Alone with Dementia in Rural Areas

EXECUTIVE SUMMARY

Report for the Department of Health

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Introduction

- "Alone with Dementia in Rural Areas" was carried out by researchers: Ann McDonald (Principal Investigator) and Becky Heath (Research Associate) at the School of Social Work and Psychosocial Sciences at the University of East Anglia. The advisory group for the research was Dementia Focus. The project was carried out between September 2004 and September 2005 and was funded by a Section 64 grant from the Department of Health.

- Full details of the methodology used; literature review; overview of community services mapping; and findings, conclusions and recommendations can be found on the Dementia Focus website: http://www.uea.ac.uk/swk/research/dementia/welcome.htm

Aims of the Study

In response to the recent accumulation of policy and practice guidance relevant to older people with dementia. "Alone with Dementia in Rural Areas" aimed to:

- Describe how agencies in Norfolk, Suffolk and Cambridgeshire work through and apply this guidance;
- Describe the range of services for people with dementia living alone in a predominantly rural area, and to compare and contrast service provision in the three counties;
- Identify for national dissemination opportunities and gaps in service provision that are attributable to rurality.

Methodology

- A literature review undertaken of UK sources for policy documents and research studies relevant to the experience of dementia and service provision in rural areas.
- Data collection for the project was carried out using the following methods:

- o Organisational document review;
- o Interviews with (30) staff from the statutory, voluntary and independent sectors at strategic, managerial and practitioner level;
- o Focus group discussions with carers groups.

Full details of the methodology used and research protocol can be found on the Dementia Focus website.

Key Findings: Literature Review

- The National Service Framework for Older People (DH, 2001), set in the context of the modernising agenda for health and social care, has enabled new ways of working and new types of service provision to emerge.

- Currently, mental health and well-being in later life are seen as a major challenge (Third Sector First, 2005). Ageism is the major form of discrimination experienced by older people (Age Concern, 2005). The individual experience of people with dementia is affected both by personal factors such as isolation and family support, and by socio-cultural factors such as gender, class and ethnicity (Hulko, 2004).

- There is considerable variation around the country in mental health services in both health and social care for older people; the under-detection of mental illness is widespread, due to the nature of the symptoms and fact that many people live alone (DH, 2005; SCIE, 2000; Audit Commission, 2000 and 2002).

- For people with dementia, there are pressing issues relating to: appropriate long-term care; easy access to respite; good quality day care; specialist housing; and skilled support in the home (CSCI, 2005).

- Carers of people with dementia generally value a broad range of services within a multi-dimensional package of care. Little has been written in the literature about respite services for carers of younger people with dementia; black and minority ethnic carers; carers of people with Down's syndrome and dementia; young carers and rural carers (Arksey, 2004).

- There is a limited literature specifically on working with people with dementia in rural areas, though research for the Joseph Rowntree Foundation's Action in Rural Areas Programme (Godfrey et al.2004) found that older people valued locally based services, but experienced barriers in knowing about and accessing services. Dementia was seen by older people themselves as a greater threat to well-being than a decline in physical health.

- Access and mobility are key to effective services, given that a lack of reliable transport has a disproportionate impact on older people (ODPM, 2005).

- Locality-based work has been carried out in Northern Ireland by Gilmour (2002); in Scotland by Innes, Sherlock and Cox (2003, 2003a); and in Wales by Wenger et al (1999, 2002). These surveys identified problems relating to accessibility, lack of choice, shortage of skilled staff and cost of services. Rural areas tended to develop services in innovatory ways, using outreach and joint working between agencies to key into community networks. Individually tailored services and good inter-impersonal relationships are seen as strengths by people with dementia and their carers.

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Key Findings: Service Mapping

An overview of community services for people with dementia in rural Suffolk, Cambridgeshire and Norfolk, illustrated by case studies is available on the Dementia Focus website. These are some of the themes arising from this mapping exercise.

