

The All-Party Parliamentary Group (APPG) on Dementia

**Inquiry into the dementia care skills of social care staff  
supporting people with dementia in care homes  
and their own homes**

**Submission by the  
Joseph Rowntree Foundation**

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The Joseph Rowntree Foundation (JRF) and Joseph Rowntree Housing Trust (JRHT) are pleased to submit the following response to the APPG on Dementia's Inquiry into the dementia care skills of social care staff supporting people with dementia in care homes and their own homes. We would be happy to supply any further information as required.

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The Joseph Rowntree Foundation (JRF) is one of the largest social policy research and development charities in the UK. For over a century JRF has sought to understand the root causes of social problems, identify ways of overcoming them, and show how social needs can be met in practice.

JRF aims to influence policy and practice by searching for evidence and demonstrating solutions to improve the circumstances of people experiencing poverty and disadvantage, the quality of their homes and communities, and the kind of services and support available to them.

The Joseph Rowntree Housing Trust (JRHT) shares the aims of the Foundation and engages in practical housing and care work. A proportion of JRHT's residents – in the Continuing Care Retirement Community, eight care homes, two new extra care schemes and the village of New Earswick – are affected by dementia.

# **Response to the APPG on Dementia inquiry into the dementia care skills of social care staff supporting people with dementia in care homes and their own homes.**

## **Introduction**

In line with the APPG on Dementia's interest in receiving a wide range of evidence, particularly from social care staff and older people, this response draws on four main sources of evidence:

- Relevant research supported by JRF (a full list of references appears at the end of this response).
- The operational experience of JRHT as a provider of care, housing and housing-and-care, gathered through a discussion group held in York in February 2009 with care home managers, a domiciliary service manager and a specialist dementia nurse to feed into the call for evidence from the APPG on Dementia.
- A discussion group held in York in September 2008, involving around twenty care staff members of the York Dementia Learning Network (YDLN).
- A JRF-funded event with Housing 21, held in London in January 2008, on *'Enhancing the What Works research knowledge base on dementia care and housing'*.

## Summary

JRF research and practice has identified issues that deserve greater prominence in the training and skill development of social care staff supporting people with dementia:

- Training is needed on communicating with people with dementia, and using available tools (such as Talking Mats) with confidence.
- Training is needed for night time staff supporting people with dementia in care homes; and generally for social care staff supporting people with learning difficulties who develop dementia.
- Changing models of support (e.g. more care provided in people's own homes; growth in extra-care housing schemes) necessitate changes in professional curricula, training and development.
- A more flexible range of skills in residential care homes, including training in basic nursing skills and health promotion, could help residents who develop nursing needs avoid unnecessary transfer to nursing homes or hospital.
- JRF promotes the involvement of people with dementia in the development of training and skills in this area. While this is a challenge, much can be learned from good practice elsewhere (e.g. from involving people with learning difficulties).
- JRHT has found that non-specialist staff in a range of settings can benefit from a specialist advisor such as a Specialist Dementia Nurse to provide support and guidance to both care home and housing staff and residents.
- JRHT has also found that 'Learning Networks' on dementia for front-line social care staff and housing staff improve access to and sharing of information on dementia, increase confidence and promote best practice.

**Q1: What is the current readiness of the workforce to deliver personalised care to people with dementia and their families? Do you have specific evidence about workforce readiness on dementia?**

JRF research highlights the need for improved training for social care staff on communicating with people with dementia. It identifies a lack of readiness among night time staff supporting people with dementia in care homes and staff supporting people who have learning difficulties and dementia.

***Communication skills***

Personalised care requires people to be involved in decisions about their care and key transitions in their lives. Front-line staff need a range of communication tools and skills at their disposal to achieve this. Research on the experiences of people with dementia (1) points to training and support needed by staff to work in person-centred ways and to enabling people with communication and/or cognitive impairments to exert choice and control. This is particularly important in settings where it is difficult to find opportunities to undertake communication and consultation work, and to follow through on plans.

The Talking Mat is one tool with important potential in communication and choice-making with people with dementia. JRF research (2) found that conversations using this tool were more effective for people with dementia than unstructured (ordinary) or structured conversations, with improvements in the participants' understanding, engagement, ability to keep track and make their views understood. Talking Mats may potentially extend the period during which people can play an active role in making decisions about their lives. Care staff will need to be trained and confident in using Talking Mats to achieve this.

