Dementia care at home in rural and remote areas
Summary findings of literature review

This is a short summary of a literature review undertaken as part of a one
year knowledge exchange project between UHI Millennium Institute, Scottish
Agricultural College, Orkney Islands Council and Scottish Borders Council. The
project was part of a wider programme aimed at building capacity for research
evidence to inform local authority service improvement. The full report is available
to download from www.abdn.ac.uk/crh. (Clark A, Bradford L and Robertson J (2010))

Main findings

- The review uncovered a fairly limited literature on dementia care at home in rural and remote areas
  and few evaluations of innovative approaches to dementia services.

- Research has demonstrated that people with dementia can express reliable views about
  experiences of services and innovative ways of engaging people with dementia are being developed.
  However practice still lags behind other areas of user participation in health and social care.

- People with dementia and their carers often identify gaps in services but they are generally positive
  about the services received. A key theme to emerge from the literature was diversity: of location,
  need and impact of rurality on experiences.

- Carers in rural areas face the same difficulties as elsewhere but in addition may experience social
  isolation and poorer services. More flexible respite, information at the right time and services that
  meet individual needs have been identified as important.

- Providers of dementia services in rural and remote areas have identified a range of challenges
  including distance, lack of transport and shortages of skilled staff leading to increased costs and
  a more limited choice of services than in urban areas. A key dilemma is balancing the need for
  specialist services against improving access to mainstream preventative services for older people.

- Approaches to service innovation have included very localised service delivery, peripatetic outreach
  services, mobile services, community development approaches and joint working, e.g. using ‘hub
  models’ to provide the critical mass necessary for sustainable services. Careful analysis of the
  demographic, geographic and community context of rural areas is necessary for successful service
  innovation.

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Local authorities have a key role to play in delivering community support services to the estimated 69,000 people in Scotland with dementia. National policy encourages councils to improve outcomes for older people by delivering integrated and personalised services which enhance independence and quality of life. Implementing the personalisation agenda for people with dementia and their carers presents a variety of challenges including tackling stigma, ‘professional tribalism’ and risk aversion. With a projected 75% increase in numbers of people with dementia by 2031 and pressures on public funding, it is increasingly important that councils make best possible use of all available evidence about ‘what works’. This is a summary of evidence from a review of published literature on dementia services at home in rural and remote areas.

Rural and Remote Service Challenges
The traditional challenges faced by both providers and users of health and social care services in rural and remote areas have been well documented (Box 1). The most extensive study to date of dementia services in rural and remote Scotland echoes the general literature on rural service challenges. Problems identified included distance, lack of transport and shortages of skilled staff leading to increased costs to users and a more limited choice of services than in urban areas. A key dilemma facing service providers was balancing the need for specialist services for people with dementia against improving access to mainstream older people’s services. Similar issues have been raised in a mapping exercise of dementia services in rural areas of England.

Rural and Remote Service Challenges

- The demographic structure of rural regions often makes it difficult to achieve the economies of scale necessary to support public service provision
- Sparsity of population, long distances, poor transport and workforce issues make access more difficult, increase costs, reduce choice and quality
- Third and private sector organisations tend to be fewer and more fragile making it difficult to develop a mixed economy of care and build capacity for involvement of communities
- Complex relationships between staff and communities have both positive and negative effects. Complex and shifting dynamics between communities and service providers can make change particularly difficult

Box 1
Users and Carers Experiences of Services

In the past, it was assumed that people with dementia were unable to offer views about their experiences of services. Carers and staff involved in their care were often consulted as ‘proxies’. Service providers may still overlook the views of people with dementia and practice still lags behind other areas of user participation. However various factors have contributed to new ways of thinking about dementia and the possibilities for inclusion of people with dementia in research and service consultation:

- The work of Kitwood fundamentally challenged professional thinking about the capacity of people with dementia.
- New drug therapies are delaying changes in capacity for longer.
- Tools such as ‘Talking Mats’ are enabling more effective communication between service providers and people with dementia.
- Research in the 90s demonstrated that people with dementia could express reliable views about their experiences of services.

The experiences of people with dementia and their carers receiving services in rural and remote areas has been researched in Ireland, Australia, Canada and America as well as in parts of Europe. Issues explored have included levels of use of services and barriers to use, differences between urban and rural experiences, how rurality impacts on experiences and the effectiveness of specific interventions to improve access such as telecare. Overall the evidence suggests that people with dementia and their carers living in rural and remote areas can access fewer services and have less choice of services. Common barriers to access identified internationally include:

- The stigma associated with dementia.
- Privacy issues.
- The cost and appropriateness of services.
- Acceptability of services e.g. timing, type of activities.
- Beliefs and attitudes e.g. self reliance, standards of care.
- Transport and distance.
- Lack of services including respite, home care, day care.

People with dementia and their carers often identify gaps in services but they are generally positive about services actually received. What rural users and carers value about the services they receive has some similarities with the outcomes sought by them in other studies. (Table I)

“Research has demonstrated that people with dementia can express reliable views about experiences of services and innovative ways of engaging people with dementia are being developed. However practice still lags behind other areas of user participation in health and social care.”

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<td>Choice about and access to activities</td>
<td>Activities reflect interests and stimulate</td>
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<td>Sense of control and identity</td>
<td>Social interaction with staff and others</td>
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<td>Security</td>
<td>High standards of care</td>
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<td>Hygiene &amp; comfort</td>
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<td>How services are delivered</td>
<td>Having a say</td>
<td>Reliability</td>
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<td>Feeling valued</td>
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<td>Attitudes of staff</td>
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Table 1
A key theme to emerge from the literature was **diversity**: of location, need and impact on experiences\(^\text{16}\). The ‘rural idyll’ of supportive communities is not a universal experience\(^\text{17}\). People with dementia and their carers experience both positive and negative influences on services from living in a rural location (Table 2).