- The drive towards increased integration and partnership working between health and social care which is so evident in the policy environment emerged as a key theme in all three counties. In Cambridgeshire and Norfolk, countywide specialist older people's services have been or are in the process of being developed by the Partnership Trusts. In Suffolk, the Partnership Trust does not currently deliver services to older people but is developing an Older People's Mental Health Strategy which will ultimately include services for this group. In Suffolk specialist services for people with dementia are also delivered through multidisciplinary ACCESS teams managed by Age Concern and operating in specific areas of the county. Service integration and specialist provision is most advanced in Cambridgeshire where six specialist older people's mental health teams managed by the Partnership Trust work alongside integrated locality teams managed by the PCTs.

- Across the region, the vast majority of people with dementia in the community are supported by generic older people's locality and PCT teams rather than by specialist services which tend to deal with only the more complex cases. Existing and developing specialist mental health services in all three counties have a key role to play in the training and support of these generic community teams, and also provide training and support to the independent sector.

- The voluntary sector is playing a key role in service provision across all three counties. This is despite there being no comprehensive strategic plan or commitment to funding provision for the voluntary sector as a whole. Across the region, the voluntary sector is instrumental in providing innovative solutions:

    - to assist carers and people with dementia to negotiate the statutory service environment;
    - to provide information and advice;
    - to provide ongoing support and guidance to carers and people with dementia.

  In addition, in many areas, the voluntary sector delivers alternatives to or replacements for statutory services such as day centres, respite services and, in Suffolk, multidisciplinary specialist older peoples and younger people's dementia teams. Local commitment from voluntary management committees has created pockets of excellence of voluntary sector provision but this local focus coupled with a lack of specific strategic and funded commitment to the voluntary sector as a whole has left large areas in all three counties without these services.

- The private sector also emerged as a key provider of services for people with dementia and an important partner in the roll-out of the vision and strategy for service provision in the future. However, there were difficulties in all three counties with the interface between the statutory and private sector with regard to funding, consistency of contracts and equality of working conditions between the two sectors. Staff recruitment and retention act as ongoing barriers to improvements in service despite commitment from individuals in both sectors.

- Across the region, a commitment to providing person centred care through flexible services was evident in the planning of new services. Day services for older people were a particularly good example of this where the majority of interviewees talked about a move away from traditional day care provision towards a model which was more able to provide greater choice, use of other generic community services and flexibility over time in order to meet service user needs.

- A shortage of specialist services for people with dementia was identified in domiciliary care, day services and respite care. There was a particular shortage of EMI registered beds for respite and for long-term care.

- There was limited evidence in any of the counties of services developed specifically to target groups such as:

    - minority ethnic communities;
    - people with a dual-diagnosis of learning difficulties and dementia;
    - younger people with earlier onset dementia;
    - those with some of the rarer forms of dementia.

All interviewees acknowledged the importance of specific services for these groups but felt they were a second step on from the current target of providing generalist services for people with dementia across the area. Of these four groups, services for people with early-onset dementia are the most developed. Suffolk leads in the area with its specialist county wide ACCESS team for younger people with dementia (Age Concern Suffolk) and the SPACE Project (Alzheimer's Society) in Lowestoft and Waveney. Norfolk and Waveney Mental Health Partnership Trust also manages a team focused on this client group which covers the central belt of Norfolk. Support workers from Social Services and CPNs provide services to people with early onset dementia in Cambridgeshire. The voluntary sector (Alzheimer's Society, Friends of Fulbourn) also run projects for younger people.

Key Findings: Interviews

The interviews with strategic planners, managers, practitioners and carers were analysed under three broad themes: service configuration and philosophy; barriers to service; and "what makes a difference".

Service Configuration and Philosophy

- Older people's mental health services are undergoing change in all three counties with the development and/or implementation of older people's strategies linked to government funding and targets, particularly those associated with the National Service Framework for Older People.

- Interviewees whether from the statutory, voluntary or independent sector identified the emerging priorities for dementia services in their areas as:

  - A focus on maintaining people at home for longer, reducing admissions to long stay care and improving hospital discharge rates;
  - The adoption and implementation of a philosophy of person-centred care; and
  - The drive towards working in partnership with other agencies within a mixed economy of care, and more specifically, the focus on health / social care partnership working.