***Staff who support people with dementia at night***

Recent JRF research (7) suggests that night staff in care homes have less access to training and awareness than their day-time colleagues, and possibly little or no training on responding to people with dementia.

Where training is available to night staff, it is rarely focused on night time issues. Yet the way night time staff respond to the needs of residents with dementia can have a major impact on their sleep, peace of mind, nutrition, hydration and social interaction.

The evidence (7) also showed that even small changes in practice and modest training could result in major improvements to the night-time care experience of those with dementia.

Managers and inspectors or regulators also need a good awareness of, and training in, these issues.

### ***Staff who support people with learning difficulties who develop dementia***

Consistent, practice-based training of the social care workforce supporting this group can be critical in diagnosing dementia, and determining the type of care given and the likelihood of the person remaining at home (3, 4). Without these skills, *ad hoc* arrangements can lead to inappropriate moves of relatively young people to nursing homes for very elderly people.

JRF evidence (3, 4) shows staff can play a role in preserving and maximising people's involvement in everyday matters and future planning. However, there is a need for more time, resources and appropriate training to support this role.

There is evidence (5) of unrecognised and untreated pain among people with learning difficulties who have dementia, pointing to a need for training on pain recognition, pain management and use of pain assessment tools. We have published a practice resource pack on these issues (6).

### ***Operational evidence from JRHT on workforce readiness***

Evidence from JRHT operational staff is that readiness to deliver personalised care is enhanced by ensuring that a core quantity of staff undertake recognised dementia training (in JRHT, the 'Introduction to Quality Dementia Care' is used). This is complemented by support groups within individual care settings, where staff can discuss issues in confidence with experienced personnel. This enables them to reflect on their practice from a person-centred perspective.

**Q2: What are the barriers to improving the skills of the workforce in dementia at a national, local and organisational level?**

JRHT care managers know that the impact of induction and ongoing training can be negatively affected by high staff turnover, which brings a constant demand for basic training in addition to updating longstanding staff members.

Personalised care is also affected by the demands placed on staff by the dependency levels of other residents. Staff working in generic settings highlight the challenge of meeting the needs of those with dementia alongside those whose needs are physical.

JRHT operational staff highlighted the following issues in their discussion, which are common to the sector:

- low rates of pay, which can force experienced staff to leave for better-paid work outside the sector;
- lack of training that focuses specifically on domiciliary settings;
- cost of training (both funding the course, and 'backfilling' to cover for the staff attending);
- lack of specific training to meet different needs e.g. those for whom English is not their first language.

Care staff contributing to the York Dementia Learning Network discussion group in September 2008 identified the following barriers:

- lack of rigorous evaluation (it is often unclear which course or programme would be most helpful);
- duration of training – short courses (one to two hours) could be more helpful than longer courses (one or two days);
- lack of training brokerage;
- lack of support for managers to achieve Continuing Professional Development (CPD);
- differences between private sector homes and Local Authority or NHS provision (in pay, conditions, resources and equipment);
- low status of staff working with dementia (low pay suggests that front-line care staff do not need, or are not worth, training);

- cultural factors – managers may or may not encourage training while staff may or may not feel they need training;
- lack of attention to training needs of night staff and agency/bank staff (e.g. timing of training, content and focus);
- lack of confidence amongst care staff, preventing them from attending courses and conferences;
- isolation from peers in similar situations;
- lack of internet access for many care staff;
- lack of accessible, simplified ‘knowledge into practice’ resources;
- impact of increased management and budget-led services, competitiveness between providers and constraints on funding from commissioners.

### **Q3: What do you see as the solutions to delivering system wide workforce change in dementia skills?**

In addition to addressing the training needs highlighted here, JRF evidence identifies the following solutions:

#### ***Flexible skill-mix in care homes: training in basic nursing skills and health promotion roles***

The introduction of a more flexible skill-mix in residential care homes could help those who develop ‘nursing needs’ avoid transfer to a nursing home or hospital. Both care home staff and residents themselves usually prefer this. A JRF evaluation of an initiative aiming to achieve this (8) shows that, by training staff in basic nursing, such transfers can be prevented.

Non-nursing care home staff can be supported and trained to take on health-promotion roles and play a stronger role in early diagnosis and intervention. This is challenging at first, but confidence and professionalism do grow, enabling staff to identify early signs of health problems (not always picked up in people with dementia because of communication difficulties). Benefits include early intervention and improved quality of life for the resident and cost savings from avoiding transfers.