<table>
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<tr>
<th>Characteristics of rural location</th>
<th>Positive Influences</th>
<th>Negative Influences</th>
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<tbody>
<tr>
<td>Rural Landscape</td>
<td>‘Community support’</td>
<td>‘Community surveillance’</td>
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<tr>
<td>Close-knit relations with staff</td>
<td>Improves access and increases personalisation</td>
<td>Change difficulty; fears re confidentiality</td>
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<td>Culture of self-reliance</td>
<td>Tolerance of difference</td>
<td>Stigma/fear of gossip</td>
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<tr>
<td>Strong community ties</td>
<td>Strong informal, practical support</td>
<td>Isolation if no local networks</td>
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Carers in rural areas appear to face the same difficulties as those elsewhere but in addition may experience social isolation and poorer services. Carers have identified more flexible respite, information and greater access to more appropriate services as important. Accessing information at the right time is also important in preventing matters reaching a crisis point\(^\text{18}\).

**Responses of Service Providers**

Studies have identified various approaches to tackling the challenges faced by service providers of health and social care in rural and remote areas\(^\text{19}\) (See Table 3). Smith and Homer (2009) found a wide range of service innovations including some for dementia services. Many service changes were opportunistic rather than planned and strategic. The process of achieving change in rural and remote areas required additional resources for staff and community engagement. Several authors agree that although the challenges may be similar, it cannot be assumed that what works in one area will work in another\(^\text{20}\). Reasons include population structure, geography and local service histories\(^\text{21}\).

<table>
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<tr>
<th>Asthana &amp; Halliday</th>
<th>Hudson</th>
<th>Smith and Homer</th>
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<tr>
<td>Improve co-ordination, avoid duplication</td>
<td>Reducing distance through technology</td>
<td>Partnership working</td>
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<tr>
<td>Flexible roles and responsibilities</td>
<td>Workforce strategies for recruitment and retention, new roles and team working</td>
<td>Co-location/integration of community services</td>
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<td>Mobile, outreach services and multi-purpose facilities</td>
<td>Supporting independence e.g. extra care housing</td>
<td>Workforce strategies</td>
</tr>
<tr>
<td>Appropriate and affordable transport</td>
<td>Area based strategies – community development</td>
<td>Strategies to build community resilience</td>
</tr>
<tr>
<td>Improving information for professionals</td>
<td>Rural proofing of national, regional and local policies</td>
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<tr>
<td>Improve gateways and signposting for users</td>
<td>Partnership strategies</td>
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Like Innes et al (2006) this review uncovered few evaluations of dementia services in rural and remote areas in the UK. The use of village halls and other community buildings to provide day care has been evaluated in Northern Ireland. Services were valued but could have offered more individualised provision. Careful analysis of the demographic, geographic and community context of rural areas is necessary for successful service innovation\(^\text{22}\). Peripatetic and mobile day care services include use of a bus to collect people and drop them off at pubs and other locations for lunch and to do activities\(^\text{23}\). In rural England, partnership working and dementia ‘champions’ have been found to make a difference to services. Approaches have included very localised service delivery, peripatetic outreach services and using local people to act as signposts and to stimulate community responses\(^\text{24}\).
In remote and rural Scotland, Innes et al (2006) found that interventions tended to be around transport solutions, outreach services and joint working to overcome accessibility problems. They suggested that greater flexibility in the use of resources and provision of services, improved information provision, specialist advisers and care managers and better joint working were all needed. ‘Hub’ models can provide the critical mass necessary for sustainable services in rural areas. Thomson Court on the Isle of Bute provides a range of services with staff working across all to provide continuity and flexibility of care. Staff raise awareness of dementia in the community, provide activities which reflect rural interests and support people to carry on activities in the community. A significant debate in the wider dementia services literature concerned the effectiveness of specialist as opposed to generic services.

Systematic reviews of interventions for carers identify a range of success factors for services but say little about issues specific to rural carers. Carers UK recommend a number of good practice responses to the needs of rural carers including wider respite opportunities, transport solutions, and using local media to raise awareness of services. Interventions focused on reducing social isolation and combining social opportunities with education include Alzheimer Cafés and use of the telephone to provide information, support and education.

The Scottish Government has invested heavily in assistive technology (telecare) interventions but there are some difficulties associated with managing response arrangements in rural areas. Benefits of telecare include helping people to live longer in their own homes, reduced hospital admissions, reduction in consequences of risks and reduced service costs.

The approach of West Lothian Council has been positively evaluated. Concerns about telecare include possible adverse impact on inclusion and personalisation, resistance from service providers, design and structural issues and the danger of technology replacing personal contact.

Extra care housing, or self contained dwellings that offer flexible care and a ‘homely’ environment were another featured intervention, although not specifically in rural and remote areas. On the one hand they were seen as helping older people to maintain autonomy, something that people with dementia consider important, creating a ‘normal’ non-institutional environment, and offering specialist services. On the other hand, extra care housing may be somewhat isolating and may not be suitable for people with advanced dementia. More research into the benefits and drawbacks of this type of housing for people with dementia is required.

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16 See 13 above
18 Wenger 11 above and 14
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