Other priorities mentioned can also be linked directly to the National Service Framework for Older People. They are:

  - Initial diagnosis;
  - Early intervention;
  - Crisis intervention and intermediate care;
  - Support for carers;
  - Consultation with users and carers;
  - Training and sharing of specialist skills;
  - Educating the wider public about dementia;
  - The development of services for marginalised groups within older people's services.

- Enabling people to live at home for longer as a service aim has been accompanied by a drive to provide more services in local communities. This is accompanied by a desire to provide more preventative and primary care services.

- The drive towards partnership working is particularly valuable in rural areas, enabling skills to be shared and the voluntary and private sector to develop services to meet local needs. Integrated team working (between health and social care) in order to share skills and thus to cover a wider area, was perceived as a strength in rural areas. The voluntary sector has assumed a particular role in "signposting" users towards statutory services, in developing innovative projects for people with dementia and for carers and in providing longer-term support.

- The development of age-inclusive services (spanning working age and older people's services), is a current debate in all three counties.

- Getting access to an early diagnosis of dementia or appropriate services following diagnosis was seen as variable across the region and depended upon the responsiveness of primary care. Memory clinic services had been devolved to community teams in some areas to serve a wider population. The majority of people with dementia received services from non-specialist teams.

- An overall shortage, or under-development, of services specifically for people with dementia was noted. This affected all services: domiciliary care; day services and respite care. Closing in-patient beds and day hospital services were seen by some as freeing resources for community development, but by others as specifically disadvantaging people in rural areas as the remaining specialist resources tended to be located in urban areas. Balancing service provision needs and professional specialisms on a county or regional scale against localised service provision was seen to be problematic.

- All three counties have a specific service for younger people with dementia. Where specialist services were active, staff were enthusiastic about their potential, but were aware that they were not fully meeting the need. Boundaries with older people's services, and appropriate use of specialist staff were also issues to be resolved.

- The importance of engaging with minority ethnic communities is acknowledged, but a lack of critical mass meant that examples of service development were limited. Cases tended to be dealt with on an individual basis.

- Services for people with learning difficulties and dementia were also provided on an ad hoc basis.

- Consultation and partnership working with users of services (including carers) was evident in policy documents and in interviews with managers and with practitioners. Themes arising from focus groups with carers were:

  - The need for joined up information;
  - Flexible and affordable services; and
  - The need for reliable and supportive relationships

- Domiciliary services on the whole were non-specialist and found it hard to service people in isolated areas.

- Day services were seen as sources of advice, understanding and respite, though opportunities to participate in social events alongside the person with dementia were also valued by carers.

- Specialist EMI residential care was in short supply, though housing with care schemes were being developed for people with dementia in some areas.

- Physical isolation, but also the impact of a diagnosis of dementia on social networks, is attenuated in a rural area. This can lead to a faster deterioration both medically and socially for those who live alone. Community development models and increasing sources of communication through helplines and support groups are seen as possible responses to rural isolation. Services recognise the need to support the carer as well as the person with dementia.

- There is an important role for relationship-based work with people with dementia and with carers, though services may not be delivered until there is a crisis. The voluntary sector appears better able to deliver a greater continuity of service than the hard-pressed statutory sector.

Barriers to Service

- Many of the services described in the Service Mapping with Case Studies section of the Final Report of this study, have grown up historically from individual or local initiative rather than centralised planning. Strategic development between sectors is likely however to lead to more cohesive services in the future.

- The need for specialist training in dementia for care managers, locality teams, and domiciliary care staff in the statutory and the independent sector were all mentioned.

- All interviewees identified travel as a problem in a rural area, though a minority felt that it was not necessarily more time consuming than urban travel. Transport costs and availability could however be a real barrier to accessing services and to domiciliary staff recruitment.