In one of its own residential care homes, JRHT is trialling a new approach to determining and meeting nursing need without requiring people to move. A Nursing Care Co-ordinator assesses, plans and



co-ordinates nursing care, drawing on the flexibility of new skills among care staff. The wider adoption of such a model would, however, require a change in policy on the registration of homes.

### ***Training on the social model of disability***

Training needs to be underpinned by an understanding of the social model of disability. Concepts of personalisation, choice and control must be integral to improving the skills and capacity of the social care workforce. JRF research (9, 10, 11) on direct payments and person-centred planning found that an understanding of disabling barriers, and a commitment to promoting choice and control, are crucial for care workers at all levels.

The relationship between the service user and front-line worker is pivotal to good quality person-centred care (13). In recruiting staff, the applicants' values, attitudes and warmth of feeling are more useful predictors of good care practice than prior experience or qualifications (12). So, alongside training, JRF would like to see greater prominence given to the involvement of front-line practitioners in helping change the culture and value-base of care settings.

### ***Emotional support for staff***

Front-line workers often feel they receive little support from managers in their day-to-day work. JRF evidence (12) is that, because dementia care is emotionally demanding for both staff and managers, training will not be effective on its own. The most effective managers recognise this, ensuring clear communication; a sense of staff involvement and ownership; careful handling of staff emotions and relationships; and good staff supervision.

### ***Specialist support***

JRHT's operational experience suggests that non-specialist staff in a range of settings can benefit from a specialist advisor. JRHT employs a Specialist Dementia Nurse to provide support and guidance to both care home and housing staff and residents.

### ***Learning Networks***

JRF supports the development of learning networks among front-line social care staff (community and residential), and also housing staff (e.g. sheltered housing wardens). We are currently supporting our

local network, York Dementia Learning Network (YDLN), set up in 2004 to improve access to and sharing of information and best practice on dementia, in response to a need identified by local care providers. Members value the confidence they gain from discussing problems and opportunities with other professionals, freedom to speak confidentially in a non-judgmental forum, and learning from speakers and each other.

Although this Network requires a very modest annual budget, it is hard to raise from members. JRF is providing two years' interim funding until a sustainable solution can be found. Networks such as this need to develop further to improve the knowledge base of the workforce and, in particular, to enable small independent care homes to gain knowledge from larger organisations. Government support for such low-cost, high-value initiatives is crucial if they are to be sustainable. Such networks would also benefit from greater co-ordination and status: currently, networks around the country remain essentially unconnected.

JRHT operational staff highlighted the following possible solutions to delivering system-wide workforce change:

- graded performance-related pay, within a clear career structure;
- mandatory recognised dementia training for all staff at induction;
- mandatory training for home managers, to ensure commitment to and understanding of personalised care;
- regular update sessions, which should include wider issues and policies relating to dementia care;
- care to be delivered in smaller groups to match abilities of staff to individual residents;
- use of benchmarking standards, or evidence-based observational tools such as 'Enabling', Dementia Care Mapping or Short Observational Framework for Inspection (SOFI) to ensure that learning is applied in the care setting. This is, however difficult in domiciliary care.

**Q4: What role can your organisation play to deliver a workforce which is better able to meet the needs of people with dementia over the next two years?**

JRF is currently:

- scoping new programmes of work on options for older people with high support needs (including dementia), covering residential, housing-with-care and non-residential options, including how the workforce can be supported;
- exploring and promoting the potential of Talking Mats through further research and a programme of training for care staff working with people with dementia across the UK (an evaluation of the latter will be available by the end of 2009);
- supporting a study of social well-being in extra care housing and researching the views of older people and carers from ethnic communities in Bradford;
- raising awareness of the practice messages from our research on pain (5) through a series of tailored posters and fact sheets aimed at front-line care staff and at GPs.

On the operational side, JRHT is:

- working with Alzheimer's Society to pilot a new learning programme 'Tomorrow is Another Day'. This is partly based on the 'Introduction to Quality Dementia Care' (2005), which was originally supported and tested by JRF;
- continuing to support our own care staff and residents through the provision of a Specialist Dementia Nurse;
- providing interim funding and support for the local Dementia Learning Network;
- reviewing arrangements at our continuing care retirement community in York, Hartrigg Oaks, for residents whose needs are growing due to dementia. This includes assessing the impact of their needs on the care home and domiciliary care service, and implications for the workforce;
- implementing mandatory recognised dementia training for all staff at induction;
- updating all staff, through regular training and briefings, on the latest news and research;
- raising awareness of dementia in all staff in our extra care housing schemes.

