveness

The evidence for differences in costs between the different forms of domiciliary care for people with dementia is limited. In terms of unit cost, whilst, on average, specialist domiciliary care was slightly more expensive than generic, given the overlap in costs, this was not always the case. With regard to cost effectiveness there are multiple perspectives. There is some evidence that generic domiciliary care may be a cost effective alternative to care home admission for people with dementia and that the combined use of both specialist and generic domiciliary care services found that this was cost effective in terms of meeting the needs of carers. An indirect measure of cost-effectiveness is user and/or carer preferences, expressed in monetary terms as an expression of value. Here continuity of care and training were the most valued attributes and neither of these is the exclusive preserve of specialist or generic provision.

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Overall, it did not particularly appear to matter in terms of cost or effectiveness whether domiciliary care for people with dementia is organised on a ‘specialist’ or ‘generic’ basis; thus form is of less significance than content (Challis et al., 2010b). What mattered more is whether the service conforms to good practice or quality standards for dementia care, and the evidence suggested that both generic and specialist providers may often offer this.

5. References

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