- Finding suitable office accommodation for staff could be a barrier to providing services locally. In terms of inter-agency working, though the Single Assessment Process was seen as having potential to facilitate the sharing of information, there were difficulties in terms of incompatible I.T. systems, complex forms and co-ordination with the Care Programme Approach.

- Heavy caseloads and stringent eligibility criteria define the content of the care management role in the statutory sector. The positive contribution of domiciliary care and of residential care can be undermined by being commissioned too late.

- Staff recruitment and retention in rural areas is a major problem for all sectors, but especially acute in the private domiciliary sector. Changing terms and conditions of service is seen as having potential for attracting more staff.

- Lack of joined up information about services is a deficit recognised by both service providers and carers. For the carers it was a major concern and a source of anxiety. Very localised mapping of services responds to local needs and also contributes to social capital by enabling people to feel part of what is happening close to them.

- The 'culture' of rural communities can exclude people with dementia if there is a lack of social cohesion or no pool of local people able to provide accessible care.

- Changing the culture of services in favour of the independence and empowerment of service users is seen as a theoretical shift which needs further development.

What Makes a Difference

- A national policy agenda with funding linked to it is critical if services for people with dementia are to have any priority.

- People "willing to go the extra mile" or act as Champions for people with dementia have made a striking difference to the quality and quantity of service available.

- Both the statutory and particularly the voluntary sector have recognised the importance of community development approaches; recruiting and informing key local people to disperse support to people with dementia and enabling communities to take a more positive role.

- Innovatory working; very localised or peripatetic outreach services have been used to overcome problems of distance.

- Consultation with service users and carers had become embedded in strategic planning, though there is an identified gap in hearing directly the voice of people with dementia, and carers still felt that their need for flexible, individualised services was not fully understood or responded to. Formal assessments do not necessarily lead to service provision.

Conclusions and Recommendations

- Older people's mental health services are undergoing change in all three counties at the strategic and operational levels. Emerging priorities are:
    - A focus on maintaining people at home for longer;
    - The adoption and implementation of a philosophy of person-centred care, and
    - The development of partnership working.

- Integrated agency and team-working is perceived as a strength in rural areas, although co-ordinated differently across the three counties. Such a way of working meets service users' desire for joined-up services.

- There are significant debates current around both the desirability and practicality of age-inclusive services, and around geographical equity in the location of services.

- Though all areas have specialist provision for younger people with dementia, boundaries with specialist older people's services are in need of clarification. There is little formal development of services for people with learning difficulties or those from minority ethnic groups.

- Specialist resources for people with dementia are seen as desirable but limited in all services, whether domiciliary care, day services or residential care. There is a continuing need for training across all sectors, and an important consultative / advisory role for the statutory sector.

- Flexible, innovatory service tend to be small scale, localised and championed by the voluntary sector on limited funding. They are rated highly by carers.

- 'Process' issues; how a service can be sensitively delivered; are seen as important by carers and by service providers and practitioners, and include strong inter-personal relationships, longer term support and networking opportunities.

- Transport costs and journey times are a significant barrier to service delivery and staff recruitment in a rural area.

- Heavy caseloads and budget cuts have jeopardised both preventative and longer-term work.

- Carers in particular feel disadvantaged or disempowered by a lack of joined up information.

- The culture of rural communities requires a very localised approach to understand and respond to traditional allegiances and preferences. Small community-based projects have been successful in recognising and responding to this and in enabling people with dementia and their carers to take advantage

of ordinary community facilities. More detailed “mapping” of such services would enable best practice to be shared and updated.

- Further research could explore directly the views of people with dementia in rural areas, and could be fed into service evaluation.

- A further group of people who are hard to access are rural carers not involved either with formal services or support groups. Accessing their views could provide further insights into which community development approaches are likely to be successful.

There are many innovatory projects throughout the region and these are highly regarded, but there has been limited evaluation of their effectiveness in supporting people with dementia and their carers. Such evaluation could provide guidance for commissioners on the type or combination, of services producing best outcomes.