## **Q5: What opportunities are there to develop the professional curricula in the next two years on dementia?**

A professional curriculum would give recognition to the importance of the role and skills required of a high quality dementia carer. The new course 'Tomorrow is Another Day' should enable care staff to develop skills and knowledge to provide person-centred care that is endorsed by a nationally recognised organisation (the Alzheimer's Society).

In relation to the current popularity – and Government funding – of housing with care schemes, including Continuing Care Retirement Communities and extra care schemes, it is important to consider specific professional curricula needs in relation to staff who may support a growing number of people with dementia who live in such settings.

Although housing with care/extra care schemes may have much to offer people with dementia, the evidence base for this is still scanty (14, 15). The available evidence suggests tensions around the capacity of such schemes to accommodate individuals with high levels of care needs, while remaining true to the concept of promoting independence in later life. While schemes can provide an alternative to residential care for people in some circumstances, the evidence consistently reports people – typically those with dementia-type illnesses and/or challenging behaviours – moving on from housing with care into both residential care and nursing homes. Careful thought will need to be given to improving the skills and workforce readiness of staff in extra care to make 'a home for life' a realistic aspiration.

JRHT staff highlight the need for training to have a greater focus on domiciliary care, as care within an individual's own home becomes more popular. This should focus on ensuring that people have access to a wide range of 'low-level' services. JRF research (16, 17) shows that many older people remain isolated in their own homes, with no support or contact. The support and services which older people value concern negotiating the ordinary things in life – relationships, learning, transport, housing, contact – in their words, 'being comfortable' and having 'that bit of help' (16 - 23). These values and concerns apply to those with dementia as much as to older people in

general, and are crucial if more people with dementia are to be enabled to stay at home.

**Q6: What opportunities are there for collaboration with other organisations to improve the dementia care skills of the workforce and rates of diagnosis? Who would you like to see playing a role in this work?**

Collaboration is needed across the *range* of settings currently available for people at different stages of dementia. Distinctions should be made, for example, between home care and housing with care or extra care settings, and between residential care and nursing home care. Learning disability providers and organisations must also be included.

JRHT operational staff identified the following collaboration opportunities in their focus group:

- between social care, health, the private and voluntary sectors, to achieve ‘seamless care’;
- between care providers and regulators, so that clearer guidance on, and expectations of, dementia care are available;
- between care providers and community psychiatric nurses (CPNs) (JRHT’s domiciliary care team now meets monthly with local CPNs to exchange information and advice, and there is scope for CPNs to be involved in staff support group meetings);
- between care providers and training organisations, to provide consistent training and knowledge, within a recognised standard accreditation system;
- between care providers and research organisations, to publicise the latest evidence and ensure it is acted upon.

Organisations which JRF highlight for collaboration (and we would ourselves be keen to explore collaboration and partnership) include:

- Social Care Institute for Excellence (especially the new ‘Dementia Gateway’);
- Care Services Improvement Partnership;
- Journal of Dementia Care;
- Alzheimer’s Society;

- User groups, such as the Scottish Alzheimer Group;
- Bradford Dementia Care Group;
- Talking Mats (Stirling University);
- My Home Life;
- Care Home Learning Network – Scotland;
- UK regulators;
- Connect in Care (Scotland);
- The UK network of Dementia Development Centres.

## **Research gaps**

A recent event supported by the JRF on '*Enhancing the What Works research knowledge base on dementia care and housing*' (24) led to the establishment of a new research consortium of housing associations with a special interest in dementia. It also highlighted research gaps with relevance to training care staff: early intervention, psycho-social intervention, knowledge of existing evidence, and change management.

JRF promotes the involvement of people with dementia in the development of training and skills in this area. This is a difficult but important challenge. Much can be learned from work with people with learning difficulties, and more generally with people who have cognitive or communication impairments.

## References

1. Allen, K. (2001) 'Exploring ways for staff to consult people with dementia about services' JRF *Findings* (Ref: 541)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/541.asp>
2. Murphy, J., Gray, C.M., Cox, S. (2007) 'Using 'Talking Mats' to help people with dementia to communicate', JRF *Findings* (Ref: 2159)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/2159.asp>
3. Stalker, K., Duckett, P. and Downs, M. (1999) 'Choice, dementia and people with learning difficulties', JRF *Findings* (Ref: D19)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/D19.asp>
4. Wilkinson, H., Kerr, D., Cunningham, C. and Rae, C. (2004) 'Support for people with learning difficulties in residential settings who develop dementia', JRF *Findings* (Ref: 614)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/614.asp>
5. Kerr, D., Wilkinson, H. and Cunningham, C. (2006) 'Pain management for older people with learning difficulties and dementia', JRF *Findings* (Ref: 0306)  
<http://www.jrf.org.uk/publications/pain-management-older-people-with-learning-difficulties-and-dementia>
6. Kerr, D. and Wilkinson, H. (2005) *In the Know: Implementing good practice – Information and tools for anyone supporting people with a learning disability and dementia*. Brighton: Pavilion Publishing.
7. Kerr, D., Wilkinson, H. and Cunningham, C. (2008) 'Supporting older people in care homes at night', JRF *Findings* (Ref: 2201)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/2201.asp>
8. Wild, D. and Szczepura, A. (2008) 'Providing nursing support within residential care homes', JRF *Findings* (Ref: 2202)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/2202.asp>

9. Clark, H., Gough, H. and Macfarlane, A. (2004) 'Making direct payments work for older people', JRF *Findings* (Ref: 234)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/234.asp>
10. Ryan, T. (1999) 'Implementing direct payments for people with learning difficulties', JRF *Findings* (Ref: 349)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/349.asp>
11. Evans, C. and Brown, L. (2002) 'A user-controlled Best Value Review of direct payments', JRF *Findings* (Ref: 592)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/592.asp>
12. Cantley, C. and Wilson, R. (2002) 'Designing and managing care homes for people with dementia', JRF *Findings* (Ref: 312)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/312.asp>
13. Innes, A., Macpherson, S. and McCabe, L. (2006) 'Promoting person-centred care at the front line', JRF *Findings* (Ref: 0296)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/0296.asp>
14. Croucher, K., Hicks, L. and Jackson, K. (2006) 'Housing with care for later life: a literature review', JRF *Findings* (Ref: 0076)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/0076.asp>
15. Croucher, K., Hicks, L., Bevan, M. and Sanderson, D. (2007) 'Comparing models of housing with care for later life', JRF *Findings* (Ref: 2158)  
<http://www.jrf.org.uk/knowledge/findings/housing/2158.asp>
16. Raynes, N., Clark, H., and Beecham, J. (eds) (2006) *The report of the Older People's Inquiry into 'that bit of help'*. York: Joseph Rowntree Foundation.  
<http://www.jrf.org.uk/publications/report-older-peoples-inquiry-bit-help>
17. Older People's Steering Group (2004) 'Older people shaping policy and practice'. JRF *Foundations* (Ref. 044)  
<http://www.jrf.org.uk/knowledge/findings/foundations/044.asp>



18. Cordingley, L., Hughes, J. and Challis, D. (2001) *Unmet need and older people: Towards a synthesis of user and provider views*. York: Joseph Rowntree Foundation.
19. Kerr, L. and Kerr, V. (2003) *Older people doing it for themselves: Accessing information, advice and advocacy*. York: Joseph
20. Bowers, H. with Mendonca, P. (2002) *Living well in later life*. Unpublished conference papers.
21. Godfrey, M., Townsend, J. and Denby, T. (2004) 'Building a good life for older people in local communities', JRF *Findings* (Ref: 014).  
<http://www.jrf.org.uk/knowledge/findings/socialcare/014.asp>
22. Butt, J. and O'Neil, A. (2004) 'Let's move on': *Black and minority ethnic older people's views on research findings*, JRF *Findings* (Ref: 564)  
<http://www.jrf.org.uk/knowledge/findings/socialcare/564.asp>
23. Carter, T. and Beresford, P. (2000) 'Older people shaping policy and practice'. JRF *Foundations* (Ref. 044)  
<http://www.jrf.org.uk/knowledge/findings/foundations/044.asp>
24. Summary of the JRF-funded event on '*Enhancing the What Works research knowledge base on dementia care and housing*',  
<http://www.housing21.co.uk/downloads/QCHRPWDForumSummary.pdf>